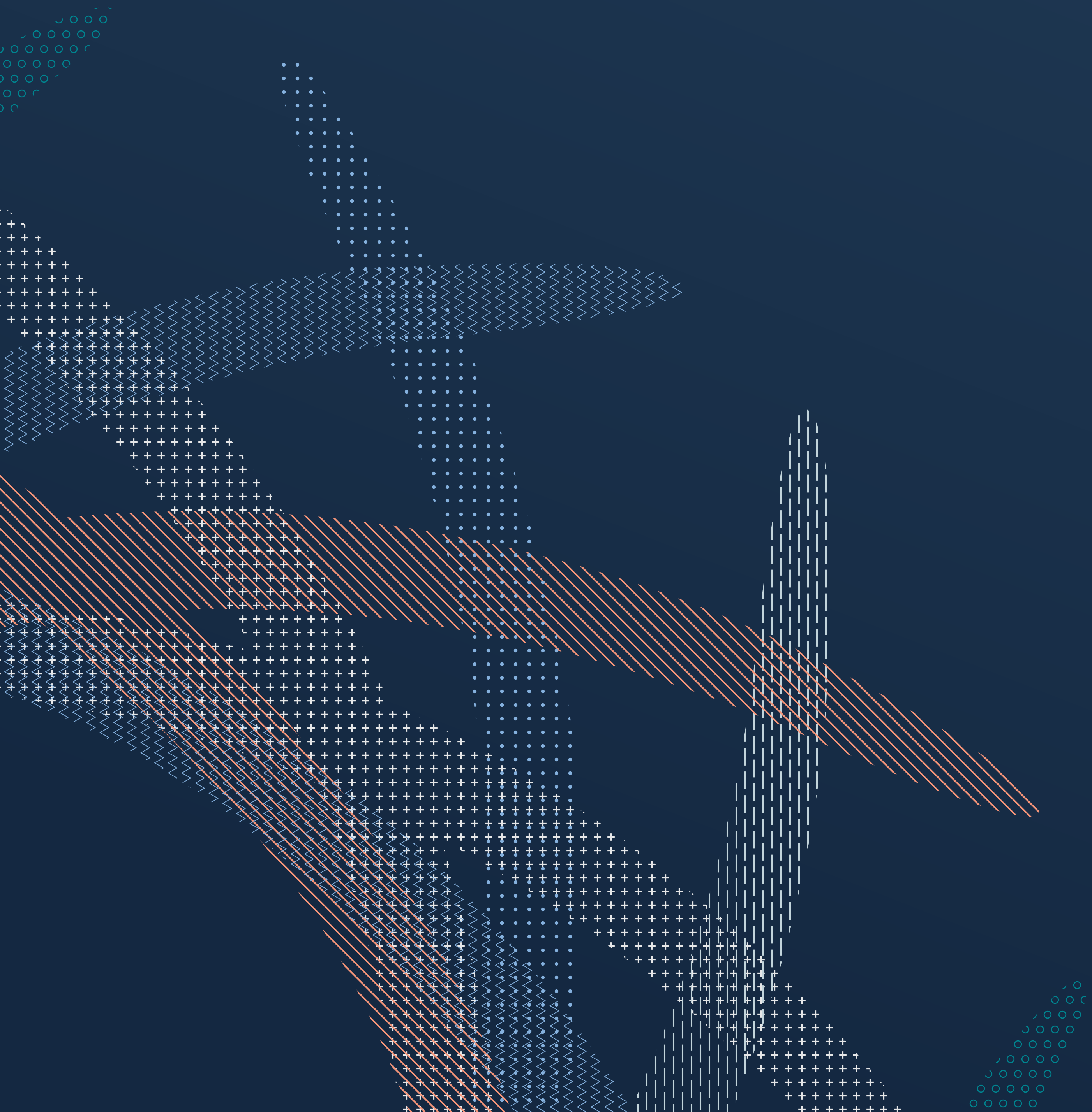
Royal Commission into
Victoria's Mental Health System

Final Report

Volume 3

Promoting inclusion and addressing inequities



Royal Commission into
Victoria's Mental Health System

Volume 3
Promoting inclusion and addressing inequities

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Except where otherwise indicated, the images in this publication show models and illustrative settings only, and do not necessarily depict actual services, facilities or recipients of services. This publication may contain images of deceased Aboriginal and Torres Strait Islander peoples.

In this document, 'Aboriginal' refers to both Aboriginal and Torres Strait Islander people. 'Indigenous' or 'Koori/Koorie' is retained when part of the title of a report, program or quotation.

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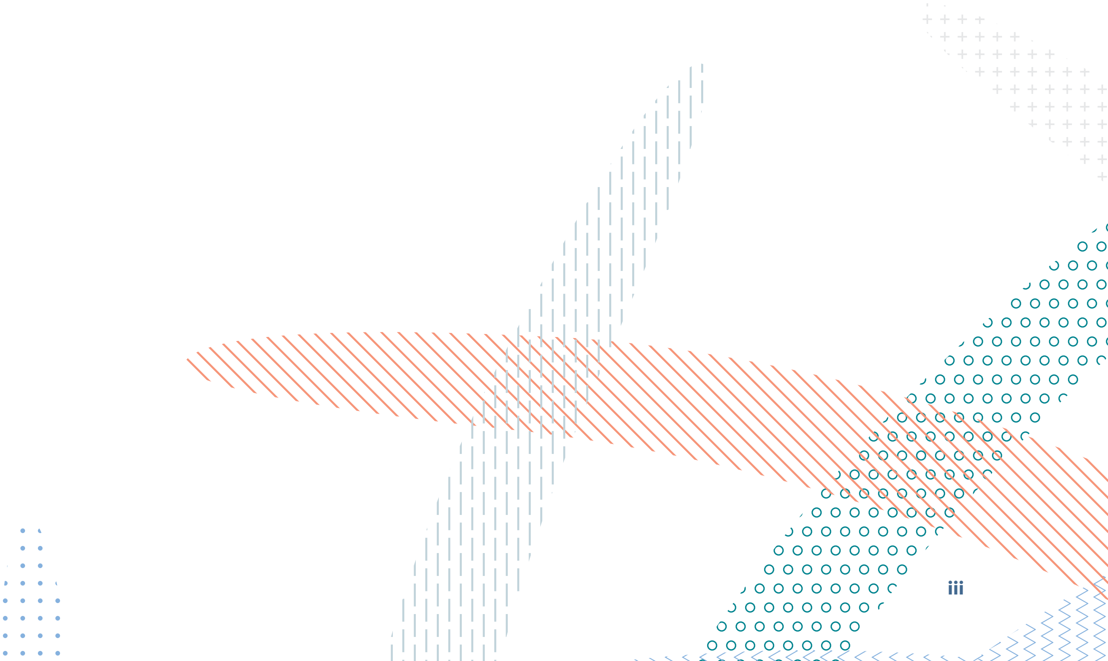
Acknowledgement of Aboriginal land and peoples

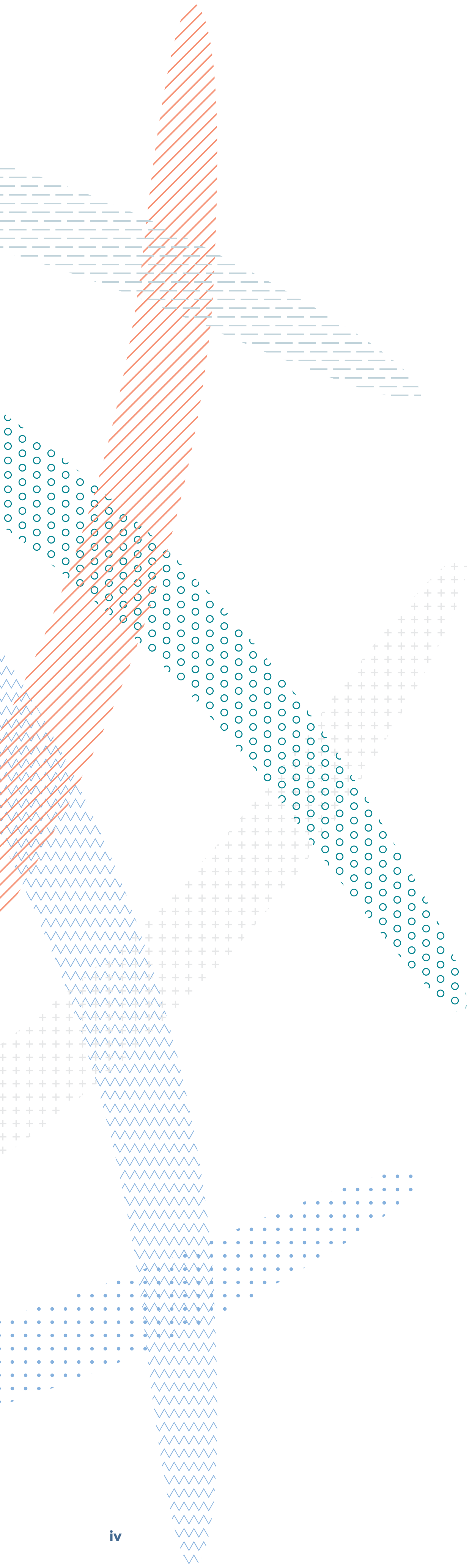
The heritage of Aboriginal communities throughout Victoria is vibrant, rich and diverse. We value these characteristics and consider them a source of strength and opportunity. We recognise that the leadership of Aboriginal communities and Elders in Victoria is crucial to improving outcomes for Aboriginal people. Also to be acknowledged, however, are the devastating impacts and the accumulation of trauma resulting from colonisation, genocide, the dispossession of land and children, discrimination and racism.

The Royal Commission into Victoria's Mental Health System proudly acknowledges Aboriginal people as the First Peoples and Traditional Owners and custodians of the land and water on which we rely. We acknowledge that Aboriginal communities are steeped in traditions and customs, and we respect this. We acknowledge the continuing leadership role of the Aboriginal community in striving to redress inequality and disadvantage, and the catastrophic and enduring effects of colonisation.

We recognise the diversity of Aboriginal people living throughout Victoria. Although the terms 'Koorie' and 'Koori' are commonly used to describe Aboriginal people of south-east Australia, we use the term 'Aboriginal' in this report to include all people of Aboriginal and Torres Strait Islander descent who are living in Victoria. This approach is consistent with the language conventions of key Victorian frameworks such as the *Aboriginal Affairs Framework 2018–2023*.

The Royal Commission is conscious that its work is taking place concurrently with renewed efforts to achieve constitutional recognition of Aboriginal peoples and treaty processes that are underway in Victoria. We commit to building on this momentum and to ensuring our work is shaped by the voice of Aboriginal people.





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A note on content

The Royal Commission recognises the strength of people living with mental illness or psychological distress, families, carers and supporters, and members of the workforce who have contributed their personal stories and perspectives to this inquiry.

Some of these stories and the Commission's analysis may contain information that could be distressing. You may want to consider how and when you read this report.

Aboriginal readers are advised that this report may contain photos, quotations and/or names of people who are deceased.

If you are upset by any content in this report, or if you or a loved one need support, the following services are available to support you:

- If you are not in immediate danger but you need help, call **NURSE-ON-CALL** on **1300 60 60 24**.
- For crisis support, contact **Lifeline** on **13 11 14**.
- For phone-based support contact **Beyond Blue** on **1300 224 636**.
- If you are looking for a mental health service, visit **betterhealth.vic.gov.au**.
- **For situations that are harmful or life-threatening, contact emergency services immediately on Triple Zero (000)**.

Terminology and language

Language is powerful and words have various meanings for different people.

There is no single set of definitions used to describe how people experience their mental health. This diversity is reflected in the many terms used to capture people's experiences throughout the evidence put before the Commission.

As stated in the Commission's interim report, words and language can have a lasting impact on a person's life. They can empower and embolden. They can be used to convey hope and empathy. But they can also be divisive when used to dispossess and divide, and to stigmatise and label.

The Commission has considered the many perspectives on terminology, and acknowledges that language can be deeply contested and nuanced. Although it has at all times tried to use inclusive and respectful language, the Commission is aware that not everyone will agree with the terminology used.

Another consideration for the Commission has been this report's broad audience, including people with lived experience of mental illness or psychological distress, families, carers and supporters, workers in the mental health system, government and the wider Victorian community. This diverse audience needs to be able to read the report and understand its intent at this point in time in the development of the mental health system.

Below is a list of important terms in the report and how the Commission understands them. This list largely reflects the requirement to align with definitions outlined in the Commission's letters patent. It is also consistent with the Commission's interim report for the purposes of clarity.

Carer	Means a person, including a person under the age of 18 years, who provides care to another person with whom they are in a relationship of care.
Consumer	People who identify as having a living or lived experience of mental illness or psychological distress, irrespective of whether they have a formal diagnosis, who have used mental health services and/or received treatment.
Family	May refer to family of origin and/or family of choice.
Good mental health	A state of wellbeing in which a person realises their own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to their community.

Lived experience	People with lived experience identify either as someone who is living with (or has lived with) mental illness or psychological distress, or someone who is caring for or otherwise supporting (or has cared for or otherwise supported) a person who is living with (or has lived with) mental illness or psychological distress. People with lived experience are sometimes referred to as 'consumers' or 'carers'. The Commission acknowledges that the experiences of consumers and carers are different.
Mental health and wellbeing system	The Commission outlines in this report its vision for a future mental health and wellbeing system for Victoria. Mental health and wellbeing does not refer simply to the absence of mental illness or psychological distress but to creating the conditions in which people are supported to achieve their potential. As part of this approach, the Commission has also purposefully chosen to focus on the strengths and needs that contribute to people's wellbeing. To better reflect international evidence about the need to strike a balance between hospital-based services and care in the community, the types of treatment, care and support the future system offers will need to evolve and be organised differently to provide each person with dependable access to mental health and wellbeing services and links to other supports they may seek. The addition of the concept of 'wellbeing' represents a fundamental shift in the role and structure of the system.
Mental illness	A medical condition that is characterised by a significant disturbance of thought, mood, perception or memory. The Commission uses the above definition of mental illness in line with the *Mental Health Act 2014* (Vic). However, the Commission recognises the Victorian Mental Illness Awareness Council Declaration released on 1 November 2019. The declaration notes that people with lived experience can have varying ways of understanding the experiences that are often called 'mental illness'. It acknowledges that mental illness can be described using terms such as 'neurodiversity', 'emotional distress', 'trauma' and 'mental health challenges'.
Psychological distress	One measure of poor mental health, which can be described as feelings of tiredness, anxiety, nervousness, hopelessness, depression and sadness. This is consistent with the definition accepted by the National Mental Health Commission.
Social and emotional wellbeing	Being resilient, being and feeling culturally safe and connected, having and realising aspirations, and being satisfied with life. This is consistent with *Balit Murrup*, Victoria's Aboriginal social and emotional wellbeing framework.

Treatment, care and support	The Commission uses this phrase consistently with its letters patent. This phrase has also been a deliberate choice throughout this report to present treatment, care and support as fully integrated, equal parts of the way people will be supported in the future mental health and wellbeing system. In particular, wellbeing supports (previously known as 'psychosocial supports') that focus on rehabilitation, wellbeing and community participation will sit within the core functions of the future system.

The Commission only departs from these terms when referring to specific data sources, describing research works, or quoting an individual or organisation. The original language is retained wherever possible to accurately reflect the views and evidence presented to the Commission. For example, the Commission quotes individuals and organisations that sometimes refer to 'mental disorder', rather than the Commission's preferred terms of 'mental illness or psychological distress'. Terms such as 'disorder' can be pathologising and stigmatising, so the Commission only retains them if others use them to convey a specific meaning.

Personal stories and case studies

Throughout all phases of its work, the Commission has heard from people with lived experience of mental illness or psychological distress, families, carers and supporters, members of the workforce, organisations, experts and members of the broader Victorian community through consultations, submissions, correspondence, public hearings and witness statements.

Based on these sources, the Commission has included a selection of personal stories that appear throughout this report. These stories provide the individual's personal recollections of their interactions and experiences with Victoria's mental health system.

The Commission has also included a selection of case studies that are primarily about services or approaches that illustrate reform opportunities or innovation.

The Commission wanted to consider a broad range of ideas for improving the mental health system. Therefore, some of these personal stories and case studies include perspectives from outside of Victoria.

With the permission of the individuals involved, these have been modified for privacy and confidentiality where appropriate. In some instances, the Commission has also made non-publication orders to protect privacy and confidentiality.

Introduction

As required by the Commission's letters patent, the Commission was a policy-based inquiry. This report presents the findings from this process and sets out recommendations to inform the design of a new mental health and wellbeing system.

The Victorian community made more than 12,500 contributions to inform the Commission's work. The Commission has listened to this diversity of voices and analysed a wide variety of data and research. These inputs have illustrated the factors that shape people's experiences of mental health and wellbeing and have formed the basis for the design of the future system and services.

Volume 1 of this report outlines a new approach to providing Victorians with the right mental health treatment, care and support at the right time, and in the right places across the state. Volume 2 describes the collaboration needed to support good mental health and wellbeing. Volume 4 explains the features that will ensure the system provides high-quality and safe services. Volume 5 sets out the enablers of system transformation, including the technology, information and expertise needed to make the system work effectively, and how it will drive continuous improvement.

This volume outlines how the system will promote inclusion and address inequities in the mental health and wellbeing system. It describes the central role of people with lived experience of mental illness or psychological distress, families, carers and supporters in the future system. It explains how the new system will support Aboriginal social and emotional wellbeing, and how it will respond to the needs of diverse communities. It details integrated approaches to treatment, care and support for people with co-occurring mental illness and substance use or addiction. It also details the future system design for people living with mental illness who are in contact with the criminal justice system, including the youth justice system. It addresses how the new mental health and wellbeing system will provide an improved response to people who live in rural and regional Victoria. Finally, it describes what will be done to address stigma and discrimination.

Placing lived experience at the centre

The current system does not adequately value or respond to the knowledge and expertise of people with lived experience of mental illness or psychological distress, or families, carers and supporters of someone living with mental illness or psychological distress. These failures must be addressed.

The Commission is recommending a central role for people with lived experience of mental illness or psychological distress and families, carers and supporters in the ongoing design and development of the system, and in the delivery of services.

The Commission acknowledges the knowledge and expertise of mental health and wellbeing that people with lived experience of mental illness or psychological distress, families, carers and supporters have, based in their individual and shared experiences.

At times, people with lived experience of mental illness or psychological distress and families, carers and supporters may have shared interests based in common experiences, but this is not always the case. At times, their views may differ. In creating opportunities for the leadership of people with lived experience of mental illness or psychological distress and families, carers and supporters, the future system will respond to the differing knowledge and expertise that each group draws on (and indeed the differing knowledge and expertise of each individual).

The future system will provide dedicated, separate spaces for people with lived experience of mental illness or psychological distress and family, carer and supporter leadership, as well as opportunities for these groups to come together.

A future mental health and wellbeing system will see people with lived experience of mental illness or psychological distress in multiple and substantive leadership positions, working collaboratively with others to lead and influence change and balance power.

A new agency led by people with lived experience of mental illness or psychological distress will help establish organisations, including services led by people with lived experience of mental illness or psychological distress. These organisations will be supported to develop over time through accredited training and resources.

In the new mental health and wellbeing system, understanding consumers' social contexts will be a key part of service delivery. This means that involving families, carers and supporters in care and recovery will become standard practice for all services. Family, carer and supporter inclusion will also be a routine aspect of the commissioning of mental health and wellbeing services, and of workforce development and training.

The system will respond to the significant role that relationships of care and support play in promoting mental health and wellbeing for people living with mental illness or psychological distress. Families, carers and supporters will have access to dedicated supports from eight family- and carer-led centres. Tailored and intensive supports will also be provided to young carers.

Refer to Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress* and Chapter 19: *Valuing and supporting families, carers and supporters* for detailed descriptions of these reforms.

Improving responses to the community's diverse needs

Victoria's population is diverse, growing and changing, and the mental health and wellbeing system needs to extend its responses to better meet the specific needs of different communities.

The interim report acknowledged the urgent need to support the mental health of Aboriginal people. As an immediate response, the Commission outlined how the Victorian Government will expand Aboriginal social and emotional wellbeing services and establish a new Aboriginal Social and Emotional Wellbeing Centre to support these services.

The next stage of reform will establish new healing centres that will draw on Aboriginal knowledge and expertise on healing from trauma, distress and mental illness. These centres will be co-designed, developed and delivered through partnerships between the Aboriginal Social and Emotional Wellbeing Centre and Aboriginal community-controlled health organisations and Aboriginal communities.

A detailed description of the reforms to address Aboriginal mental health and wellbeing are described in Chapter 20: *Supporting Aboriginal social and emotional wellbeing*.

The new system will also have increased oversight and accountability for supporting the mental health and wellbeing of Victoria's diverse communities.

People who identify as LGBTIQ+; refugees; asylum seekers; people living with disabilities; and people from culturally diverse backgrounds are exposed to a range of factors, including stigma and discrimination that increase the likelihood they will have poor mental health outcomes.

Consumers will experience safe and responsive care, including access to appropriate and accessible information and language services. Community-led organisations will be recognised as important partners in supporting and delivering services to their communities. Service providers will be required to report on how well they are meeting the needs of Victoria's diverse communities.

Multiple social and environmental factors influence mental health outcomes, and people are best served when services are both universally accommodating and tailored to different population groups and communities. The new system will strengthen current services that target specific communities and support community-led organisations by increasing their capacity to address diversity and geographic challenges.

For a detailed description of the ways in which the new system will respond to the diversity of Victoria's population, refer to Chapter 21: *Responding to the mental health and wellbeing needs of a diverse population*.

Integrating care for those often marginalised and excluded

Removing the gaps and silos between sectors is vital for everyone but especially for groups that comprise some of the most marginalised and excluded Victorians. The future system will ensure services are integrated for people living with mental illness or psychological distress who also need help with substance use or addiction, and for those who are involved with, or at risk of involvement with, the criminal or youth justice systems, or those in the forensic mental health system.

The Commission recognises that many people who experience mental illness or psychological distress are also affected by substance use or addiction. In the new system, consumers will be able to get integrated treatment, care and support for mental illness and substance use or addiction across the care continuum. A new statewide service will be established to support existing services to deliver these joined-up responses, and to provide a specialist mental health and substance use or addiction response for those consumers who need it. Refer to Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction* for details of these reforms.

People living with mental illness are over-represented throughout the criminal and youth justice systems, including in prisons and youth justice centres. They are also more likely to be victims of crime.

The Commission's suite of reforms across crisis and emergency responses and the new community mental health and wellbeing system will go some way to address this. The new system will also deliver specific measures in response by improving coordination between justice and community mental health services and delivering a range of strategies including expanded access to 'problem-solving' courts (in particular the Assessment and Referral Court). Problem-solving courts seek to understand and address the underlying issue behind a person's offending behaviour and to develop, with the individual and a multidisciplinary team, a management plan that considers legal aspects and wider issues.

The Victorian Government will expand community-based mental health and wellbeing services to offer more forensic mental health services to people who need them. The system will also provide improved transitions out of the criminal justice system to ensure people who need ongoing intensive treatment, care and support receive it when they leave prison. They will be supported to begin or continue their involvement with the appropriate Area Mental Health and Wellbeing Service.

Thomas Embling Hospital provides treatment, care and support to consumers who are transferred from prison or ordered by courts to be detained for psychiatric assessment and treatment. The hospital will receive funding for a full refurbishment and to increase its capacity to meet demand through building new beds for both those it currently provides services to and for those consumers who cannot receive safe and appropriate treatment, care and support in extended rehabilitation settings or other inpatient services. The Victorian Government will also establish a statewide youth forensic mental health service.

Refer to Chapter 23: *Improving mental health outcomes across the criminal justice, forensic mental health and youth justice systems* for details of these reforms.

Addressing inequities for rural and regional Victorians

In its interim report the Commission stated that, wherever possible, people living in rural and regional Victoria should be able to obtain mental health services close to home, and close to their families and loved ones. The new system is designed to respond to the changing composition, needs and choices of rural and regional Victorians through a networked service approach across rural and regional areas.

Regional Mental Health and Wellbeing Boards will commission Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services, ensuring these services respond to the needs of local communities and recognise the unique strengths and challenges of each region. Area Mental Health and Wellbeing Services based in regional centres will have more responsibility for providing inreach services (services to people in their own communities) to more geographically isolated or smaller rural communities.

Services will be supported to attract, develop and retain a more sustainable mental health and wellbeing workforce through a multifaceted Mental Health Workforce Rural Incentive Scheme that will support meaningful career pathways. Digital service delivery will also be accelerated to provide more flexible and accessible options for treatment, care and support.

For a detailed description, refer to Chapter 24: *Supporting the mental health and wellbeing of people in rural and regional Victoria*.

Tackling stigma and discrimination

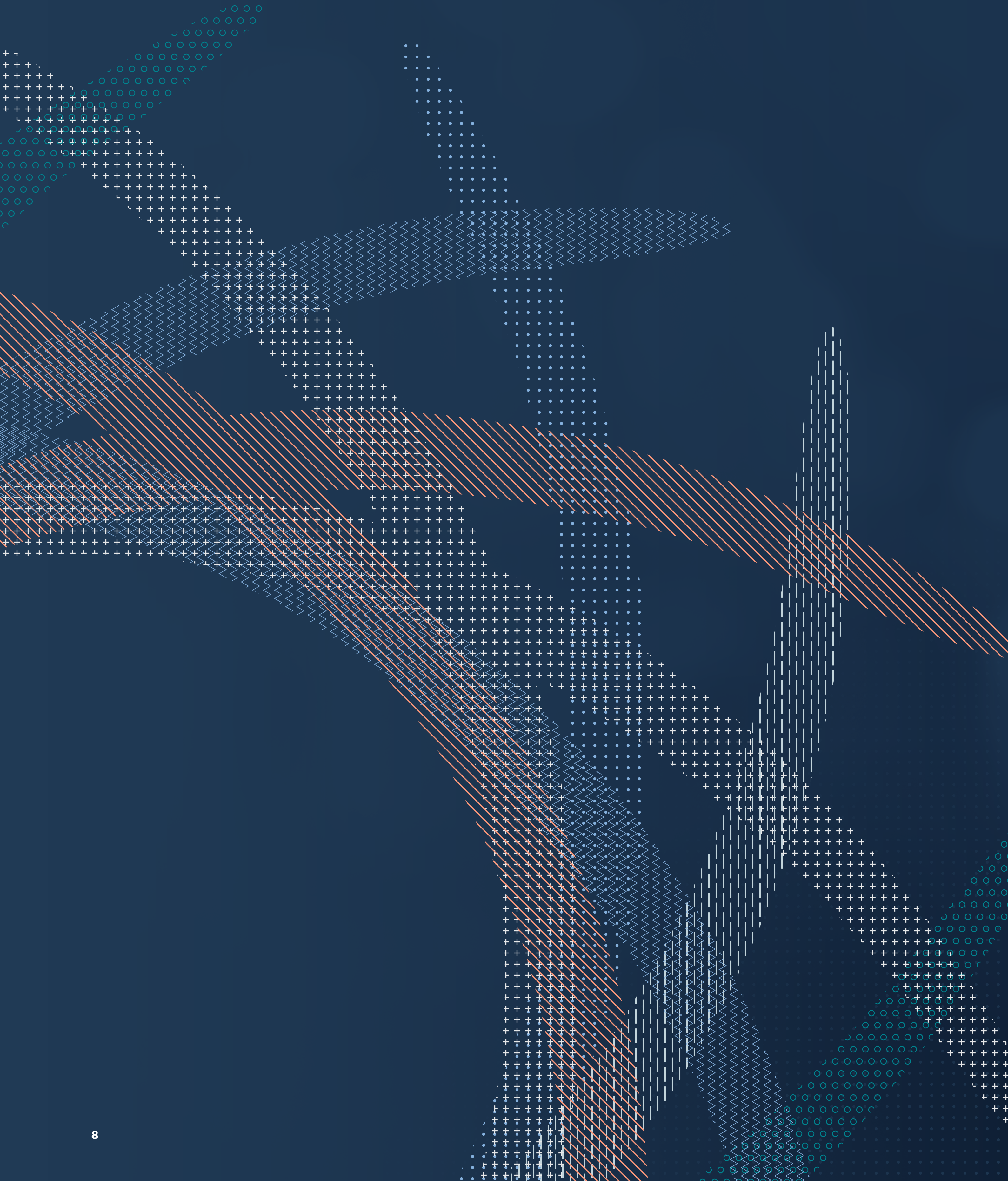
Finally, this volume outlines how stigma and discrimination are significant contributors to poor mental health and how people with lived experience of mental illness or psychological distress are significantly affected. The new system will tackle stigma and discrimination through targeted programs in the settings where Victorians live, work and learn, and by empowering consumers to challenge discrimination when they experience it.

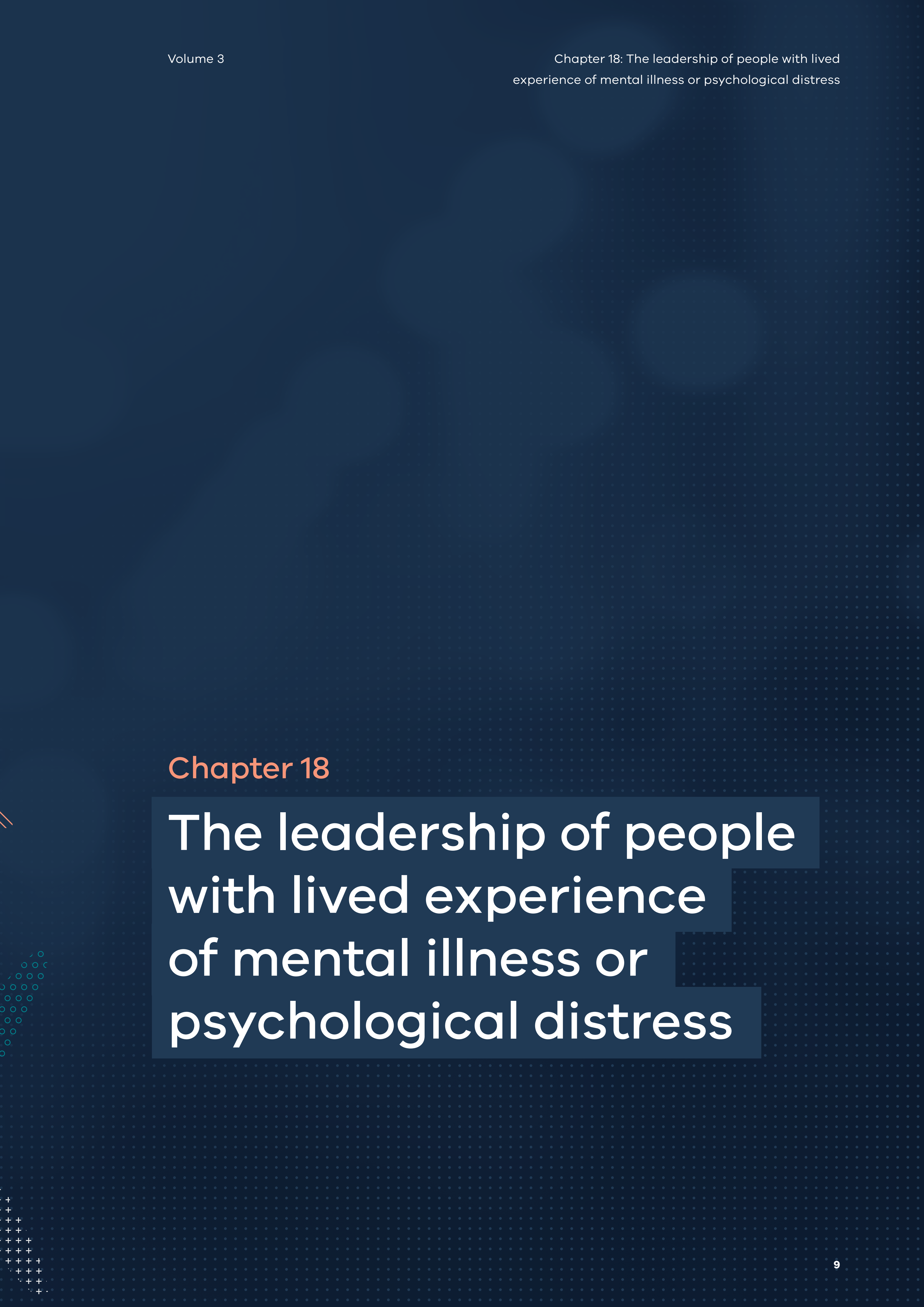
The Victorian Government will establish a Mental Health and Wellbeing Commission (see Volume 4), which will lead a long-term, funded program in partnership with healthcare providers, schools and employers to confront stigma and discrimination in those settings and more broadly. Community-led organisations and community members will be able to apply for grants to undertake initiatives that respond to stigma and discrimination in their communities. This program of activity will be comprehensively evaluated and findings fed back into the system as it develops.

The Victorian Government will establish mechanisms to address systemic mental health discrimination and will support people with lived experience to access legal advice.

Refer to Chapter 25: *Addressing stigma and discrimination* for details of these reforms.

Together, the recommended reforms described in this volume will create a more inclusive and equitable mental health and wellbeing system so that all Victorians can get treatment, care and support that meet their needs.





Chapter 18

The leadership of people with lived experience of mental illness or psychological distress

Recommendation 28:

Developing system-wide roles for the full and effective participation of people with lived experience of mental illness or psychological distress

The Royal Commission recommends that the Victorian Government:

1. in addition to the nominated roles specified in other recommendations, develop key roles across the mental health and wellbeing system for people with lived experience of mental illness or psychological distress.
2. enable the Mental Health and Wellbeing Commission (refer to recommendation 44) to:
   - **a.** elevate the leadership and support the full and effective participation of people with lived experience of mental illness or psychological distress in decision-making about policies and programs, including those directly affecting them;
   - **b.** develop and support the leadership capabilities of people with lived experience of mental illness or psychological distress through learning and development opportunities;
   - **c.** design and deliver initiatives to prevent and address stigma towards people living with mental illness or psychological distress; and
   - **d.** design and deliver initiatives to develop awareness and understanding of the experiences and perspectives of people with lived experience of mental illness or psychological distress.

Recommendation 29:

A new agency led by people with lived experience of mental illness or psychological distress

The Royal Commission recommends that the Victorian Government:

1. build on the interim report's recommendation 5 and establish a new non-government agency, overseen by a skills-based board chaired by and consisting of a majority of people with lived experience of mental illness or psychological distress, to:
    - **a.** deliver accredited training and resources to aid the development of organisations led by people with lived experience of mental illness or psychological distress;
    - **b.** develop and deliver mental health and wellbeing services led by people with lived experience of mental illness or psychological distress; and
    - **c.** facilitate co-location, shared resourcing, learning opportunities and the creation of new partnerships and networks between people with lived experience of mental illness or psychological distress and the organisations they lead.

18.1 Establishing the foundations for the leadership of people with lived experience of mental illness or psychological distress

The leadership of people with lived experience of mental illness or psychological distress is a fundamental tenet of an inclusive, compassionate and humane mental health and wellbeing system. Many people have shared their aspirations with the Commission for a future system where people with lived experience of mental illness or psychological distress lead and make decisions about the matters that affect their lives, and where their contributions are recognised and acted on.

Ms Honor Eastly, a witness before the Commission, shared her ambitions:

> Now is an opportunity for Victoria to join with the global progress in mental health and be a leader in the world in this arena, and to truly value and elevate the wisdom of lived experience.[1]

The Consumer Foundations Working Group[2] shared their hopes for a future mental health and wellbeing system that is led by consumers, '[a] new system will require new and innovative ideas. At the heart, and leading this, should be consumers.'[3]

Others have reflected on the value and benefits of people with lived experience of mental illness or psychological distress participating in policy development, practice and research. As Dr Sarah Pollock, Executive Director of Research and Advocacy at Mind Australia, said:

> It is a means to shore up people's humanity, dignity and right to decide for themselves about how they live their lives. It is a means of achieving systems that are anti-oppressive and just in the ways in which they achieve outcomes and benefits for all—consumers, families, workers, the general public.[4]

The Commission shares the aspirations of those who have contributed to its inquiry. It, too wants a reformed mental health and wellbeing system in which people with lived experience of mental illness or psychological distress are valued as leaders and change-makers, in the community and as part of reforms to the system.

The leadership and participation of people with lived experience of mental illness or psychological distress is not only a response to a moral matter. It is, in fact, recognised in international human rights frameworks, the most important of these being the United Nations *Convention on the Rights of Persons with Disabilities*, ratified by Australia in 2008.[5] It states, among other things, that 'persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them'[6] and promotes their 'full and effective participation and inclusion in society'.[7]

Reflecting the intent of the *Convention on the Rights of Persons with Disabilities*, the Commission's guiding principles describe a future mental health and wellbeing system in which the inherent dignity of people with lived experience of mental illness or psychological distress is respected and support is provided to ensure their full and effective participation in society.[8]

The Commission's interim report made a number of priority recommendations to elevate the expertise and perspectives of people with lived experience of mental illness or psychological distress and work with them as equal partners and contributors throughout the mental health and wellbeing system. These recommendations included reforms to: better support, expand and establish lived experience workforces[9] as a recognised profession; create Victoria's first residential service designed and delivered by people with lived experience of mental illness as a true alternative to acute hospital-based care; and establish the Victorian Collaborative Centre for Mental Health and Wellbeing to drive a more inclusive and interdisciplinary research agenda, with joint executive leadership by a clinical academic and a person with lived experience of mental illness.[10]

Alongside these interim report recommendations, the Commission also committed to redesign a system in which people with lived experience of mental illness or psychological distress, families, carers and supporters will be at the forefront, listened to and valued as active contributors and leaders.[11]

Delivering on this commitment requires that people with lived experience of mental illness or psychological distress are at the centre of reform. Ms Mary O'Hagan MNZM, former New Zealand Mental Health Commissioner and current Manager of Mental Wellbeing at Te Hiringa Hauora in New Zealand, giving evidence in a personal capacity, emphasised the deep change that is required of the system:

> In my view, the reforms we need are not about 'giving greater voice' to people with lived experience. Rather, we need to transform the system from within, so that those voices are central to the discourses and are deeply heard.[12]

To this end, there are a number of recommendations detailed in this report that will further strengthen and pave the way for the leadership of people with lived experience of mental illness or psychological distress across the reformed mental health and wellbeing system.

These recommendations call for:

- employing people with lived experience of mental illness or psychological distress in multiple and substantive positions, including leadership positions, in the Mental Health and Wellbeing Division in the Department of Health, as outlined in Chapter 27: *Effective leadership and accountability of the mental health and wellbeing system—new system-level governance*
- ensuring representation of people with lived experience of mental illness or psychological distress on Regional Mental Health and Wellbeing Boards with responsibilities including planning, funding and monitoring mental health and wellbeing services, as described in Chapter 5: *A responsive and integrated system*
- establishing new services led by people with lived experience of mental illness or psychological distress as part of a diverse community-based service offering, delivering innovative treatment, care and support, referred to in Chapter 5: *A responsive and integrated system* and Chapter 28: *Commissioning for responsive services*
- expanding and creating new lived experience workforce roles, supported by a new approach to building workforce capabilities, with access to professional learning and development opportunities, as stated in Chapter 33: *A sustainable workforce for the future*
- strengthening the role of people with lived experience of mental illness or psychological distress in research and innovation, including establishing collaborative networks that include people with lived experience as key partners in efforts to expand innovative practice across the mental health and wellbeing system, as outlined in Chapter 36: *Research innovation and system learning*.

In addition to these nominated roles specified in other recommendations in this report, it is imperative that proactive efforts to develop key roles across the mental health and wellbeing system for people with lived experience of mental illness or psychological distress continue. This chapter makes specific recommendations to support this ambition by expanding lived experience leadership and shifting power to people with lived experience of mental illness or psychological distress so that they can lead and influence decisions on an equal basis as others. These reforms include establishing at least one Commissioner with lived experience of mental illness or psychological distress within the new Mental Health and Wellbeing Commission to elevate the leadership of people with lived experience of mental illness or psychological distress in decision-making processes about policies and programs, including those directly concerning them.

As with all individuals in leadership roles, in the reformed mental health and wellbeing system deliberate efforts must be made to build and strengthen the existing capabilities and skills of people with lived experience of mental illness or psychological distress so that they can thrive as leaders and decision-makers.

Together, these reforms will help build a critical mass of diverse people with lived experience of mental illness or psychological distress in leadership positions, working collaboratively, to lead and influence change and innovation.[13] As Ms Robyn Kruk AO, Interim Chair of Mental Health Australia, giving evidence in a personal capacity, stated: '[h]aving the lived experience voice embedded in health systems needs to become business as usual, rather than something that exists on the side of the system.'[14]

This chapter also recommends an approach to support the establishment of new and emerging organisations including services led by people with lived experience of mental illness or psychological distress that will mature through accredited training and resources.

While these reforms will help change community attitudes and responses, shifting leadership to people with lived experience of mental illness or psychological distress means action will be needed at all levels. It is not the role of people with lived experience of mental illness or psychological distress to bring about changes in community attitudes and responses alone; a system has to be designed that respects and works alongside them, providing them opportunities to lead and make decisions. As the Victorian Mental Illness Awareness Council said:

> It is not appropriate to have consumers responsible for bringing about a major cultural change … The management of cultural change needs to rest with the management and leadership of the system both at the systems level and within each hospital and service.[15]

The reforms detailed in this chapter will set the foundations for a future system in which people with lived experience of mental illness or psychological distress are leading and influencing across all aspects of the mental health and wellbeing system.

18.1.1 Different experiences and perspectives

Throughout the course of its inquiry, the Commission has considered how the different sets of experiences, knowledge and expertise held by people with lived experience of mental illness or psychological distress and families, carers and supporters inform their perspectives in relation to themselves and to the wider system.

The Commission reflected on the different experiences of people with lived experience of mental illness or psychological distress and families, carers and supporters as well as the need for nuanced and tailored responses to respond to the different perspectives and experiences of these two distinct groups.

For example, the Consumer Foundations Working Group submitted:

> Mental health and the systems that surround it affect us all. But as consumers, we experience these impacts in a direct way, but often with limited avenues or space to advocate for change.
>
> Where spaces are created aside from clinical perspectives, it is common that consumers must share this space with carer perspectives. While there are significant shared interests between consumers and carers, there are also often significant differences in our positions and experiences.[16]

The Commission acknowledges that people with lived experience of mental illness or psychological distress are experts in their own life, just as families, carers and supporters are experts in theirs. While at times these groups may have shared interests, they speak from their own perspectives and experiences and at times may have different views.[17]

This potential for difference is not always undesirable, noting that people within the field of mental health and across other related disciplines often hold different views and perspectives. In many respects, creating safe spaces that actively seek to address power dynamics and allow for this healthy contestability of ideas may lead to more innovative practices that are respectful of people's different needs and experiences. A future mental health and wellbeing system will recognise the differing knowledge, expertise and perspectives of these two groups and create opportunities for dedicated spaces, such as services led by people with lived experience of mental illness or psychological distress, as well as avenues for these groups to come together, including in practice approaches that can involve a consumer's family, carers or other supporters.

Acknowledging these dynamics, the Commission has considered how the system can first meet the individual needs and preferences of people with lived experience of mental illness or psychological distress and, second, meet the individual needs and preferences of families, carers and supporters. While the reforms detailed in this chapter focus on creating an enduring foundation for the leadership of people with lived experience of mental illness or psychosocial distress, opportunities to better promote the leadership, contributions and involvement of families, carers and supporters are an important consideration, detailed in the next chapter of this report.

18.2 Shifting power

Complex power imbalances rooted in professional, historical, social and statutory hierarchies continue to influence the opportunities available for people with lived experience of mental illness or psychological distress to lead, shape and participate in Victoria's mental health system.

Power can be understood as the ability to influence or control, and it can be held and distributed among individuals, groups and organisations. There are different forms and types of power operating across different structures and environments.[18]

Many aspects of Victoria's mental health system are characterised by 'old power', a currency held by a privileged few to the exclusion of others, with a focus on consumption, ownership and control.[19]

This form of power is evident in some of the professional and institutional hierarchies that operate in Victoria's mental health system. It is also often evident in the lack of structural support for people with lived experience of mental illness or psychological distress to lead and make decisions about the matters that affect their lives.

Experiences of stigma and discrimination related to mental illness or psychological distress demonstrate the power imbalances that permeate the current system. Some of the impacts of inadvertent experiences of stigma and discrimination on developing the peer workforce are described in *Peer Work in Australia: A New Future Mental Health System*:

> Inadvertent stigma and discrimination take many forms and can prevent the development of peer work [for example] ... Managers that do not support peer workers to apply for opportunities to advance their careers out of misguided concern that the advance would place extra pressure on the individual. This may be done out of concern that the peer worker is not capable of achieving in the new position not because there is any evidence of this but rather because of the knowledge that the person has lived experience.[20]

The language used to describe people's experiences of mental illness or psychological distress also exemplify the power structures present across Victoria's mental health system. Ms Janet Meagher AM, an advocate for people with lived experience of mental illness, described the importance of language in shifting culture and attitudes:

> I am quite against people being seen as a "patient" (i.e. as a passive recipient of service), because patienthood is only ever a small proportion of anyone's life. I want a person who uses mental health supports to be seen as someone with potential, who has something to offer the world, who just needs assistance at this point in time to enable them to move forward to achieve those hopes and dreams.[21]

These power imbalances can mean that the experiences, perspectives and expertise of people with lived experience of mental illness or psychological distress are not valued, understood or recognised. This poses a fundamental challenge to the realisation of the leadership and equal participation of people with lived experience of mental illness or psychological distress and can conflict with established human rights conventions.

One member of the Consumer Foundations Working Group described the negative impacts of power on consumers and peer workers:

> **the basic issue is power and the power imbalance is so strong, that consumers and peer workers who've been employed, talk to us about how, they are not respected, they are not listened to, they have no capacity—because they are not given the mandate to take it on.**[22]

Acknowledging, understanding and actively seeking to confront power imbalances is crucial to a future in which people with lived experience of mental illness or psychological distress are recognised as leaders and equal partners in system transformation. But the Commission has heard that some people do not recognise the power that operates within the mental health system. Ms Rachel Bateman, a witness before the Commission, reflected on the power held by the mental health workforce, '[o]ften people do not recognise the power that they hold, and it is hard to encourage them to proactively choose to view things differently.'[23] The first step, then, is to be able to openly explore power, before tackling its manifestations.

Shifting power is not about removal or loss. It is more about designing a system that acknowledges, challenges and actively seeks to redistribute power more evenly—providing space for those who have traditionally held less power with opportunities to lead and influence decision making on an equal basis to others. As Ms Cath Roper, Consumer Academic of the Centre for Psychiatric Nursing at the University of Melbourne, suggests:

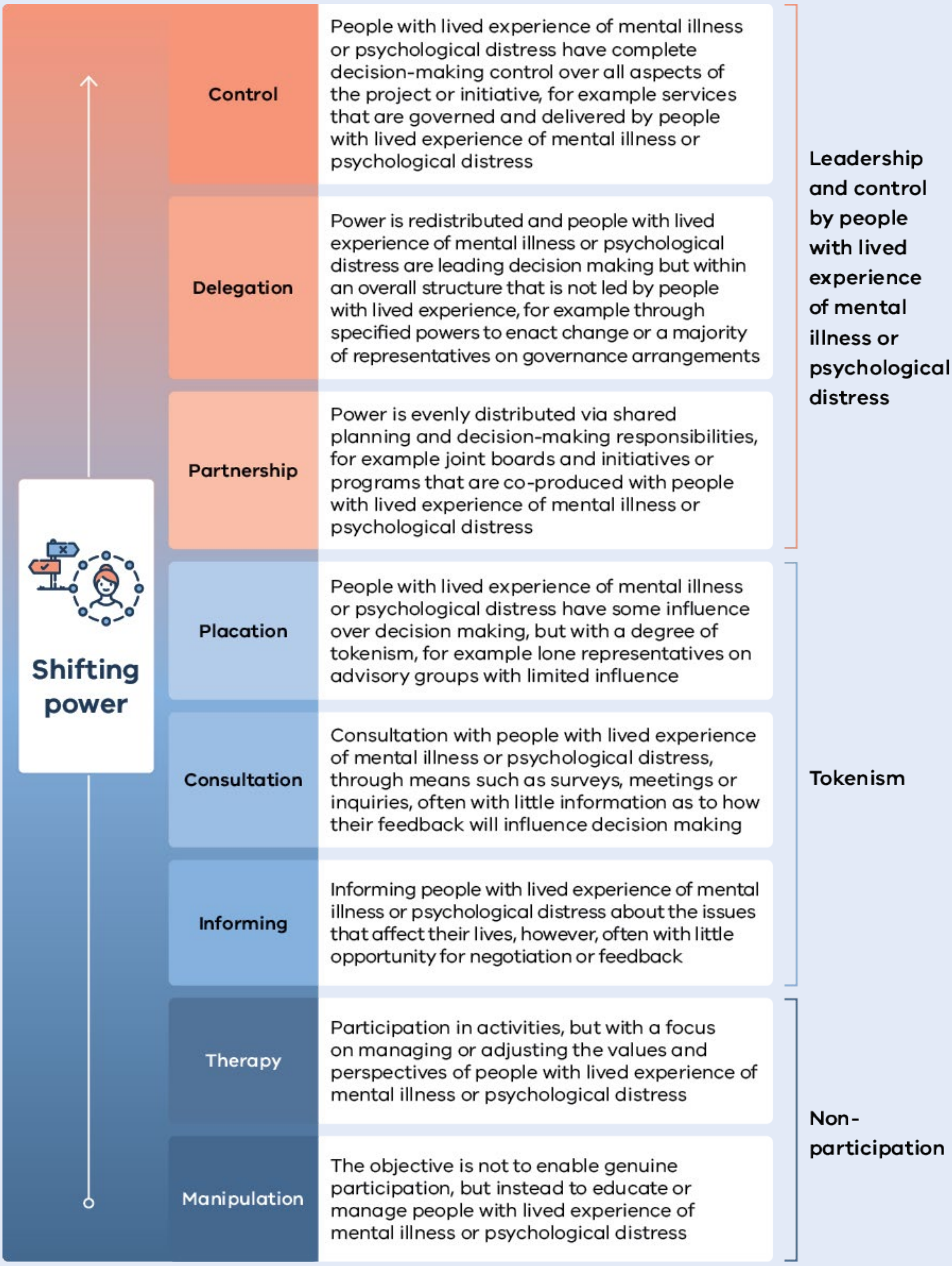
> **We need approaches in which we deliberately and proactively try to understand issues around power. We need to think consciously about whose voice might be the thinnest or the hardest to hear (and that approach will usually help the consumer).**[24]

It is important to consider the leadership and participation of people with lived experience of mental illness or psychological distress in light of power imbalances.

The sharing of power can take many forms and could include, for example, projects and initiatives that are co-produced,[25] founded on equal partnerships with people with lived experience of mental illness or psychological distress. It can also include leadership roles for people with lived experience of mental illness or psychological distress and founding organisations that are led by people with lived experience of mental illness or psychological distress.

A commonly cited way of conceptualising types of participation is by drawing on Arnstein's Ladder of Citizen Participation. As depicted in Figure 18.1, Arnstein describes eight levels of participation across a spectrum of shifting power, from non-participation to tokenism, and through to complete control.[26] Arnstein's approach suggests that there remains a risk of tokenism, where power is not shared or evenly distributed.

Figure 18.1: Types of participation, drawing on Arnstein's Ladder of Citizen Participation



Control	People with lived experience of mental illness or psychological distress have complete decision-making control over all aspects of the project or initiative, for example services that are governed and delivered by people with lived experience of mental illness or psychological distress	**Leadership and control by people with lived experience of mental illness or psychological distress**
Delegation	Power is redistributed and people with lived experience of mental illness or psychological distress are leading decision making but within an overall structure that is not led by people with lived experience, for example through specified powers to enact change or a majority of representatives on governance arrangements	
Partnership	Power is evenly distributed via shared planning and decision-making responsibilities, for example joint boards and initiatives or programs that are co-produced with people with lived experience of mental illness or psychological distress	
Placation	People with lived experience of mental illness or psychological distress have some influence over decision making, but with a degree of tokenism, for example lone representatives on advisory groups with limited influence	**Tokenism**
Consultation	Consultation with people with lived experience of mental illness or psychological distress, through means such as surveys, meetings or inquiries, often with little information as to how their feedback will influence decision making	
Informing	Informing people with lived experience of mental illness or psychological distress about the issues that affect their lives, however, often with little opportunity for negotiation or feedback	
Therapy	Participation in activities, but with a focus on managing or adjusting the values and perspectives of people with lived experience of mental illness or psychological distress	**Non-participation**
Manipulation	The objective is not to enable genuine participation, but instead to educate or manage people with lived experience of mental illness or psychological distress	

Source: Adapted from Sherry R Arnstein, 'A Ladder Of Citizen Participation', *Journal of the American Planning Association*, 35.4 (1969), 216–224 (p. 217) and Cath Roper, Flick Grey, and Emma Cadogan, *Co-Production: Putting Principles into Practice in Mental Health Contexts*, 2018, p.4.

Others have described the importance of changing from the rhetoric of 'participation' to that of 'leadership'—to challenge the attitudes held by some about the role that people with lived experience of mental illness or psychological distress can and should play, and further develop these leadership roles in practice. For example a 2005 edition of *Australasian Psychiatry* states, '[i]t is contended that the paradigm shift from consumer 'participation' to consumer 'leadership' may be more fruitful in realizing the considerable benefits that result from effective consumer involvement in mental health services.'[27]

Current approaches to partnering with people with lived experience of mental illness or psychological distress often sit at the lower rungs of Arnstein's Ladder and can be hampered by tokenism. Processes can also lack transparency about parameters and intent and may be inauthentic.[28] This needs to change, to ensure that a future mental health and wellbeing system is founded on the needs and perspectives of people with lived experience of mental illness or psychological distress and to drive broader cultural and behavioural change.

Proactively redistributing and balancing power across the redesigned mental health and wellbeing system will ensure that people with lived experience of mental illness or psychological distress have the same opportunities to lead and be influential, as afforded to others.

The Commission's reforms detailed in this chapter, complemented by other proposed reforms throughout this report, actively shift power by cultivating the leadership of people with lived experience of mental illness or psychological distress and encouraging approaches to participation that sit at the top rungs of Arnstein's Ladder of Citizen Participation.

18.3 Limited opportunities to genuinely lead and drive change

Over past decades, there has been a gradual shift to more active and measurable participation of people with lived experience of mental illness or psychological distress across some aspects of service delivery, policy and planning. This shift has been demonstrated by the development of numerous guidelines, policies and international human rights frameworks with varying degrees of emphasis on protecting the rights of people and their participation.[29]

Over time, Victoria has witnessed the expansion of lived experience workforces. Some limited leadership positions have been created and advisory groups both established and dissolved, with varying degrees of power and influence, to advise government and take on specific projects.[30] These developments have also been accompanied by the emergence of some limited mental health and wellbeing services delivered by people with lived experience of mental illness or psychological distress, typically operating within the governance structure of an organisation that is not led by people with lived experience.

While the shift to increase the participation of people with lived experience of mental illness or psychological distress has been visible across Victoria's mental health system, there are several structural barriers that continue to prevent people with lived experience of mental illness or psychological distress from genuinely leading and driving change. The most pervasive of these barriers is the effect of power imbalances, as discussed earlier.

The Commission was told that the current system can encompass unconsidered and tokenistic approaches to partnering with people with lived experience of mental illness or psychological distress. These approaches include consultation after major decisions have already been made, lone lived experience workers who are expected to represent the views of all people with lived experience of mental illness or psychological distress, inadequate remuneration and limited career pathways.[31]

Giving evidence in a personal capacity, Ms Indigo Daya, Consumer Academic of the Centre for Psychiatric Nursing at the University of Melbourne, conveyed some of these challenges:

> Most work in the sector still excludes consumers/survivors, and the next biggest group of work tends to use tokenistic consultation: where a big group can offer small feedback on something that is already mostly planned. We have no say in whether or not our advice is taken and often we never find out what happened with our advice. Often these opportunities are unpaid or at very low levels of remuneration.[32]

Also giving evidence in a personal capacity, Ms Julie Anderson, Senior Consumer Advisor in the Office of the Chief Mental Health Nurse and the Office of the Chief Psychiatrist, described similar experiences:

> There have also been instances when government has funded a service system and made a model of care without consulting consumers. At the time they consulted consumers on the model of care, they had already decided on what the model of care was going to be so the consultation was tokenistic and was not meaningful participation.[33]

Where people with lived experience of mental illness or psychological distress do participate, they often describe feeling disempowered, with their views and advice given insufficient consideration or being discounted altogether. Ms Bateman shared reflections from participating on various committees:

> I sit on more than 15 different committees at work, which is a lot, but I am the only consumer in my area. If I have an agenda item, I am usually given 5 to 10 minutes to discuss that item. In that kind of setting, there is no way I can get my views across, genuinely be heard, and have the opportunity to engage in discussion and explore multiple worldviews.[34]

The Commission has also been made aware of instances in which the needs and perspectives of some people with lived experience of mental illness or psychological distress are privileged over others.[35] For example, Ms Meagher described experiences of 'preferred consumers' being 'hand-picked' for particular positions:

> some of us are picked because we are "tame" and will "go along" with whatever is said and done … others of us are picked to "represent" because we are known and it's easier to pick us because we are a "known" element.[36]

In a 2020 article published in the *International Journal of Mental Health Nursing,* staff from the Centre for Psychiatric Nursing at the University of Melbourne argue that authentic and respectful participation must actively seek out diverse views and perspectives that include different experiences of treatment, care and support and that are relevant to the specific context and purpose.[37]

Elevating the perspectives and expertise of some people (while excluding others) means that opportunities are missed to genuinely engage with different experiences and to foster appreciation of diversity. This approach poses fundamental challenges to developing policies, programs and services that are nuanced and reflect the diversity of people's experiences and perspectives.

While there have been some notable exceptions, leadership opportunities for people with lived experience of mental illness or psychological distress within Victoria's mental health system remain a rarity. The few roles that do exist tend to be advisory, without the power to enact systemic change.[38] Mr Graham Panther, a witness before the Commission, suggests that shifting power to people with lived experience of mental illness or psychological distress beyond advisory positions requires that they have decision-making authority, with influence over policy and resourcing decisions.[39]

People with lived experience of mental illness or psychological distress holding positions as directors, heads of departments or funded agencies are not overt nor visible across the current system. As the Consumer Foundations Working Group reflected:

> As consumers, we do not see ourselves in any leadership positions in the current mental health system … there are no designated consumers in leadership roles in services, in the department, in regulators …[40]

The Commission was told, however, that there may be people with lived experience of mental illness or psychological distress who are working in leadership positions across Victoria's mental health system but have made the decision to not disclose their experiences.[41] Ms Elizabeth Porter, a witness before the Commission, reflected, '[i]n one organisation, I knew that a member of a leadership team had significant lived experience, and she didn't feel safe to disclose that to the lived experience team.'[42] This reluctance to disclose is likely a response to a system that continues to stigmatise and discriminate against people living with mental illness or psychological distress.[43] While it is possible that people may draw on their lived experience to inform the ways in which they lead, if this is not actively encouraged and supported, it may not always occur.[44]

The Commission was told that leadership roles for people with lived experience of mental illness or psychological distress are often not enduring. This may be explained in part by a lack of designated roles that are allocated to people with lived experience of mental illness or psychological distress.[45] Ms Erandathie Jayakody, a witness before the Commission explained:

> in Victoria in both the public and community sector, there have been lived experience positions at senior levels, which have been short lived. These positions get lost in restructures or when the person occupying the position leaves the role changes so that it is no longer designated as a lived experience role.[46]

Others have made similar observations. The Victorian Council of Social Service described how consumer leadership can sometimes be an afterthought:

> consumer leadership is sometimes "tacked on" instead of being embedded at all levels of an organisation. Services may employ a single peer worker, or establish a consumer advisory service, but they are unable to impact and influence the broader organisations practice or policy.[47]

Victoria Legal Aid reflected on the work required to further transform consumer leadership to realise its potential:

> Although there have been consumer positions in the mental health system for a long time, much more must be done to embed consumer leadership, at all levels, in order for it to be truly influential and to realise its potential in improving services.[48]

This variability in commitment and susceptibility to tokenism may be partly explained by discriminatory and stigmatising assumptions about the capabilities of people with lived experience of mental illness or psychological distress to lead and participate. There may be a perception that other types of experiences are more valued without adequate consideration of the unique expertise that people with lived experience of mental illness or psychological distress have to offer. Ms O'Hagan explained:

> There is still a lot of stigma, discrimination and negative assumptions about people with lived experience in the mental health system. I think some people still hold a view that people with lived experience don't possess the capabilities required to perform certain roles. There needs to be greater recognition of the expertise, supports and services that people with lived experience have to offer.[49]

The Commission considers that negative assumptions and experiences of stigma and discrimination may be partly fuelled by the use of language and words that do not reflect the perspectives and worldviews of people with lived experience of mental illness or psychological distress. For example, it has been suggested that using diagnostic terms can serve to label people,[50] posing a fundamental challenge to the participation and leadership of people with lived experience of mental illness or psychological distress.

A lack of access to professional development and training to support people with lived experience of mental illness or psychological distress to thrive in leadership roles has also been raised as a deficiency of the current system, which may inhibit people's potential.[51]

Resourcing and time constraints may also hamper opportunities to partner with people with lived experience of mental illness or psychological distress. As Professor Bruce Bonyhady AM, Executive Chair of the Melbourne Disability Institute at the University of Melbourne, giving evidence in a personal capacity stated:

> When people are under pressure to get things done quickly, they tend to take shortcuts—co-design will often be neglected in those circumstances. This is not to downplay the difficulties involved with co-design; it generally always leads to better outcomes.[52]

These challenges may also be coupled with a lack of commitment, understanding and structural supports to embed lived experience leadership and effective approaches to partnering with people with lived experience of mental illness or psychological distress.[53] In the current system, the leadership of people with lived experience of mental illness or psychological distress is often not considered an essential part of core business, meaning that it is susceptible to being marginalised by other priorities.

People with lived experience of mental illness or psychological distress must be integral to all aspects of a reformed mental health and wellbeing system. Challenging and transforming the rudimentary and somewhat stifled approaches to the leadership of people with lived experience within the current system will require foundations to be reset and power to be balanced.

This statement from Ms Roper resonated with the Commission:

> There are some examples of consumers in leadership roles, but those examples have not come about as a result of systemic change. We need to embed in the existing system structural expectations about consumers taking leadership roles. Unless we do that, nothing much will change, and those few existing leadership roles will remain vulnerable.[54]

The recommendations in this chapter are not simply about adding more roles throughout the system—they seek to deal with power imbalances, promote human rights and shift community attitudes and responses to a future where people with lived experience of mental illness or psychological distress are recognised as leaders and active partners in reforming the mental health and wellbeing system.

18.4 Constraints on systemic advocacy efforts

Systemic advocacy can be understood as promoting community and system-wide change to deal with structural inequalities and inadequacies. It is critical to ensuring individuals and groups of people are actively involved in decision-making processes about the things that affect them, galvanising community support for reform and promoting enduring change.

Systemic advocacy also plays a role in designing and developing new initiatives and ideas that reflect the needs, aspirations and desires of communities.[55] Some have also suggested it is vital to ensure the continued prioritisation of mental health and wellbeing.[56] The Consumer Foundations Working Group pointed out the important link between research that is led by and co-produced with people with lived experience of mental illness or psychological distress in informing systemic advocacy efforts.[57]

It is important to acknowledge that individual and systemic advocacy are not always mutually exclusive, with many advocacy organisations drawing on individual experiences to inform systemic advocacy and related reform ideas.[58]

The Commission's interim report noted that while there are examples of systemic advocacy in comparable systems that have resulted in considerable change in recent years, strong and sustained levels of systemic advocacy are not as apparent in the mental health sector.[59] For example, Every Australian Counts was a grassroots advocacy campaign made up of thousands of people living with disability, families, carers and workers that came together to advocate for the introduction of the National Disability Insurance Scheme.[60] It is arguably one of the driving forces behind the implementation of the scheme,[61] demonstrating the value of lived experience leadership in leading and driving change. As Professor David Copolov AO, Professor of Psychiatry and Pro Vice Chancellor Major Campuses and Student Engagement at Monash University suggested:

> In particular, the early history of the [National Disability Insurance Scheme] teaches us that we need … people with lived experience of the mental health system playing a key public role as advocates from the outset.[62]

The same ambitions are yet to be realised across Victoria's mental health system. One member of the Consumer Foundations Working Group described how advocacy in mental health was often thought of as an 'add on' rather than a foundational aspect of the system, '[s]o often advocacy is thought of systemically as a nice thing to add on, but not an essential embedded part of core business.'[63]

Advocacy organisations and countless individuals play important roles in gaining recognition of the perspectives and experiences of people with lived experience of mental illness or psychological distress. Yet inadequate resourcing and diverse priorities among advocacy organisations can limit their impact.

A lack of resources may have culminated in a tendency for advocacy entities to focus their efforts on the most pressing problems.[64] While understandable, this may have detracted from broader systemic advocacy projects and ambitious reform agendas. Dr Tricia Szirom, the CEO of the Victorian Mental Illness Awareness Council at the time of giving evidence, said:

> **Advocacy should be a blueprint for supporting mental health services as they develop. However, advocacy currently attempts to 'fill the gaps' missing in mental health service. In the future advocacy will identify and direct mental health services to address their own service gaps in a more timely and effective manner.**[65]

An article published in the 2015 edition of *The Australian Journal on Psychosocial Rehabilitation*, reflected on the historical lack of funding for advocacy entities, '[h]istorically, there have been competing demands for funding dollars between individual advocacy and other forms of existing or potential systemic advocacy, particularly for consumer organisations.'[66]

In its submission to the Productivity Commission, Mental Health Australia made similar observations, reflecting on the impacts of inconsistent and inadequate funding for peak bodies providing systemic advocacy:

> **Peak bodies, which carry out systemic advocacy, are subject to funding uncertainty created by unpredictable and short term contracts that do not provide enough funding to ensure organisational sustainability. This has resulted in inadequate support for robust systemic advocacy in a period of significant change and upheaval, precisely when such activities are needed most. It appears that both individual and systemic advocacy are largely missing from the ecosystem imagined by governments.**[67]

As well as a lack of resources and competing advocacy priorities, real or perceived conflicts of interest, where advocacy entities must raise concerns with the very bodies that fund them, may also influence and affect advocacy efforts.[68] At the systemic level, the Commission considers that these challenges are obstructing people with lived experience of mental illness or psychological distress from leading and influencing change.

Systemic advocacy will be integral to a future mental health and wellbeing system where people with lived experience of mental illness or psychological distress are respected as equal partners and leaders, and their participation in public life is promoted.

18.5 Cross-cutting reforms to strengthen the leadership of people with lived experience of mental illness or psychological distress

The experiences, preferences and expertise of people with lived experience of mental illness or psychological distress must be integral to the implementation of all recommendations in this report.

Victoria Legal Aid expressed a similar belief:

> People whose lives are directly affected by the mental health system should shape and have influence over the re-imagined mental health system that emerges from the Royal Commission. In examining and reforming Victoria's mental health system, consumers must be central, not just as users of the services, but in co-producing, delivering and evaluating them.[69]

As described earlier, and building on the recommendations in the interim report, the Commission recommends a number of complementary reforms that will embed leaders with lived experience of mental illness or psychological distress throughout the reimagined mental health and wellbeing system, detailed throughout this report.

As described in Chapter 27: *Effective leadership and accountability of the mental health and wellbeing system—new system-level governance*, the Department of Health must lead by example in paving the way for the expanded leadership of people with lived experience of mental illness or psychological distress. This includes employing people with lived experience of mental illness or psychological distress in multiple and substantive positions, including leadership positions in the Mental Health and Wellbeing Division in the Department of Health. These positions will ensure people with lived experience have an enduring and influential role in government decision making, with particular regard to implementing the Commission's recommendations and developing policy decisions related to mental health and wellbeing.

Further, as established in Chapter 5: *A responsive and integrated system*, people with lived experience of mental illness or psychological distress will also be represented on the Commission's recommended Regional Boards. Here they will play a role in decision-making with respect to service and capital planning, commissioning mental health and wellbeing services, alongside other related services, workforce planning, as well as research and evaluation initiatives. These arrangements will ensure the views, experiences and perspectives of people with lived experience of mental illness or psychological distress are a part of planning and resourcing decisions, driving progress towards a system that recognises and responds to the differing needs of consumers.

A reimagined mental health and wellbeing system will also see new service providers led by people with lived experience of mental illness or psychological distress emerge. This includes, for example, investment in consumer-led innovative 'safe spaces' and crisis respite facilities as stated in Chapter 9: *Crisis and emergency responses*. As established in Chapter 5: *A responsive and integrated system*, the Department of Health and Regional Boards will support providers, including services led by people with lived experience of mental illness or psychological distress, to thrive and develop over time as part of a diverse service offering. This endeavour will also be supported by a new set of service standards, with tools, resources and supports to develop the capabilities of providers, including providers led by people with lived experience of mental illness or psychological distress, described in Chapter 28: *Commissioning for responsive services*.

A number of future community mental health and wellbeing services will be delivered in part by lived experience workforces. Acknowledging the priority reforms put forward in the Commission's interim report to support, expand and establish lived experience workforces as a recognised profession, Chapter 33: *A sustainable workforce for the future,* details a number of additional priorities to support the growth of a more diverse lived experience workforce, with a range of new and expanded roles. This ambition will be supported by a new whole-of-workforce approach to develop the collective values, knowledge, skills and attributes the workforce needs to provide consumer-focused, recovery-oriented treatment, care and support.

As described in the Commission's interim report, the Collaborative Centre for Mental Health and Wellbeing, with joint executive leadership from a person with lived experience of mental illness and a clinical academic, will lead exemplary practice for the leadership of people with lived experience of mental illness or psychological distress in the design, development and co-production of research.[70] The Commission recommends a number of additional reforms in Chapter 36: *Research, innovation and system learning,* to strengthen the role of people with lived experience of mental illness or psychological distress in research and innovation. This includes calling on the Collaborative Centre to have a priority focus on research that is co-produced and led by people with lived experience of mental illness or psychological distress, with a focus on experiential knowledge,[71] as well as the creation of innovation networks supported by flexible funding to expand and diversify innovative practice across the mental health and wellbeing system. The recommended innovation collaborative networks will include a flexible and evolving group of partners, including people with lived experience of mental illness or psychological distress, ensuring they have influence over the design and development of promising innovation.

In addition to roles specified in other recommendations, it is imperative that the Victorian Government continues efforts to develop key roles across the mental health and wellbeing system for people with lived experience of mental illness or psychological distress. This chapter makes specific recommendations to support this endeavour, as detailed in the following sections.

Collectively, the Commission's reform approach will fundamentally alter the way in which people with lived experience of mental illness or psychological distress lead and shape decisions. No longer will the expertise of people with lived experience of mental illness or psychological distress be seen as the 'icing on the cake';[72] rather, they will have an equal seat at the table, working in partnership with others to lead and drive change.

18.6 Lived experience of mental illness or psychological distress within the Mental Health and Wellbeing Commission

Progressing towards a future that values people with lived experience of mental illness or psychological distress as active leaders and equal partners takes determination, leadership and the redistribution of power. The implementation of the Commission's recommendations is a rare opportunity to transform the leadership of people with lived experience of mental illness or psychological distress.

As established in Chapter 27: *Effective leadership and accountability of the mental health and wellbeing system—new system-level governance*, a new independent statutory authority— the Mental Health and Wellbeing Commission— will provide strong system leadership and keep government and the system accountable to the Victorian community. The Mental Health and Wellbeing Commission will exemplify and enable the leadership of people with lived experience of mental illness or psychological distress across the redesigned mental health and wellbeing system.

To set the foundations for lived experience leadership, the Commission recommends that at least one Commissioner within the Mental Health and Wellbeing Commission has lived experience of mental illness or psychological distress. All appointments to the Mental Health and Wellbeing Commission will be merit-based, with lived experience of mental illness or psychological distress made explicit as a condition of at least one appointment, which will be established in legislation and made by the Governor-in-Council. The new Mental Health and Wellbeing Commission will also include designated roles across its structures that only people with lived experience of mental illness or psychological distress can apply for.

The new Mental Health and Wellbeing Commission will, as part of its broader functions, promote the leadership and the full and effective participation of people with lived experience of mental illness or psychological distress in decision-making processes about policies and programs, including those directly concerning them. The Mental Health and Wellbeing Commission will act as a statewide voice, representing the diversity of people with lived experience of mental illness or psychological distress across age ranges, locations, experiences and backgrounds (refer to Figure 18.2).

Having designated leadership positions within the new Mental Health and Wellbeing Commission held by people with lived experience of mental illness or psychological distress will be critical to ensuring these arrangements are meaningful rather than tokenistic.

Victoria is falling behind other jurisdictions with respect to leadership roles for people with lived experience of mental illness or psychological distress, and the absence of these voices is a detriment to individuals, to the operation of the system itself and to the quality of mental health policy and reform processes.

Figure 18.2: Responsibilities of the new Mental Health and Wellbeing Commission to elevate the leadership of people with lived experience of mental illness or psychological distress

The Mental Health and Wellbeing Commission

A statutory authority, established in legislation with responsibility for elevating the status of mental health and wellbeing; holding government to account; and exemplifying and enabling lived experience leadership.

A Chair Commissioner

Established in legislation and appointed by the Governor-in-Council.

Commissioners

Including at least one designated commissioner with lived experience of mental illness or psychological distress and a commissioner with lived experience as a family member or carer of a person with lived experience of mental illness or psychological distress, established in legislation and appointed by the Governor-in-Council.

Elevating the leadership of people with lived experience of mental illness or psychological distress:

- elevate the leadership and support the full and effective participation of people with lived experience of mental illness or psychological distress in decision making about policies and programs, including those directly affecting them
- develop and support the leadership capabilities of people with lived experience of mental illness or psychological distress through learning and development opportunities
- design and deliver initiatives to prevent and address stigma towards people living with mental illness or psychological distress
- design and deliver initiatives to develop awareness and understanding of the experiences and perspectives of people with lived experience of mental illness or psychological distress.

System monitoring and improvement, as detailed in Chapter 3: *A system focused on outcomes* and Chapter 30: *Overseeing the safety and quality of services*

Promoting the role, value and inclusion of families, carers and supporters, as detailed in Chapter 19: *Valuing and supporting families, carers and supporters*

Personal story:

Mary O'Hagan MNZM

As a young woman, Mary used New Zealand's mental health services for eight years. She said these experiences had a profound impact on her.

> Ever since then, I have worked to make a difference to the way society and services respond to people with major mental distress.

Mary has now been involved in mental health support for more than 30 years. She was an initiator of the mental health service user movement in New Zealand in the late 1980s, and since then she has occupied several roles, including mental health adviser to the United Nations and the World Health Organization and is a former New Zealand Mental Health Commissioner.

Reflecting on her time as a Mental Health Commissioner, Mary spoke about the need for more lived experience leadership.

> As a collective, we need to take up leadership roles. I was a Commissioner in the New Zealand Mental Health Commission … I was amazed at the power of position, which is quite ridiculous. I'd been an advocate, and nobody took any notice of me, and as soon as I became a Commissioner everyone [listened to] what I said. I was saying exactly the same thing!
>
> I think we need 'position power' in the mental health system. Very few of us have it.

Mary believes that roles for people with lived experience must go well beyond peer support.

> Importantly, roles for people with lived experience should not be limited to roles that require lived experience, like a peer support role. Rather, we need to develop the capacity for people with lived experience to take on generic roles—to be the managers, receptionists, chief executives, analysts, social workers, doctors or nurses. This would be one solution to the problem of low labour market participation of people with mental distress.

Following her role as a New Zealand Mental Health Commissioner, Mary established a peer-led social enterprise called PeerZone, delivering peer-led workshops for people with lived experience and providing group and one-to-one peer support.

> As a small business, one of the big difficulties we faced at PeerZone was that there were not many organisations in the mental health marketplace who wanted what we were offering—because the system is skewed towards 'pills and pillows' responses and traditional community service responses.

Mary advocates for growth in peer-led organisations and said more sustainable funding mechanisms are required.

> We need to nurture peer-led organisations and grow the peer workforce. The way the system currently operates, peer-led organisations tend to be poorly funded and they can't grow.
>
> To support peer-led organisations to flourish, we need to address the way the system as a whole is organised and the biases in the system which influence how we think about and value different ways of responding to people in distress.

In Mary's view, 'a transformation of the mental health system from within' is required to put the views and perspectives of consumers at the centre.

> We need to change the whole way we think about people with distress and about the system, so that we make decisions and distribute resources in a way that creates the space for the lived experience voice to be strong. Otherwise, the values and preferences of people with lived experience are no more than an afterthought, tacked on to a system that doesn't truly notice or value them.

Source: *Witness Statement of Mary O'Hagan MNZM,* 16 June 2020; Mary O'Hagan, First Person: The Role of Lived Experience in Shaping Mental Health Services (presented at the Communities in Control Conference, Melbourne, 2010).

Other jurisdictions have championed the leadership of people with lived experience of mental illness or psychological distress at the highest levels. For example, more than a decade ago Ms O'Hagan, who used New Zealand mental health services for eight years as a young woman, held the position as fulltime New Zealand Mental Health Commissioner (refer to personal story for further information).[73] Similarly, the New South Wales Mental Health Commission is currently led by part-time deputy Commissioners with lived experience of mental illness, with a requirement made clear in legislation that either the Commissioner or at least one Deputy Commissioner 'must be a person who has or has had a mental illness'.[74] More recently, one fulltime Mental Health Commissioner and two deputy part-time Commissioners were appointed in South Australia in 2020, with a requirement for 'lived experience of mental health as either a consumer of services or carer'[75] made explicit as conditions of their appointments.

To ensure the leadership of the new Mental Health and Wellbeing Commission is streamlined and able to make effective decisions across the breadth of its functions, the appointment of at least one Commissioner with lived experience of mental illness or psychological distress is preferred.

The Commission acknowledges that some people have provided a rationale for creating at least two or more positions when establishing new roles for people with lived experience of mental illness or psychological distress, to reduce the risk of isolation and tokenism.[76] The Commission has sought to achieve this through its aspiration for a future in which people with lived experience of mental illness or psychological distress are represented in multiple leadership positions across entities involved in the future mental health and wellbeing system. As described earlier, to begin this work the Commission has recommended creating substantive leadership roles for people with lived experience of mental illness or psychological distress with significant power and influence. These leadership positions will usher in collective learning opportunities in ways that have never existed before, providing opportunities for designated leadership positions and other roles performed by people with lived experience of mental illness or psychological distress to work together and learn from one another and others.

While the Chair of the new Mental Health and Wellbeing Commission is not designated as a position that must be held by a person with lived experience of mental illness or psychological distress, the Commission considers that a person with lived experience of mental illness or psychological distress who has the relevant skills and expertise can lead the Commission.

There should be an assumption that all Commissioner roles are fulltime-equivalent, with relevant supports and reasonable adjustments made. Flexible working arrangements, such as hours of work, days of work or location, should be made available to all Commissioner roles, to accommodate personal circumstances and individual preferences. The intent of fulltime-equivalent positions reflects the breadth of work required by the new Commission and a desire to mitigate against these appointments being tokenistic. A persistent voice and presence is pivotal to transforming lived-experience leadership and to countering the sometimes-held belief that people with lived experience of mental illness or psychological distress cannot handle fulltime work.[77]

Like with all individuals in leadership roles, proactive efforts must be made to support and build the strengths and capabilities of people with lived experience of mental illness or psychological distress who may hold a role as a Commissioner. Providing professional development and mentorship with a focus on leadership, policy making and government processes will be essential. This professional development should include supervision that is specific to the consumer perspective discipline[78] and/or co-reflection[79] as well as broader training and shadowing opportunities to support leaders to be influential in their roles.

This approach to the leadership of the new Mental Health and Wellbeing Commission, supported by designated positions for people with lived experience of mental illness or psychological distress across the Mental Health and Wellbeing Commission's structures and working alongside other leadership roles across the mental health and wellbeing system, will begin the work of shifting power and pave the way for greater lived experience leadership.

18.6.1 Responsibilities to elevate the leadership of people with lived experience of mental illness or psychological distress

All Commissioners in the Mental Health and Wellbeing Commission will work collectively to fulfil its broader objectives including to elevate mental health and wellbeing, to hold government to account and to exemplify and enable lived experience leadership.

Strengthening government accountability and delivering independent, statewide oversight of the whole system will require continuous collaboration between the Chair and Commissioners, noting that each will bring their own unique set of skills and expertise to their roles. The success of the new Mental Health and Wellbeing Commission will be measured on the ability of the Chair and Commissioners to harness each other's strengths, learn from one another and work together. These arrangements represent a new model of collaborative leadership within the reimagined mental health and wellbeing system, requiring new leadership skills and capabilities to shift power and reset culture and values.

The other responsibilities of the Mental Health and Wellbeing Commission, including system monitoring and improvement and promoting the role, value and inclusion of families, carers and supporters, are detailed in separate chapters in this report. The Commission's responsibilities to promote the leadership of people with lived experience of mental illness or psychological distress in decision making about the things that affect their lives are detailed in this chapter (refer to Figure 18.2). The Royal Commission considers that the initiatives described in the following sections should be prioritised by the new Mental Health and Wellbeing Commission as part of its lived experience leadership functions, following the establishment and recruitment phase.

These initiatives include practical ways to support the development of key leadership roles for people with lived experience of mental illness or psychological distress across the reimagined mental health and wellbeing system, as well as initiatives that focus on resetting culture and values and tackling stigmatising beliefs so that lived experience leadership can flourish.

18.6.2 Develop and support leadership capabilities

People with lived experience of mental illness or psychological distress have significant skills, experience and expertise to bring to the design and delivery of innovative services and to the creation of policy, systems reform and social change. They have expertise and wisdom that no one else has. Alongside this distinct knowledge and discipline of the consumer perspective,[80] people with lived experience of mental illness or psychological distress can offer a range of skills and strengths that are integral to a redesigned mental health and wellbeing system.

As Dr Pollock reflected:

> When we involve people with lived experience of mental distress and recovery in service design, development and delivery, and treat their knowledge and input as equal to other ways of knowing, then we understand things about what we are trying to do that we cannot find out any other way.[81]

Fostering and embedding this wisdom and expertise is vital to a mental health and wellbeing system that is compassionate. An article published in a 2018 edition of the *Psychiatric Rehabilitation Journal* suggested that true system transformation can only occur with the leadership of people with lived experience of mental illness or psychological distress:

> For true system transformation to occur, we argue it is essential for more attention and resources to be allocated to cultivating leadership skills among persons with lived experience of recovery and for opportunities to be created for such individuals to take on senior-level leadership positions within their respective countries and communities.[82]

Like all people in leadership roles, people with lived experience of mental illness or psychological distress must have opportunities to build and further strengthen their existing capabilities and skills so they can flourish as leaders and decision-makers. Opportunities for people to strengthen their leadership, governance and management skills will be important for leaders at all levels across the new system. This includes individuals who are stepping into executive leadership roles across the new system, for example the Mental Health and Wellbeing Division of the Department of Health and the Collaborative Centre for Mental Health and Wellbeing.

Currently, there are few opportunities for people with lived experience of mental illness or psychological distress to access relevant training, education and professional development opportunities focused on strategic leadership, governance and policy development, compromising their ability to be effective and influential in these roles. As Ms Jayakody stated:

> If we are to create career progression and introduce lived experience positions in senior management the workers need to have the appropriate training such as financial literacy, governance, management and leadership training. Such opportunities are rare for lived experience workers.[83]

The Consumer Foundations Working Group told the Commission that consumers are often required to perform leadership roles without the same structural supports and resources that can be provided to others, submitting that 'consumers are currently asked to enter spaces without the same resources, cultural legitimacy and professional supports to contest ideas with other stakeholders in the sector'.[84]

Evidence before the Commission suggests that additional training and professional development across a range of diverse areas is required to develop and build on the skills and capabilities of people with lived experience of mental illness or psychological distress.[85] In its report, *Sit Beside Me, Not Above Me*, the National Mental Health Commission made the following observations about the need to build capacity across a range of areas:

> Of itself, having a lived experience does not make an individual an expert in systems, strategy, governance, policy or service delivery. In the same way that training as a clinician … does not of itself equip a person with the expertise to sit on boards and national advisory structures … Building capacity in a broad range of areas – such as leadership, clinical and corporate governance, financial management, strategy, policy development, advocacy, conflict management, co-design, co-production, monitoring and reporting – is required to fill the increasing number of roles needed for a contemporary and future-focused system.[86]

An initial priority of the new Mental Health and Wellbeing Commission will be to co-produce leadership and learning and development initiatives with people with lived experience of mental illness or psychological distress. Initiatives should include training, professional development, mentoring and supervision, with a focus on leadership, policy making and government processes. Opportunities to connect with leaders with a range of expertise and skills, both within and outside of the consumer community should also be made available.

The Commission envisages that these opportunities will be made available to all executive teams with leadership roles for people with lived experience of mental illness or psychological distress and emerging leaders within the reimagined mental health and wellbeing system. Leadership and learning and development initiatives will further develop the expertise and talent of individuals and embed a new culture that is founded on collaboration and equal partnerships.

Leadership and continuing learning and development initiatives would encompass both 'depth training', focusing on the foundations of the consumer movement, and 'breadth training', to develop a broader set of skills and capabilities, for people with lived experience of mental illness or psychological distress to lead across a diverse range of areas. Ms Daya explained:

> In terms of depth, there would be significant value in developing more training that addresses a deeper knowledge of the consumer movement and our history of debates and conclusions on many different issues in mental health ... Breadth training could add significant value in areas such as critical thinking, influence and negotiation, coproduction, practice supervision, leadership, research, governance, policy and management skills, depending on career interest. Potential learning streams in these and other breadth topics could be targeted towards different career pathways.[87]

Leadership and continuing learning and development initiatives will respond to the individual ambitions of people with lived experience of mental illness or psychological distress and reflect broader system-wide need. Based on comparative leadership initiatives and skills frameworks[88] and leadership opportunities identified in the evidence before the Commission,[89] this may include a focus on the following skills:

- fostering individual leadership styles and competencies, including career development planning
- leading transformational change, with a focus on executive leadership skills and driving collaboration for change
- broadening structures and systems that support people to lead, including mentoring, supervision and co-reflection
- identifying, influencing and driving strategic outcomes, including understanding government processes, policy design and development, and leadership on boards and advisory groups
- enhancing problem-solving skills, with a focus on critical thinking and designing and developing effective solutions
- developing stakeholder management skills, including co-production and partnering with others, with a focus on how to influence decision making and interpersonal skills
- managing people and teams, with a focus on fostering talent, building capabilities and leading and managing change.

The Commission's interim report called for deliberate and systemic efforts to promote and embed lived experience workforces in area mental health services and identified non-government organisations. To achieve this, it recommended, among other things, learning and development pathways, education and training opportunities and a statewide approach to organisational readiness training[90] to ensure all agencies receiving government funding for mental health and wellbeing services are equipped to support lived experience workforces.[91] Promoting the understanding and value of lived experience expertise and perspectives at all levels of an organisation is integral to the 'introduction, ongoing support and sustainability of lived experience work'.[92]

In addition, the Commission recommends a whole-of-workforce approach to capability development and training to be led by the Collaborative Centre for Mental Health and Wellbeing. As described in Chapter 33: *A sustainable workforce for the future*, these reforms focus on building the expertise of individual frontline workers to deliver treatment, care and support in the future mental health and wellbeing system. Leadership initiatives led by the Mental Health and Wellbeing Commission will have a broader focus, supporting executive teams with leadership roles for people with lived experience of mental illness or psychological distress and emerging leaders to lead and make decisions about the policies and programs that affect their lives, including engaging in the design, delivery and implementation of policy reform.

The new Mental Health and Wellbeing Commission may partner with other entities to design and deliver leadership training and education, including the new agency led by people with lived experience of mental illness of psychological distress recommended in this chapter and the Collaborative Centre for Mental Health and Wellbeing.

18.6.3 Prevent and tackle stigma

The new Mental Health and Wellbeing Commission will be responsible for preventing and tackling experiences of stigma related to mental illness or psychological distress. A Commissioner with lived experience of mental illness or psychological distress will play an important role, working alongside other Commissioners to deliver the Royal Commission's recommended lived experience-led initiatives to reduce stigma.

The new Mental Health and Wellbeing Commission will work in partnership with people with lived experience of mental illness or psychological distress to design and deliver long-term, evidence-informed stigma-reduction programs, focusing on organisational settings. It will also establish an anti-stigma community grants program aimed at communities and social groups at risk of stigma—for example, Aboriginal people, rural and regional communities and older Victorians—as recommended in Chapter 25: *Addressing stigma and discrimination*.

Dismantling stigmatising and discriminatory beliefs about people with lived experience of mental illness or psychological distress is central to a future in which the experiences, skills and expertise of people with lived experience of mental illness or psychological distress are valued as assets in leadership roles.

Despite some progress, stigma and discrimination remain pervasive influences on the lives of people with lived experience of mental illness or psychological distress, and these prejudiced beliefs are inhibiting people from leading and contributing on an equal basis. The Commission considers that this minimal progress may be explained, in part, by the fact that stigma reduction efforts do not always meaningfully partner with the people who are most affected by stigma and discrimination.

The need for the perspectives and experiences of people with lived experience of mental illness or psychological distress to be at the forefront of stigma-reduction efforts and innovations has been impressed upon the Commission.[93] As Ms Georgie Harman, CEO of Beyond Blue, reflected:

> Another opportunity to address stigma in Victoria is through lived experience leadership. People with an experience of mental health conditions are drivers of social change and should be supported and empowered to challenge stigma at all levels.[94]

Mr Panther said that current stigma-reduction efforts are sometimes designed and delivered without adequate input from people with lived experience of mental illness or psychological distress, thereby compromising their effectiveness:

> There are many, well-funded programs and campaigns that aim to 'raise awareness' or 'reduce the stigma' of psychological distress. But so often, these campaigns and programs are not run by people like us, and it shows. They often use the language of the system—a language of deficits and disorder that, to many of us, feels like a laundry list of our worst traits, rather than a description of our rich internal experience.[95]

The new Mental Health and Wellbeing Commission will be well placed to lead and build the evidence base for stigma-reduction efforts, with a view to progress towards an equal Victoria, where the human rights of people with lived experience of mental illness or psychological distress are promoted, as is their leadership and participation in public life.

As a public and statewide voice promoting the experiences and perspectives of all people with lived experience of mental illness or psychological distress, the new Mental Health and Wellbeing Commission will play a critical role in dismantling the discriminatory and stigmatising practices that persist and impact negatively on people living with mental illness or psychological distress, including preventing them from leading.

Across all stigma-reduction efforts led by the new Mental Health and Wellbeing Commission there will be an expectation that people with lived experience of mental illness or psychological distress are leaders, not only participants. Future stigma-reduction initiatives should see approaches to participation that sit at the top rungs of Arnstein's Ladder of Citizen Participation (refer to Figure 18.1), including some initiatives that are entirely led by and co-produced with people with lived experience of mental illness or psychological distress.

Confronting prejudice and stigmatising beliefs will not be the responsibility of people with lived experience of mental illness or psychological distress alone; rather, it will require continuous collaboration, connection and dialogue across the Victorian community.

This sentiment from Ms Julie Dempsey, a witness before the Commission, spoke to the importance of a shared response to tackling stigma:

> We are all someone else's someone else. Mental illness does not discriminate and neither should we. We need to share the struggle together, not push consumers to the fringe of common social existence.[96]

As a community, we must work together to build a compassionate and humane society that better understands and respects the profound experiences and perspectives of people with lived experience of mental illness or psychological distress.

18.6.4 A new language guide

The new Mental Health and Wellbeing Commission will develop and implement strategies that help reset the culture and values across the reformed mental health and wellbeing system so that the leadership of people with lived experience of mental illness or psychological distress can thrive.

Calls have been made to the Commission for support and resources to improve the way in which government and service providers support lived experience leadership. As Victoria Legal Aid submitted, '[g]uidance should be developed to support mental health services to embed consumer leadership and advocacy (e.g. how to establish, consult with, and implement recommendations from Community Advisory Committees).'[97]

The use of language is central to progressing the leadership of people with lived experience of mental illness or psychological distress. Language is powerful and plays an influential role in shaping people's beliefs and attitudes. Thus, an important part of addressing stigma and discrimination and progressing towards a society that values people with lived experience of mental illness or psychological distress as leaders and change-makers is using language that accurately reflects the diversity of people's experiences. As the Victorian Mental Illness Awareness Council stated, '[a] key part of cultural change is the adoption of more appropriate language which describes the world as we want it to be.'[98]

As an initial priority, the Commission suggests that the Mental Health and Wellbeing Commission lead a project, in co-production with people with lived experience of mental illness or psychological distress, to develop a language guide that acknowledges and respects the diversity of experiences, language use and worldviews of people with lived experience of mental illness or psychological distress.

Rather than providing singular language suggestions, the language guide will make space for difference and foster appreciation of diversity. This approach reflects the fact that, as observed in the Commission's interim report and elsewhere in this report, 'there is no single set of definitions used to describe how people experience their mental health'.[99] The Victorian Mental Illness Awareness Council Declaration, for example, notes that there are varying ways of understanding the experiences that are frequently called 'mental illness'. It acknowledges that these experiences are informed by different worldviews and can be described using terms such as 'emotional distress', 'trauma', 'mental health challenges' and 'neurodiversity'.[100]

The guide will explain, in practical terms, how to enquire into people's worldviews and appreciate and use their preferred language and concepts. This guide will be used to inform development of subsequent policies, programs and services across government, funded organisations and service providers and will also be made publicly available.

The new Mental Health and Wellbeing Commission, with leadership from a Commissioner with lived experience of mental illness or psychological distress, will lead efforts to promote the language guide. This includes delivering training and education programs and working with government and service providers to support implementation.

The Commission's interim report and this report acknowledges the power of language and that words have different meanings for different people:

> Words and language can have a lasting impact on a person's life. They can empower and embolden. They can be used to convey hope and empathy. But they can also be divisive when used to dispossess and divide, and to stigmatise and label.[101]

Mr David Pearl, Innovator, Author and Public Speaker of The Studios, London, spoke in a personal capacity about the importance of words:

> the choice of words is important. The story is different if the words used are "mental wellness" and when the words used are "mental illness". Vocabulary shapes meaning, clearly. New words stimulate new ways to think about things.[102]

The origins of words and language are often not well understood. In her memoir, Merinda Epstein, a self-proclaimed 'old-campaigner', described how the frequently used term 'consumer' originated within a broader health context in the 1970s, reflecting the desire of health system users to make informed decisions about their treatment, care and support.[103] In the decades following, it is understood that a group of activists in the United States agreed to replace the word 'patient' with 'consumer,' a term that was subsequently adopted in Victoria in the 1990s, in the hope that it would improve the rights of people to make their own decisions and have their choices respected and promoted.[104]

Language preferences have continued to evolve to reflect the changing needs, preferences and experiences of people with lived experience of mental illness or psychological distress. As Ms O'Hagan described in her submission to the New Zealand Government Inquiry into Mental Health and Addiction, the *Wellbeing Manifesto*:

> From time to time we need to change our terminology. In the early 1900s people stopped using the term 'lunatic' and after World War Two they stopped referring to 'mental hygiene'. We think 'mental health' and 'mental illness' have now reached their use-by date.[105]

People's experiences of mental health services can influence how they identify with and use different words to describe themselves and their experiences. For example, a study by the Centre for Psychiatric Nursing at the University of Melbourne explored the relationship between people's experiences of treatment, care and support and the views they hold.[106] The study suggested that where a person has a positive experience of treatment, care and support, they may be more likely to embrace clinical and diagnostic terms such as 'patient'. In contrast, a person with negative experiences may prefer language that deliberately contrasts with this terminology, such as 'survivor'.[107]

While the Commission is bound by language used in its letters patent, evidence before it identifies future opportunities to refine language for a redesigned mental health and wellbeing system.[108] Language that reflects the dignity and diversity of people's experiences and perspectives is central to advancing cultural change towards a more equal and compassionate Victoria, where people with lived experience of mental illness or psychological distress are leaders, actively participating in public life.

18.6.5 Develop awareness and understanding of people's experiences

Opportunities for people to share their individual stories, and to have their experiences heard and acknowledged, is integral to a respectful and compassionate mental health and wellbeing system. Alongside individual benefits, the sharing of individual stories and experiences plays an important role in creating a system that responds to people's changing needs and expectations.

The new Mental Health and Wellbeing Commission will be adept at developing partnerships across the breadth of the Victorian public, including community leaders and the media. It will provide opportunities for people to share their stories so the mental health and wellbeing system can continue to improve and learn from these experiences.

Efforts must proactively contact and partner with people with lived experience of mental illness or psychological distress from all walks of life. Like any cross-section of the population, people with lived experience of mental illness or psychological distress are not a homogenous group—they have different experiences and hold different perspectives and views. Countering tokenistic approaches to engagement will require inclusive approaches and active efforts to partner with diverse groups and communities, including those who may have previously been silenced or had insufficient opportunities to participate.[109] This includes deliberate efforts to partner with Aboriginal people, culturally diverse people, people living with disability and LGBTIQ+ people.

Geographical location will not be a barrier because the new Mental Health and Wellbeing Commission will make concerted efforts to reach into metropolitan, rural and regional Victoria. This may be supported by an online and digital presence, as well as local and tailored approaches to engagement.

The new Mental Health and Wellbeing Commission, with leadership from people with lived experience of mental illness or psychological distress, will act as a public voice, promoting the experiences and perspectives of people with lived experience of mental illness or psychological distress across Victoria. This work will include engaging with the media to promote continuous improvement in reporting of mental health and wellbeing and to counter unfounded assumptions that perpetuate stigma and discrimination associated with mental illness or psychological distress.

The Commission's interim report noted that perspectives on community safety may be partly influenced by media coverage that does not accurately portray the experiences of people with lived experience of mental illness or psychological distress.[110]

Associate Professor Nicola Reavley, Head of the Population Mental Health Unit and Deputy Director of the Centre for Mental Health at the University of Melbourne, described the role of the media in influencing people's perception of mental illness:

> People are more likely to have stereotypical beliefs where they don't know anyone personally with a mental illness and are instead informed by representations of the mental illness in the media. These have a considerable impact, particularly in cases of extreme acts of violence, which often receive significant media coverage in Australia.[111]

In an individual contribution to the Commission, Greg Calder made similar observations:

> Media and social media platforms can often contribute to or heighten a perception that mentally ill people are incapable or violent, whereas in fact people who are mentally ill are overwhelmingly the victims rather than perpetrators of violence.[112]

The Commission recognises the significant efforts made to improve media reporting of mental illness and the notable example of SANE Australia's StigmaWatch program. Dr Michelle Blanchard, Deputy CEO of SANE Australia and Founding Director of the Anne Deveson Research Centre, explained how the program monitors and responds to stigmatising media reporting, providing advice to media professionals to promote responsible reporting.[113] Yet, despite the best efforts of many and some signs of progress, the Commission was told that much reporting still contains stigmatising content about mental illness, with media content described as 'inaccurate, irresponsible or offensive'.[114]

Inaccurate reporting may be partly influenced by the absence of the voices and perspectives of people with lived experience of mental illness or psychological distress, including reporting of mental illness that does not include interviews from those with first-hand lived experience.[115]

The Commission considers that proactive partnerships between the new Mental Health and Wellbeing Commission and media organisations are essential to changing the narrative and encouraging media content that is respectful and reflects the needs and perspectives of people with lived experience of mental illness or psychological distress.

The Mental Health and Wellbeing Commission will partner with and contact the media in a number of ways to promote the experiences and perspectives of people with lived experience of mental illness or psychological distress, ensuring they are represented in public reporting on the matters that affect their lives. For example, it could provide training, guidance and advice on how to develop media content about mental illness or psychological distress that is accurate and sensitive. The Mental Health and Wellbeing Commission could also promote the voices of people with lived experience of mental illness or psychological distress in media content and reporting.

The Royal Commission was told that co-producing media content with people with lived experience of mental illness or psychological distress is crucial to ensuring their representation in stories about the matters that affect their lives. For example, Ms Eastly said that on completion of the *No Feeling is Final* series (a podcast that was co-produced with the ABC and documented Ms Eastly's experiences of suicidality), the executive producer at the ABC reflected that working on the series had assisted him to develop a deeper understanding of the perspectives of people with lived experience of mental illness or psychological distress and the intricacies associated with reporting on these experiences.[116] To this end, Ms Eastly advocated for opportunities to build the capabilities of mainstream journalists and consumers with an interest in writing and media, including professional development and networking opportunities:

> I see these as being akin to leadership programs rolled out to educate, and empower consumer leaders, or leaders in other sectors. We need to develop allies in the media space to build on and make space for consumer voice and concerns.[117]

In addition, Ms Dempsey called for more investment in monitoring of stigmatising media reports, as well as reporting that actively sources contributions from consumers, families, carers and supporters to 'increase the understanding and appreciation of struggles faced by consumers, carers and their friends and families, fighting the ongoing and devastating nature of mental illness'.[118]

Accurate and sensitive media reporting that reflects a diversity of experiences and perspectives—and, most importantly, includes the voices of people with lived experience of mental illness or psychological distress—is essential to promoting a diversity of leadership and reducing stigma.

18.7 A new agency led by people with lived experience of mental illness or psychological distress

The Commission's interim report acknowledged that despite the positive impacts of services led by people with lived experience of mental illness or psychological distress, including improved outcomes and experiences for people and return on investment, the current suite of services in Victoria's mental health system is very narrow.[119]

The Commission subsequently recommended establishing Victoria's first residential mental health service designed and delivered by people with lived experience of mental illness or psychological distress. It also acknowledged that, at the time of preparing its interim report, Victoria lacked an organisation led by people with lived experience of mental illness or psychological distress able to offer an alternative to acute hospital-based care as a result of structural failings with the mental health system.[120]

To deal with this shortcoming, the Commission committed to help the emergence of organisations, including services led by people with lived experience of mental illness or psychological distress.[121] Evidence before the Commission indicates the benefits and value of these organisations, with many people and organisations advocating for their expansion across the system:

> I'd like to see the establishment of peer-led organisations, peer respites and peer support groups prioritised. We need alternative support options to become available in addition to the current mental health services in place.[122]
>
> it is now time for consumer-led services to be brought into the community, for and by people with lived experience around the impacts of mental health issues, consequences, strategies for coping and recovery, and ways people can re-position themselves into the world, perhaps finding strength in doing things more in their own terms.[123]
>
> It would be good if we had a collective of consumer thinkers, leaders and people with expertise around alternative forms of care. The government should bite the bullet and fund services that are governed and delivered by consumers.[124]

The Commission has reached the view that cultivating the emergence of organisations led by people with lived experience of mental illness or psychological distress requires accredited training and resources, including organisational supports to help these new initiatives to develop and flourish over time.

To this end, the Commission recommends establishing an agency led by people with lived experience of mental illness or psychological distress (the agency) to aid the development of other organisations, including services led by people with lived experience of mental illness or psychological distress. It will also deliver its own mental health and wellbeing services and create opportunities for networking and new partnerships across the community (refer to Figure 18.3).

Figure 18.3: Functions and governance arrangements of an agency led by people with lived experience of mental illness or psychological distress

The Department of Health establishes the governance of a non-government organisation to be the agency

This will involve running an open and transparent process, which is co-produced with people with lived experience of mental illness or psychological distress, to appoint the initial board.

Initial establishment

A new non-government organisation is established to be the agency and provide strategic direction and oversight

Governed by a skills-based board, chaired by a person with lived experience of mental illness or psychological distress and consisting of a majority of people with lived experience of mental illness or psychological distress.

A Chief Executive Officer to run the day to day operations of the agency and implement its functions

A majority of positions throughout the agency's structures designated to people with lived experience of mental illness or psychological distress.

A new non-government agency led by people with lived experience of mental illness or psychological distress

Accredited training, resources and service delivery

- Deliver accredited training and resources to aid the development of organisations led by people with lived experience of mental illness or psychological distress
- Develop and deliver mental health and wellbeing services led by people with lived experience of mental illness or psychological distress
- Develop and deliver training and support to mainstream organisations

Formal opportunities for collaboration

- Facilitate the physical co-location of new and existing organisations led by people with lived experience of mental illness or psychological distress
- Facilitate shared resourcing, accommodation and operational expenses
- Provide a centralised location for people to access services led by people with lived experience of mental illness or psychological distress

New partnerships and networks

- Create safe, welcoming and inclusive places for people with lived experience of mental illness or psychological distress, the organisations they lead and the Victorian community to connect and network
- Design and deliver programs, events and forums that celebrate and foster appreciation of the diversity of people with lived experience of mental illness or psychological distress

The agency will be established by the Department of Health as a new non-government organisation that is governed and delivered by people with lived experience of mental illness or psychological distress. The Commission recommends that the agency has a set of functions that will enable it to aid the establishment of new organisations led by people with lived experience of mental illness or psychological distress, create opportunities for networking and help it interact with the breadth of the Victorian community (refer to Figure 18.3).

Independence in the form of a new non-government organisation is preferred to ensure the agency is truly led by people with lived experience of mental illness or psychological distress. The Commission did consider whether there was an existing organisation that could perform this role, noting that there are established organisations within Victoria's mental health system that play an exceptional role in advancing the leadership of people with lived experience of mental illness or psychological distress, including the consumer-led peak body the Victorian Mental Illness Awareness Council. For the past 40 years the Victorian Mental Illness Awareness Council has played a vital role promoting the rights and choices of people with lived experience of mental illness or psychological distress (refer to Box 18.1 for further information). It also played an important role throughout the Commission's inquiry, including supporting people who participated in the Commission's consultations, as described in Chapter 39: *The work of the Commission*.

As described earlier, advocacy plays a critical role in ensuring people with lived experience of mental illness or psychological distress are actively involved in decision making and in promoting community support for system reform.

The role of the Victorian Mental Illness Awareness Council is therefore essential, both to advancing the leadership of people with lived experience of mental illness or psychological distress and to progressing the Commission's reform agenda. Dr Szirom shared her hopes for the future of advocacy:

> Advocacy should be independent in funding and governance and hold services accountable. It will continue to be a voice for consumers and help identify what is and isn't working, and beyond the mental health system itself to social determinants. Advocacy will actively engage with and respond to minority groups.[125]

The Commission has reached the view that rather than recommending that the Victorian Mental Illness Awareness Council performs additional functions, a new non-government organisation will be established to be the agency and partner and work alongside it.

Recognising the significant contribution of the Victorian Mental Illness Awareness Council in advancing the rights, will and preferences of people with lived experience of mental illness or psychological distress, the Commission considers that service agreements between the Department of Health and the Victorian Mental Illness Awareness Council should be extended for at least five years.

Box 18.1: The Victorian Mental Illness Awareness Council

The Victorian Mental Illness Awareness Council has a long and proud history in progressing the rights, will and preferences of people with lived experience of mental illness or psychological distress across Victoria's mental health system. Established in 1981, it was originally created by two social workers who wanted to bring the experiences of people with lived experience of mental illness or psychological distress to the fore of the 'International Year of the Disabled'.[126] In the decades that followed it has continued to advocate with, by and for people with lived experience of mental illness or psychological distress.[127] The late 1990s saw the Victorian Mental Illness Awareness Council gain a reputation for its formidable approach to advocacy, and in the 2000s it played a pivotal role in supporting the growth of the consumer workforce.[128] Today, the Victorian Mental Illness Awareness Council is the peak Victorian non-government organisation for people with 'direct lived experience of mental health issues or emotional distress'.[129] It is entirely consumer-led and governed,[130] and strives to work towards a future 'where all mental health consumers stand proud, live a life with choices honoured, rights upheld, and these principles are embedded in all aspects of society'.[131]

Consumer-led advocacy is at the heart of the Victorian Mental Illness Awareness Council's approach. It performs its advocacy role at the individual, group and systemic levels with a focus on ensuring the rights and choices of people with lived experience of mental illness or psychological distress are respected and promoted. Alongside its advocacy role, it has a range of other functions, including delivering consumer perspective education and training, undertaking research, developing resources on a range of topics and working closely with other entities and across the sector more broadly on the development and implementation of projects and policies.[132]

As described earlier, while not discounting the significant efforts of many, funding constraints and diverse priorities among advocacy organisations limit their impact.[133] These responsibilities are only likely to intensify as Victoria's mental health and wellbeing system prepares for significant change and individuals and entities look to advocacy organisations for leadership and support. Funding certainty is critical to ensuring consistent and sustained levels of advocacy across Victoria's mental health and wellbeing system.[134] A funding agreement extension of at least five years will recognise the pivotal role the Victorian Mental Illness Awareness Council will play in working with the agency led by people with lived experience of mental illness or psychological distress. It will also provide it with continuity and certainty in delivering on its plan to continue elevating the experiences, perspectives and expertise of people with lived experience of mental illness or psychological distress across the future mental health and wellbeing system. Strengthening systemic advocacy via funding cycles of at least five years was also a key conclusion of the Productivity Commission's *Mental Health Inquiry Report*.[135]

As detailed in Chapter 27: *Effective leadership and accountability of the mental health and wellbeing system—new system-level governance and Chapter 37: Implementation*, the Victorian Government must also undertake proactive efforts to support and resource the Victorian Mental Illness Awareness Council, alongside other advocacy organisations and peak bodies, so it can lead and influence the significant changes associated with implementing the Commission's recommendations. These supports may include, for example, providing mentorship, executive coaching, training and professional development to ensure it can effectively engage and partner with implementers of the Commission's recommendations.

18.7.1 Accredited training, resources and service delivery

The Commission recommends that the agency aids the development of organisations led by people with lived experience of mental illness or psychological distress by providing accredited training and resources, including organisational supports. The agency will also be able to develop and deliver its own mental health and wellbeing services. This will be particularly important in the short-term, while services led by people with lived experience of mental illness or psychological distress are supported to develop and mature over time.

To perform its functions, the agency will establish itself as a registered training organisation. This will enable it to deliver accredited training focused on developing the capabilities of people with lived experience of mental illness or psychological distress to lead and manage their own organisations. This could include, for example, governance and corporate training. It may partner with an existing registered training organisation in the short-term.

Evidence before the Commission identifies the need for resources, including organisational supports and training to provide people with lived experience of mental illness or psychological distress with the support and resourcing they need to establish their own projects and initiatives. As Ms Eastly reflected:

> What is needed to establish and develop consumer-led services is significant long-term investment in the foundations that would make this genuine alternative a reality: … a long-term (10 years+) investment in skilling up of consumer-led organisations, including professional development to become sustainable, healthy businesses that provide competitive services to the public … support for strategic partnerships between lived experience-led organisations who are more matured, if sometimes from adjacent areas.[136]

Ms Daya made similar observations, advocating for a model built on maturation—that is, supporting services led by people with lived experience of mental illness or psychological distress to develop over time by providing professional supports:

> The following mechanisms could be implemented to enable the emergence of service provider organisations that are governed and delivered by consumers/survivors: … fund a staged approach that can grow over time. For example, fund small peer-run initiatives that allow skill development through experience. This could include funding small groups of consumers to run smaller scale peer support projects, like regular group programs at a neighbourhood house, or short-stay recovery camps, or even social enterprises. Funding could include access to lived experience mentoring, and/or other relevant mentoring or skills training …[137]

Similarly, reflecting on establishing an informal peer respite service, Ms Porter described the need for resourcing, training and supports to build the skills and capabilities of people with lived experience of mental illness or psychological distress to establish their own services:

> Setting people up to be able to resource their existing community connections and organising things like this would be great. We should help people to set up their own networks, to set it up for themselves. This takes a lot of skill and experience … But there are many people who don't have that level of resourcing or capability.[138]

Auspicing arrangements and partnership approaches—where an established organisation supports a new project to happen, for example, through sharing skills and resources and providing management and governance—have also been identified as essential to supporting and scaling up small organisations.[139] Mr Panther reflected on the importance of these arrangements in promoting the establishment of organisations run by people with lived experience of mental illness or psychological distress in a personal story. Further, Ms Lin Hatfield Dodds, Associate Dean for the Australian and New Zealand School of Government of the Crawford School, Australian National University, who gave evidence in a personal capacity, explained the effectiveness of these approaches:

> Resourcing a larger organisation in a community to act as a big sibling to a group of smaller ones can be quite effective. Or funding the creation of networks of smaller organisations to come together regularly to share information and experiences … Small organisations don't have the capacity to develop these kinds of support and development opportunities on their own.[140]

The agency will use various strategies to provide small-scale organisations, including services led by people with lived experience of mental illness or psychological distress, with the supports they need to develop over time. This includes auspicing arrangements, partnership approaches and accredited training described earlier.

Being able to learn from similar models, from organisations and from peers has also been identified as key to success.[141] The agency should partner with other entities to design and deliver accredited training and resources, including the recommended Mental Health and Wellbeing Commission and the Collaborative Centre for Mental Health and Wellbeing, as well as international peers to learn from their experiences. As described in Chapter 33: *A sustainable workforce for the future*, these reforms will occur in parallel with the Commission's recommended whole-of-workforce approach to capability development and training. Led by the Collaborative Centre for Mental Health and Wellbeing, these reforms will build the expertise of the frontline workforce, including the lived experience workforces, to deliver consumer-focused, recovery-oriented treatment, care and support.

The Commission is aware that it will take time and resources to cultivate the emergence of new organisations led by people with lived experience of mental illness or psychological distress. Achieving the Commission's ambition for a future in which mental health and wellbeing services led by people with lived experience of mental illness or psychological distress are operating as part of a diverse service offering will be supported by a staged and deliberate approach that is built on maturation, supporting organisations to develop their capabilities over time. As established in Chapter 5: *A responsive and integrated system*, the Department of Health and Regional Boards will support providers, including services led by people with lived experience of mental illness or psychological distress, to thrive and develop over time as part of a diverse service offering.

Personal story:

Graham Panther

Graham has been a mental health advocate for many years. He is the co-founder of the Big Feels Club, an online mental health initiative, and Redpanther, a consultancy that combines consumer expertise and evidence-based service improvement.

Prior to moving to Australia, Graham worked in New Zealand with Mind and Body Consultants, a peer-led organisation that advocates for leading change in mental health services using lived experience of mental illness and recovery.

> There is no Victorian equivalent of Mind and Body we can point to in mental health—a large, thriving peer-led organisation operating a range of service contracts that were, until Mind and Body, delivered by mainstream agencies. There is no equivalent of Mary O'Hagan, a Mental Health Commissioner who openly talks about her experience of being in psychiatric hospitals and how those experiences have shaped her views.

Graham noted that while Victoria has seen a small growth in consumer leadership roles over the past decade, these opportunities have often been informal, with limited influence. Graham believes that real change is only possible when you give consumers the power to make policy and budget decisions.

> As a leader in this space, the Victorian Government can expedite the growth of lived experience leadership in two main ways. Firstly, they can do what New Zealand did: take a calculated punt on hiring people with first-hand lived experience into prominent positions of real influence.
>
> The second immediate way forward I see is for government to invest in developing more and better-resourced peer-led organisations in Victoria ... If lived experience expertise is to truly have a voice in shaping the future service system, we need peer-led organisations that advocate for and further develop that expertise, alongside mainstream bodies and agencies.

Drawing on his experience, Graham advocates for flexible approaches, and organisational supports and structures, to promote the establishment of services and organisations that are led by consumers.

> I would argue that having more peer-led organisations—services run 'by' us—can help support the development of services run 'as' us, over time, by which I mean, truly grassroots, peer-run offerings that fill the gaps that mainstream services can't easily fill.

> The Big Feels Club is a practical example. Our 6,000-odd community members tell us we're not like any mental health initiative they've ever come across, but one of the reasons we can take that fresh approach is because we're auspiced by Self Help Addiction Resource Centre (SHARC), an alcohol and other drug organisation with significant peer leadership at the top ranks. SHARC provides us with the support on governance and funding we would struggle to find elsewhere, while also understanding that what we're doing is not business as usual, and it's not meant to be.
>
> To be truly trusted by mainstream organisations, peer-led organisations also need to be supported from the outset to develop their leadership capacity.

Graham described how greater investment in consumer-led organisations can support the consumer workforce and consumer-led organisations to flourish.

> Mind and Body Consultants became a feeder organisation of sorts, the starting point for many talented people who would otherwise never have worked in mental health, and have since gone on to lead organisations of their own.
>
> If there are more peer-led organisations in the sector, or organisations like SHARC that clearly embrace the 'it's okay to not be okay' end of the service continuum, we will have more 'natural allies' in the sector—more places we could go for funding or other forms of support, without having to worry about losing the magic of what we do.

Source: *Witness Statement of Graham Panther*, 6 July 2020; Graham Panther, *Correspondence to the RCVMHS*, 2020.

In light of this long-term endeavour, the agency will also be able to deliver its own mental health and wellbeing services. To inform its approach to service delivery, it should engage with people with lived experience of mental illness or psychological distress, across age ranges, locations and backgrounds, to understand their needs and experiences and tailor its service delivery approach. Existing services led and delivered by people with lived experience of mental illness or psychological distress vary in scope and functions and include, for example, drop-in-style centres, residential homes and post-discharge support programs.[142] The agency should not be limited by the scope of existing services, but may look to learn from these approaches.

The service offering of the agency must also align with the recommended core functions for future community mental health and wellbeing services, as described in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*, and other service features recommended by the Commission. These features should also include consideration of the role and needs of families, carers and supporters. The agency may also look to partner and work with other providers. For example, as described in Chapter 9: *Crisis and emergency responses,* the Commission recommends the agency works with the Victorian Government and non-government organisations to establish innovative 'safe spaces' and crisis respite facilities that are consumer-led.

The agency will also be able to consult with and provide expert training and supports to mainstream organisations and service providers, with the intention of supporting them to embed lived experience leadership and better reflect the needs and experiences of people with lived experience of mental illness or psychological distress. This is noting that in the immediate to medium term, its focus should be on supporting the establishment of organisations led by people with lived experience of mental illness or psychological distress and delivering its own mental health and wellbeing services.

Specialist training, consultation and support will be determined by the agency, tailored to and reflecting the different outcomes and objectives of mainstream organisations and service providers. These opportunities could include, for example, practical guidance and support to increase understanding of the principles of co-production and effective approaches to partnering with people with lived experience of mental illness or psychological distress.[143]

Contributions to the Commission have raised the importance of supports, resources and training for mainstream organisations and service providers to genuinely engage and partner with people with lived experience of mental illness or psychological distress.[144] For example, Perinatal Anxiety & Depression Australia (PANDA) said:

> Meaningful consumer engagement is a skilled and iterative process. It requires that people and organisations have access to quality training and ongoing support to facilitate consumer engagement, and resources to ensure consumers are supported and paid for their time.[145]

Consultation and providing expert advice and supports to mainstream organisations and service providers will ensure the leadership of people with lived experience of mental illness or psychological distress is ingrained in organisational structures and cultures that prepare the system for a future in which people with lived experience are leading across all aspects of Victoria's mental health and wellbeing system.

18.7.2 Co-location of organisations led by people with lived experience of mental illness or psychological distress

The agency led by people with lived experience of mental illness or psychological distress will act as a hub for innovation and new initiatives. As an initial priority, it will facilitate the co-location of new and existing organisations, including services led by people with lived experience of mental illness or psychological distress. This should be facilitated via an agreement between the agency and organisation, such as memoranda of understanding or commercial leases.

A centralised location for organisations that are led by people with lived experience of mental illness or psychological distress will be pivotal to the creation and exchange of ideas, fostering new partnerships and alliances and promoting collaboration between people with lived experience of mental illness or psychological distress and the organisations they lead.

Co-location will also ensure small-scale organisations led by people with lived experience of mental illness or psychological distress are financially viable and sustainable. For example, it would allow for shared resourcing, accommodation and operational expenses, including the use of flexible and multiuse spaces. The need for resourcing and sustainable funding is a crucial factor to support development of these organisations.[146] Early investment in providing these supports will set these organisations up for success over the long term, with the capacity to develop and mature over time.

Hosting organisations also has the added benefit of providing people with lived experience of mental illness or psychological distress with a centralised location to engage with peers and use services and supports from a home base. Alongside co-location, opportunities for other forms of collaboration are explored further below.

18.7.3 New partnerships and networks

The importance of building a community of leaders with lived experience of mental illness or psychological distress has been impressed upon the Commission.

Communities of place, identity and interest play a vital role in fostering appreciation of diversity, building connections and leading social change. Mr Rick Corney, a witness before the Commission, reflected on the importance of community, '[i]n my view, if you strengthen the individual, you strengthen the community; the community is the resource.'[147]

Some have reflected on the central role that communities play in fostering a shared sense of belonging and identity. Mr Andrew Jackomos PSM, Executive Director of Aboriginal Economic Development at the Department of Jobs, Precincts and Regions, and a Yorta Yorta man, said of culture and community for Aboriginal people:

> I know from what I have witnessed over my life time and particularly in the last twenty years, that connectedness to culture, country and community is the foundation stone for building stronger individual and collective identities.[148]

Others have noted the importance of communities and networks in supporting good mental health and wellbeing because they promote a sense of social connection and inclusion.[149] For example, witness Mr Al Gabb, a farmer who grew up in Skipton, described the strength and support of his local community:

> I've experienced a great sense of community and support. People in town know what I have been through and I walk through town with my head held high. I have received some inconsiderate comments, but I have also been told I am brave.[150]

Every community has its own unique identity and culture and the consumer community is no different. While it may be brought together by shared ideas, the individual experiences, perspectives and worldviews of the individuals within it are diverse, ever-changing and sometimes conflicting.

The need for greater investment in communities and places to network has been raised with the Commission. The Victorian Mental Illness Awareness Council, for example, advocated for investment in communities and places for people with lived experience of mental illness or psychological distress to collaborate, including community meeting places and networks, '[u]sing coproduction methods, community members can both contribute to community support spaces, and seek support from those spaces.'[151]

Similarly, Ms Sandy Jeffs OAM, a witness before the Commission, reflected on the importance of community for people to gather and have their experiences heard and acknowledged:

> The best thing about providing such a community is for people to have their mad comrades around them to offer support to each other and tell their war stories ... The problem is that there's nowhere for people to gather to tell their war stories - there are no drop-in centres, no art studios or places for people with mental illness to actually congregate and talk to each other, or support each other.[152]

The agency will create safe, welcoming and inclusive places for people to network and better understand the diverse, rich and powerful experiences of people with lived experience of mental illness or psychological distress. This will include opportunities for informal gathering places, discussion groups and forums. It will also sponsor and host a diverse range of programs and events that focus on celebrating the diversity of people with lived experience of mental illness or psychological distress and connecting community leaders.

Ro Allen, the Victorian Commissioner for Gender and Sexuality (now known as the Commissioner for LGBTIQ+ Communities), reflected on the importance of community support and community-led events in fostering a sense of pride, celebrating the diversity of difference and 'provid[ing] LGBTIQ people with the opportunity to connect and celebrate being themselves'.[153]

The agency must belong to everyone, with opportunities for all Victorians to be involved and feel they are valued, safe, included and respected. This includes deliberate efforts to partner with diverse communities and groups, including Aboriginal people, culturally diverse Victorians, people living with disability, LGBTIQ+ people and older Victorians. Networking opportunities, programs and events will be made available across the breadth of the state in a variety of accessible formats, including digitally, to ensure that geographical location is not a barrier, particularly for people living in rural and regional Victoria.

The agency will bring people with lived experience of mental illness or psychological distress together, creating opportunities for collaboration and shared learning while also acknowledging and respecting the individual identities of those within it. It will celebrate the diversity of difference and create opportunities for the Victorian community to understand the experiences and perspectives of people with lived experience of mental illness or psychological distress, and their powerful contributions.

18.7.4 Governance and initial establishment phase

As a first step, the Commission recommends that the Department of Health establishes the governance of a non-government organisation to be the agency, which will be overseen by a skills-based board chaired by and consisting of a majority of people with lived experience of mental illness or psychological distress.

Members must have a range of skills and experiences to represent the diversity of people with lived experience of mental illness or psychological distress, including across age ranges, types of mental health services accessed, backgrounds and locations. This includes people from diverse communities such as Aboriginal people, culturally diverse people, people living with disability, and LGBTIQ+ people.

Independent of demographics, identity and culture, people with lived experience of mental illness or psychological distress all hold different experiences and perspectives. Genuinely engaging with and fostering the diversity of these experiences needs an open-door approach that involves a variety of people, including those who may challenge the status quo and those who may not have been previously heard.[154]

Proactive efforts must also be made to support and build the capabilities of potential board members and staff, including providing professional development, training, mentorship, supervision and other tailored supports where required.

As is commonplace where government identifies a need or gap that could best be dealt with by an independent organisation, the Department of Health will support the initial establishment phase. This will involve running an open and transparent process to establish the board and giving the new non-government organisation legal status.

People with lived experience of mental illness or psychological distress must be involved in the process to establish the initial board. This could involve, for example, co-producing a set of criteria or skills matrix that defines desired expertise and experiences to guide the initial appointment of board members.

Following the appointment of an initial board and an establishment phase, the constitution of the agency would enable new directors to be removed and replaced from the board, without government involvement. This will ensure it is independent, led and governed by people with lived experience of mental illness or psychological distress.

Upon its appointment, the board will lead the design and development of the agency, co-producing it with people with lived experience of mental illness or psychological distress. This process would start with obtaining a building that is accessible, welcoming and inclusive, with enough space to support the co-location of new and existing organisations that are led by people with lived experience of mental illness or psychological distress.

The agency will also establish a strong digital presence, offering online resources, information, supports and services across the state in various accessible formats. Its virtual platform will ensure all people with lived experience of mental illness or psychological distress, including those living in rural and regional Victoria, can get vital resources and supports in one place.

The board will also lead the recruitment of the CEO to run the day-to-day operations and to implement the functions of the agency, with most positions throughout the organisation's structures designated to people with lived experience of mental illness or psychological distress.

The Department of Health will manage the funding contract with the agency and provide it with sustainable funding. Over the long term, it may be funded through more diverse means, including generating its own revenue to support its independence. For example, it is envisaged that the agency, in time, may seek funding via the Commission's recommended community collectives or may attract philanthropic investment. It may also consider a membership approach, corporate partnerships and funding opportunities associated with providing specialist training.

The Commission envisages that the agency led by people with lived experience of mental illness or psychological distress will lay the groundwork for a reimagined mental health and wellbeing system where these organisations are prosperous. Combined, the reforms detailed throughout this chapter and more broadly across this report will see people with lived experience of mental illness or psychological distress acting as leaders and agents of change across a reformed mental health and wellbeing system.

1 *Witness Statement of Honor Eastly*, 14 September 2020, para. 66.

2 In July 2020, the Consumer Foundations Working Group was established to provide advice to the Commission, particularly about reforms related to the leadership of people with lived experience of mental illness or psychological distress. While the Commission advocates for the leadership of people with lived experience of mental illness or psychological distress throughout implementation, the Commission's engagement process was conducted within the bounds of the *Inquiries Act 2014* (Vic), with final decision making on all matters in this report resting with the Commission. Refer to Chapter 39: *The work of the Commission*, for further information.

3 Consumer Foundations Working Group, *Correspondence to the RCVMHS: Consumer Leadership and Mobilisation*, 2020, p. 15.

4 *Witness Statement of Dr Sarah Pollock*, 14 May 2020, para. 71.

5 United Nations, *Convention on the Rights of Persons with Disabilities*, 6 December 2006, Article 1 states that Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. United Nations Treaty Collection, Chapter IV, Human Rights: 15. Convention on the Rights of Persons with Disabilities, Entry into Force: 3 May 2008, in Accordance with Article 45(1). New York, 13 December 2006, <treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4>, [accessed 18 December 2020] states that Australia issued a declaration to the Convention, stating that substituted decision making is permitted when it is necessary, when used as a last resort, and when subject to safeguards.

6 United Nations, Preamble (o).

7 United Nations, Article 3(c).

8 Royal Commission into Victoria's Mental Health System, *Interim Report*, 2019, p. 13.

9 The Commission uses 'lived experience workforces' as a broad term to represent two distinct disciplines—people with personal lived experience of mental illness ('consumers') and families and carers with lived experience of supporting a family member or friend who has experienced or is experiencing mental illness.

10 Royal Commission into Victoria's Mental Health System, *Interim Report*, pp. 391, 405, 491, 507 and 509.

11 Royal Commission into Victoria's Mental Health System, *Interim Report*, p. 2.

12 *Witness Statement of Mary O'Hagan*, 16 June 2020, para. 112.

13 Parallels can be drawn to women entering into historically male dominated workforces, refer to: Mariateresa Torchia, Andrea Calabrò, and Morten Huse, 'Women Directors on Corporate Boards: From Tokenism to Critical Mass', *Journal of Business Ethics*, 102.2 (2011), 299–317 (p. 311), which suggests that women board directors' contribution to innovation becomes evident when there is a critical mass of at least three women directors.

14 *Witness Statement of Robyn Kruk AO*, 4 May 2020, para. 32.

15 Victorian Mental Illness Awareness Council, *Consumer Led Transformational Change: Consumer Workshop and Survey Results*, 2020, p. 56.

16 Consumer Foundations Working Group, p. 10.

17 *Witness Statement of Indigo Daya*, 12 May 2020, para. 86.

18 Cath Roper, Flick Grey and Emma Cadogan, *Co-Production: Putting Principles into Practice in Mental Health Contexts*, 2018, p. 7.

19 Jeremy Heimans and Henry Timms, Understanding "New Power", *Harvard Business Review*, December 2014, p. 2.

20 Janet Meagher and others, *Peer Work in Australia: A New Future for Mental Health*, 2018, p. 57.

21 *Witness Statement of Janet Meagher AM*, 1 July 2019, para. 21.

22 RCVMHS, *Consumer Foundations Working Group, 16 July 2020: Record of Proceedings*, 2020.

23 *Witness Statement of 'Rachel Bateman' (pseudonym)*, 16 June 2020, para. 61.

24 *Witness Statement of Cath Roper*, 2 June 2020, para. 90.

25 Co-production involves people with lived experience of mental illness or psychological distress leading or partnering across all aspects of an initiative or program from the outset—that is, co-planning, co-designing, co-delivering and co-evaluating, refer to: Roper, Grey and Cadogan, p. 2.

26 Roper, Grey and Cadogan, p. 4; Sherry R. Arnstein, 'A Ladder Of Citizen Participation', *Journal of the American Planning Association*, 35.4 (1969), 216–224 (p. 217).

27 Sarah Gordon, 'The Role of the Consumer in the Leadership and Management of Mental Health Services', *Australasian Psychiatry*, 13.4 (2005), 362–365 (p. 365).

28 *Witness Statement of Erandathie Jayakody*, 4 June 2020, para. 68; *Witness Statement of Cath Roper*, para. 17.

29 Commonwealth Government, *National Mental Health Policy 1992*, 1992, pp. 7–8; Department of Health and Community Services, *Victoria's Mental Health Service: The Framework for Service Delivery*, 1994, p. 8.

30 Centre for Mental Health Learning Victoria, *History of Lived Experience Work in Victoria*, 2019, p. 1; Royal Commission into Victoria's Mental Health System, *Interim Report*, pp. 510–511; *Witness Statement of Kym Peake*, 24 July 2019, paras. 91–92.

31 *Witness Statement of Vrinda Edan*, 10 July 2019, para. 19; Ingrid Ozols, *Submission to the RCVMHS: SUB.0002.0019.0021*, 2019, p. 3; *Witness Statement of 'Rachel Bateman' (pseudonym)*, paras. 91 and 168; *Witness Statement of Erandathie Jayakody*, paras. 52 and 56.

32 *Witness Statement of Indigo Daya*, para. 113.

33 *Witness Statement of Julie Anderson*, 28 May 2020, para. 50.

34 *Witness Statement of 'Rachel Bateman' (pseudonym)*, para. 65.

35 RCVMHS, *Consumer Foundations Working Group, 14 August 2020: Record of Proceedings*, 2020.

36 Janet Meagher, 'Changing Perspectives on Consumer Involvement in Mental Health', *Health Voices*, 8, 2011, 27–28 (pp. 27–28).

37 Indigo Daya, Bridget Hamilton, and Cath Roper, 'Authentic Engagement: A Conceptual Model for Welcoming Diverse and Challenging Consumer and Survivor Views in Mental Health Research, Policy, and Practice', *International Journal of Mental Health Nursing*, 29.2 (2020), 299–311 (pp. 300–309).

38 *Witness Statement of Cath Roper*, para. 17.

39 *Witness Statement of Graham Panther*, 6 July 2020, para. 137.

40 Consumer Foundations Working Group, p. 18.

41 *Witness Statement of Erandathie Jayakody*, para. 44; *Witness Statement of Graham Panther*, paras. 128–129 and 132.

42 *Witness Statement of 'Elizabeth Porter' (pseudonym)*, 27 April 2020, para. 94.

43 *Witness Statement of Rita Brown*, 24 June 2020, para. 27; *Joint Witness Statement of Lisa Annese and David Morrison AO*, 14 July 2020, para. 24.

44 *Witness Statement of Graham Panther*, para. 129.

45 Louise Byrne, Anthony Stratford and Larry Davidson, 'The Global Need for Lived Experience Leadership', *Psychiatric Rehabilitation Journal*, 41.1 (2018), 76–79 (p. 76).

46 *Witness Statement of Erandathie Jayakody*, para. 50.

47 Victorian Council of Social Service, *Submission to the RCVMHS: SUB.0002.0029.0282*, 2019, p. 21.

48 Victoria Legal Aid, *Submission to the RCVMHS: SUB.0002.0030.0217*, 2019, p. 24.

49 *Witness Statement of Mary O'Hagan*, para. 103.

50 L. Johnstone and M. Boyle, *The Power Threat Meaning Framework: Towards the Identification of Patterns in Emotional Distress, Unusual Experiences and Troubled or Troubling Behaviour, as an Alternative to Functional Psychiatric Diagnosis* (Leicester: The British Psychology Society, 2018), p. 221.

51 *Witness Statement of Erandathie Jayakody*, para. 55; Consumer Foundations Working Group, p. 14.

52 *Witness Statement of Professor Bruce Bonyhady AM*, 16 June 2020, para. 55.

53 *Witness Statement of Erandathie Jayakody*, paras. 46–47 and 52; Perinatal Anxiety and Depression Australia, *Submission to the RCVMHS: SUB.0002.0030.0055*, 2019, pp. 4 and 28.

54 *Witness Statement of Cath Roper*, para. 43.

55 Productivity Commission, *Draft Report on Mental Health, Volume 2*, 2019, pp. 909–910.

56 *Witness Statement of The Hon. Andrew Robb AO*, 26 June 2019, para. 37.

57 Consumer Foundations Working Group, pp. 22–23.

58 *Witness Statement of Dr Tricia Szirom*, 12 May 2020, para. 24.

59 Royal Commission into Victoria's Mental Health System, *Interim Report*, p. 123.

60 Every Australian Counts, What Is Every Australian Counts?, <everyaustraliancounts.com.au/about/>, [accessed 11 May 2020]; Every Australian Counts, Journey So Far, <everyaustraliancounts.com.au/about/journey-so-far/>, [accessed 1 July 2020].

61 National Disability Insurance Agency, *Correspondence to the RCVMHS: CSP.0001.0001.0001*, 2020, p. 4; *Witness Statement of Professor Bruce Bonyhady AM*, para. 32.

62 *Witness Statement of Professor David Copolov AO*, 7 July 2020, para. 296(a).

63 RCVMHS, *Consumer Foundations Working Group, 14 August 2020: Record of Proceedings*.

64 Allan Pinches, 'Better Mental Health Advocacy: A "Virtual Panel" of Consumer Thinkers Explore Some Possibilities', *Australian Journal on Psychosocial Rehabilitation*, 2015, 24–30 (p. 25).

65 *Witness Statement of Dr Tricia Szirom*, para. 25.

66 Pinches, Better Mental Health Advocacy: A "Virtual Panel" of Consumer Thinkers Explore Some Possibilities, p. 24.

67 Mental Health Australia, *Submission to the Productivity Commission Inquiry into Mental Health*, 2019, p. 36.

68 Jenny Pearson and Associates Pty Ltd, *Research of the Models of Advocacy Funded Under the National Disability Advocacy Program Final Report*, 2009, p. 33.

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Chapter 19

Valuing and supporting families, carers and supporters

Recommendation 30:

Developing system-wide involvement of family members and carers

The Royal Commission recommends that the Victorian Government:

1. in addition to the nominated roles specified in other recommendations, develop key roles across the mental health and wellbeing system for people with lived experience as family members and carers.
2. enable the Mental Health and Wellbeing Commission (refer to recommendation 44) to:
    a. elevate the leadership and promote the valued role of family members and carers of people living with mental illness or psychological distress throughout the mental health and wellbeing system; and
    b. develop and support the leadership and governance capabilities of families and carers of people living with mental illness or psychological distress through learning and development opportunities.
3. ensure that:
    a. in commissioning mental health and wellbeing services, expectations are set for working with families, carers and supporters;
    b. families, carers and supporters are included in a range of therapeutic interventions in each Area Mental Health and Wellbeing Service; and
    c. working with families, carers and supporters is part of system-wide workforce training.
4. in addition to reforms to improve information sharing outlined in other recommendations, develop standards for services and practitioners to guide the sharing of appropriate information with families, carers and supporters.

Recommendation 31:

Supporting families, carers and supporters

The Royal Commission recommends that the Victorian Government:

1. by the end of 2022, commission non-government organisations to use consistent branding and deliver one family and carer-led centre in each of the eight regions (refer to recommendation 3(3)) to:

    - **a.** provide tailored information and supports for families, carers and supporters in the region;
    - **b.** work with families, carers and supporters to help identify their needs and connect them to the supports that will best respond to those needs;
    - **c.** provide access to increased funds for immediate practical needs including short-term respite (brokerage); and
    - **d.** deliver support for family and carer peer support groups in the region.

2. establish a statewide peer call-back service for families, carers and supporters caring for people experiencing suicidal behaviour.
3. ensure there is tailored information for families, carers and supporters, such as on the new statewide mental health website (refer to recommendation 6(4)).

Recommendation 32:

Supporting young carers

The Royal Commission recommends that the Victorian Government:

1. by the end of 2022, fund a non-government organisation such as the Satellite Foundation to co-design and expand the range of supports across Victoria for young carers and children and young people who have a family member living with mental illness or psychological distress.
2. by the end of 2022, broaden the scope and reach of the Families where a Parent has a Mental Illness program, including by:

   a. enabling each Area Mental Health and Wellbeing Service to employ new workers to support young carers in their local environment; and
   b. increasing the funding available to young carers to help with practical needs (brokerage).

3. strengthen identification and referral pathways for young carers through the mental health and education systems.

19.1 The Royal Commission's vision for families, carers and supporters

Many families, carers and supporters have shared their stories with the Commission. These are stories of dedication to the people they care for and support, and stories of a system that is failing to meet people's needs. They are also stories about hope for a better future.

Families, carers and supporters have much to contribute to a future mental health and wellbeing system, with lived experience knowledge gained from years (sometimes decades) of navigating a complex system—and for many, a passion and personal commitment to making the system better for others in the future.

The future mental health and wellbeing system will acknowledge that most consumers have relationships of care and support, and that these relationships play an important role in wellbeing and recovery.

This chapter focuses on the challenges that families, carers and supporters can experience, and makes recommendations to rebalance the relationship between the system and families, carers and supporters.

The future system will be accountable to families, carers and supporters. To support accountability, new family and carer governance and leadership roles will be created to ensure the needs, experiences and outcomes of families, carers and supporters are considered and shape the system.

The system will also be explicitly responsible for supporting families, carers and supporters. Working with the people in consumers' social contexts will be embedded in service delivery. This means that involving families, carers and supporters in care and recovery will become standard practice for all services, and an expectation from the government when commissioning providers.

Families, carers and supporters across the state will also have access to dedicated supports, including from eight family- and carer-led centres, and young carers will have access to tailored and intensive supports.

Together, these recommendations deliver on the vision the Commission expressed in its interim report for 'a system in which families and carers are supported by the mental health system in return'.[1]

Over time, the load that is currently carried by families, carers and supporters, and the trauma they themselves have experienced because of the mental health system, will ease. Families, carers and supporters will have confidence that the people they care for will receive treatment, care and support in a redesigned system that is more compassionate and more responsive.

The future system will also better support families, carers and supporters—both in their own right, and to help them to carry out their caring role.

Box 19.1: A note on terminology

The 'Terminology and language' section at the beginning of this volume defines the terms 'family', 'carer' and 'lived experience' in accordance with the Commission's letters patent.[2] Note in particular that 'family' is defined as including family of origin and/or family of choice.

The Commission acknowledges that the terms 'family' and 'carer' do not reflect the full range of relationships, social connections and supports that many people have in their lives, and the important role these relationships play as part of a support network. For example, in its interim report, the Commission noted that LGBTIQ+ communities, in particular, may draw on support from relationships beyond biological family.[3]

The terms 'family' and 'carer' are not interchangeable, and people may not identify with a particular term. Not all carers are family members, and family members do not always take on a caring role. Family members may, however, be valued supporters of a person experiencing mental illness or psychological distress, along with other people in that person's broader social and support network.

As Ms Rebecca Thomas told the Commission, 'I have never felt like the word carer was appropriate to my role, what I was, was part of my mums and my brothers support network, along with many other people'.[4]

'People with lived experience' is also defined in the Commission's letters patent to include 'people living with mental illness, their family members and carers'.[5] For clarity in this chapter, when the Commission refers to family and carer lived experience only, this is explicitly stated.

In this chapter, the Commission uses the term 'young carers' to describe young people who may be in a formal caregiving relationship (and eligible for supports such as funding). The term 'children and young people who have a family member experiencing mental illness or psychological distress' is used to describe children and young people who may or may not have a formal caregiving role, but may be affected nonetheless by mental illness or psychological distress in their family, whether that is experienced by a parent, sibling or other family member.

19.2 People live in a social context

Evidence suggests that Victoria's adult mental health system primarily takes an individualistic approach to treatment, care and support without consistently considering the social contexts within which most people live in the community.[6] This individualised approach means that the valuable role families, carers and support networks can play in a consumer's recovery is often overlooked by services, as is the notion that families, carers and supporters have needs in their own right.

In reality, people live within a relational, or a social, context. They interact with one another, form relationships and interdependencies, and influence one another.[7]

Data suggest that most people in Australia have relationships of support outside their household.[8] These social connections and relationships can be important for mental health, wellbeing and recovery.[9] Witnesses have also told the Commission that people may experience isolation despite having people around them, and that isolation and loneliness can significantly impact a person's wellbeing.[10] The Commission has therefore considered the importance of a mental health and wellbeing system that actively seeks to engage with support networks and harness the benefits they may bring.

Results of the Australian Bureau of Statistics' fourth General Social Survey, conducted in 2014, also suggested that people experiencing a mental health condition had similar levels of family and social connectedness as those not experiencing a mental health condition.[11] The General Social Survey conducted in 2019 indicated that people with a mental health condition continued to have similar levels of face-to-face contact with family and friends outside their household as people who did not have a mental health condition.[12] Results also indicated that fewer people experiencing a mental health condition were able to get support from outside their household during a time of crisis in 2019 (88 per cent) compared with 2014 (93 per cent).[13] However, these results did not examine the availability of support from within a person's household during a time of crisis.

The Commission takes as its starting point that most people live within relationships of care and support, and considers that this should also be the starting point for the design of the future mental health and wellbeing system. Dr Paul Denborough, Clinical Director of Alfred Child and Youth Mental Health Service and headspace, Alfred Health, giving evidence in a personal capacity, told the Commission that, 'in order to be effective, the mental health system must involve the patient's family and social network, and not just approach people as individuals'.[14]

In this context, we can learn from collectivist cultures that recognise the importance of family and community in wellbeing. For example, Aboriginal communities have a broad view of health, which 'does not mean the physical wellbeing of an individual, but refers to the social, emotional, and cultural wellbeing of the whole community'.[15] In New Zealand, the 'Whānau Ora approach focuses on the family, not the individual … Whānau Ora workers provide a lot of navigational support — they help to coordinate the various services or resources that a family needs to be a healthy family'.[16] In some southern African communities, *ubuntu* is a philosophy that embraces caring for each other's wellbeing and fostering mutual support;[17] it 'means that people are people through other people'.[18]

By necessity, due to the age of the consumers, Victoria's current child and youth mental health services take a less individualistic approach. Dr Denborough told the Commission, '[t]he adult system usually regards the individual as the client, whereas the child and youth system views the family unit as the client.'[19] Dr Denborough also told the Commission that young people aged 18–25 years would benefit from a system that supports family involvement in their care.[20] Professor Patrick McGorry AO, Executive Director of Orygen and Professor of Youth Mental Health at the University of Melbourne, giving evidence in a personal capacity, told the Commission that family is usually a 'vital scaffolding for the successful completion of the transition to mature adulthood and independent living'.[21]

The Commission acknowledges that any change to the individualistic culture in the Victorian mental health system as a whole will take some time, as this culture is deeply ingrained. However, the Commission's ambition is for a future where consumers, families, carers and supporters are more connected, more engaged and more supported. Support will be easier to find and to use. Services will routinely work with consumers in a way that has regard to their social context, and families, carers and supporters will receive information and education to help them with their role.

19.3 The different experiences and perspectives of consumers, families, carers and supporters

As it conducted its work, the Commission considered how the distinct experiences and knowledge of consumers, families, carers and supporters inform their views, particularly in relation to the wider system.

The Commission acknowledges that families, carers and supporters hold expertise in relation to their own lives. This is distinct from the expertise held by consumers. While at times these groups may have shared interests, they speak from their own perspectives and experiences, and at times they may have conflicting views.[22]

The Commission also notes that relationships of care and support are complex and bidirectional. As described in the Victorian Government's *Recognising and Supporting Care Relationships: A Department of Human Services Policy Framework*, there is a need to recognise 'the high degree of reciprocity and mutuality in care relationships'.[23]

The perspectives of consumers, families, carers and supporters must be considered, given the impact that decisions made in the mental health system have on both groups. To create nuanced responses for these diverse perspectives, the Commission has separated the different matters its inquiry must consider: first, how the system can most effectively support people to recover from mental illness,[24] and second, how to best support the needs of families and carers.[25]

Without separating these considerations, there is a risk of masking the differences in the lived experiences of consumers and the lived experiences of families, carers and supporters.

A human rights analysis can help to understand these broader perspectives, including what it means for the future mental health and wellbeing system to work with a focus on the whole person, rather than just a diagnosis or label—a person who exists in a social context.

19.3.1 A human rights approach

All publicly funded Victorian mental health services have a legal obligation under the *Charter of Human Rights and Responsibilities Act 2006* (Vic) to act in ways that are compatible with human rights.[26] All people have the right to protection from unlawful and arbitrary interference with their privacy. This includes the right to protection from unlawful or arbitrary interference with a person's autonomy and their inherent dignity.[27] These rights are about people being able to make decisions in relation to their own lives, including decisions about their bodies, what is meaningful and important to them, and the choice to take risks. Such rights are particularly important for consumers in the mental health system, because mental health services hold a lot of personal information and decisions about treatment, care and support can impact on individual autonomy.

All people also have human rights to family and social connection.[28] In the preamble to the *Convention on the Rights of Persons with Disabilities*, States Parties (of which Australia is one) recognise 'that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities'.[29]

Within this context, the Commission seeks to:

- acknowledge the social context that consumers live in
- acknowledge the substantial contribution families, carers and supporters make within the mental health system
- confront the barriers that currently exist for those who would like greater inclusion of their families, carers and supporters in their care
- provide support to families, carers and supporters to better meet their own needs.

Nothing proposed here in relation to families, carers and supporters is intended to detract from human rights, which are held by all people.

19.4 Families, carers and supporters are essential to the future mental health and wellbeing system

Families, carers and supporters make a substantial contribution to the wellbeing of the people they care for and support.

Ms Marie Piu, CEO of Tandem (Victoria's peak body representing family and friends supporting people living with mental health issues[30]—refer to Box 19.2) told the Commission, '[u]npaid mental health carers in Australia play an essential role in our society',[31] suggesting that:

> **Most people with mental health issues live in the community with family and friends supporting them. Mental health carers report that they provide care for the following reasons:** *first,* **because they believe they can provide better quality of care than they could otherwise afford,** *secondly*, **because of the bonds of family or friendship or** *thirdly*, **because no comparable or otherwise helpful service is available.**[32]

The contributions of families, carers and supporters benefit the mental health system as well as individuals and families. The Commission acknowledged this in its interim report, stating that '[t]he work of families and carers is crucial, not only for the people they look after but also for the functioning and sustainability of the mental health system as a whole'.[33]

The Commonwealth Department of Health and Ageing (now the Department of Health), in setting out *A National Framework for Recovery-Oriented Mental Health Services*, acknowledged the role and importance of many factors beyond the mental health system that contribute to a consumer's recovery, including not only families, but broader social connections:[34]

> **Most of a person's recovery occurs at home, so their family, friends, neighbours, local community, church, clubs, school and workplace have an important part to play.**[35]

As part of a support network, families, carers and supporters may take on multiple roles. For example, Dr Margaret Leggatt AM, Founding Director of Wellways Australia, Founder and patron of SANE Australia and board member of Tandem, outlined four main roles that families and carers assume in caring for someone living with a diagnosis of schizophrenia:

- seeking and sourcing of help for the person being cared for
- being the primary carer for the person
- being a support network for the person
- being the landlord or household supervisor for the person.[36]

The range of these caring roles will vary according to individual and family needs and circumstances, and the independence of the consumer.

Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services* formally recognises the role of families, carers and supporters in providing support in a redesigned mental health and wellbeing system (along with informal supports, virtual communities and communities of place, identity and location).

As well as making contributions on an individual level, families, carers and supporters have collectively made an important contribution to the mental health system over many decades. For example, in the Victorian context, Wellways, a not-for-profit mental health and disability support organisation,[37] was founded in 1978 (as the Schizophrenia Fellowship of Victoria) by 'families and community members to promote the welfare of people with schizophrenia and their families'.[38]

Dr Leggatt says of its establishment, '[w]e wanted to find the best ways for families and friends to help and support someone they loved to recover and lead a meaningful life.'[39] Dr Leggatt describes the foundation of the fellowship as the beginning of:

> a process to have families recognised as an important component of treatment and care—a long haul because of the existing clinical paradigm that believed in and practiced the exclusivity of the doctor–patient relationship.[40]

To give a current overview, in its interim report, the Commission estimated that there were more than 58,000 carers of people living with mental illness in Victoria in 2018–19, and that about 5,600 of these carers were aged under 25.[41] More recently, as outlined in *Victoria's Mental Health Services Annual Report 2019–20*, the then Department of Health and Human Services estimated there are 60,000 Victorians caring for an adult living with mental illness, with about 9,000 of these being young carers.[42] The Commission estimated that this group provided '$3.7 billion worth of unpaid care … annually in Victoria … ($3.1 billion after accounting for [deducting] welfare payments [from this figure])'.[43]

Box 19.2: Tandem

Tandem is Victoria's peak body representing family and friends supporting people living with mental health issues.[44] In its role as a peak body, Tandem:

- advocates for carer involvement in planning and care, participation in system change and support for families and carers
- promotes and supports mental health carer workforce development and leadership
- promotes and collaborates on the delivery of training on family inclusive practices for mental health professionals
- provides information, education and training to mental health families, friends and supporters
- collaborates on research and policy matters related to mental health carers
- administers the Carer Support Fund, which provides financial assistance to families, friends and supporters of people who are receiving services from a Victorian public mental health service or program.[45]

Tandem also runs a support and referral line with advisers and service navigators who provide carers with non-legal advocacy, peer support, assistance with the National Disability Insurance Scheme and connection to carer support groups.[46]

In its submission, Tandem told the Commission:

> Victoria can potentially have a world class mental health system. This system must be safe, inclusive, fair and well-funded. It must challenge the stigma that those with mental health issues and their carers face. It must have the resources to address all people's issues and to ensure that families and friends are seen as a critical part of the team that treat and manage mental health issues.[47]

As the peak body, and in light of the Commission's recommendations to increase family and carer involvement, the Commission envisages a substantial role for Tandem in a future mental health and wellbeing system that is more responsive to and inclusive of families, carers and supporters. Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance* outlines the Commission's expectation that the Department of Health will continue to fund Tandem to fulfil functions such as advocacy and participation in engagement activities run by government agencies.

Tandem also played an important role throughout the Commission's inquiry, including supporting families and carers who took part in the Commission's focus groups and facilitating meetings between its members and Commissioners. Tandem's role in helping to facilitate these engagement activities is outlined in more detail in Chapter 39: *The work of the Commission*.

Funding certainty is critical to ensure consistent and sustained levels of advocacy across Victoria's mental health and wellbeing system.[48] To support Tandem's critical role as the peak body, the Commission considers that service agreements between the Department of Health and Tandem should be extended to at least five years. This is consistent with the Commission's recommendation in Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress* for service agreements of at least five years with the Victorian Mental Illness Awareness Council as the consumer peak body. The Commission notes that the Productivity Commission reached similar conclusions in its *Mental Health Inquiry Report*, recommending that systemic advocacy is strengthened through funding cycles of at least five years.[49]

19.5 Concerns raised by families, carers and supporters about the mental health system

Despite their essential contribution to the mental health system, families and carers have consistently told the Commission that they do not feel adequately supported.

The challenges that families, carers and supporters face were outlined in detail in Chapter 9 of the Commission's interim report. A high-level overview of the concerns raised is provided in Figure 19.1. These concerns are explored in further detail throughout this chapter, as the Commission outlines its recommendations in relation to families, carers and supporters.

Figure 19.1: Concerns raised by families, carers and supporters

Concerns raised by families, carers and supporters

Lack of access to information about treatment, care and support

'Trying to get any sort of information or feedback was just about impossible'[1]

Lack of options in a crisis

'I'm always fearful [my son] may be injured by the police ... the real dilemma for me now is, I don't think I could call the CAT [crisis assessment and treatment] team'[3]

Lack of housing options

'And what keeps me awake at night is the idea of my son—what's going to happen to him in the future? Where is he going to go? Where is he going to live?'[5]

Feeling excluded by the system

'I wasn't treated respectfully. And so talking about communication, there was no good communication, so I didn't know what was going on'[7]

Limited opportunities for respite

'Carers need to be supported and provided opportunities that allow for a break. I am absolutely exhausted. I am doing 24-hour shifts, 7 days a week'[9]

Difficulties finding information about available supports

'my mum had a lot of trouble finding the right services for her. She spent nights just googling various questions such as: support for a partner to someone who has an addiction. She really struggled to find that information'[2]

Gaps in care options

'As soon as our young people need extra support, that next tier above the counsellor, that's where we struggle with getting them support'[4]

Safety risks in services

'My daughter was 18 and had lots of drugs to sedate her. She was vulnerable. We ended up taking shifts and staying with her in the hospital to keep her safe'[6]

Failing to use family and carer knowledge

'Why couldn't the authorities have taken a team approach and consulted people who actually knew this young woman? They could have talked to Dr D, who had spent hundreds of hours with Anna. They could have consulted John and Katie and me, who had loved and cared for her for 26 years'[8]

Stigma and discrimination

'My mother was ill. She had Schizophrenia. No worse than having diabetes or cancer yet people treated her like a second-class citizen when I was growing up. I never felt okay with telling my friends what was wrong with her. There was so much stigma and no insight or understanding'[10]

Source: 1. RCVMHS. *Box Hill Community Consultation – May 2019;* 2. *Witness Statement of Denna Healy*, 26 May 2020, para. 21; 3. RCVMHS, *Carers Human Centred Design Focus Group – Melbourne, Session 12:* Record of Proceedings, 2019; 4. RCVMHS, *Shepparton Community Consultation* – May 2019; 5. RCVMHS, *Carers of Children Under 12 Focus Group: Record of Proceedings*, 2020; 6. RCVMHS, *Warragul Community Consultation* – May 2019; 7. RCVMHS, *Carer Human Centred Design Focus Group – Information Sharing: Record of Proceedings*, 2020; 8. *Witness Statement of Mary Pershall*, 9 July 2019, para. 47; 9. *Witness Statement of 'Anna Wilson' (pseudonym)*, 3 August 2020, para. 76; 10. RCVMHS, *Preston Community Consultation* – May 2019.

19.6 Families, carers and supporters need support in their own right

Being a carer can be a rewarding role.[50] However, it can also take a toll on a carer's own health and wellbeing, and it can have financial implications due to both expenses incurred and effects on employment.[51]

While many of the issues families and carers raised with the Commission focus on their concerns for the person they care for, carers have needs in their own right.[52] As Ms Erin, Davies, witness, told the Commission:

> there were so many opportunities along the way for our family to be connected with services and supported. I feel that these opportunities were missed and turned into disasters. If we had been supported earlier on, it would have been better for both Matthew and our family.[53]

Professor Bruce Bonyhady AM, Executive Chair of the Melbourne Disability Institute at the University of Melbourne and giving evidence in a personal capacity, told the Commission that families and carers need to be supported, or else 'many of the informal supports that are provided by families and carers are at risk of being worn away or exhausted'.[54] Professor Bonyhady also stated that '[n]urturing and sustaining families and carers is a critical part of designing disability or mental health support systems. It is also essential for system sustainability.'[55]

Caring for someone living with mental illness is distinct from other types of caring roles. Reasons for this include: the need to provide higher degrees of emotional support; managing crises; maintaining vigilance to prevent self-harm or suicide attempts; having strained relationships; dealing with the unpredictable and episodic nature of care giving; and stigma and isolation.[56] According to Mental Health Carers Australia, '[p]roviding these supports, and a range of other day-to-day supports, long-term can have a significant impact on their economic security, health and wellbeing and education.'[57]

Families and carers often described their own experiences of caring and their interactions with the mental health system in terms of trauma. The following observations from two people highlight this:

> our daughter ... was too unwell to go into the private system and too well to go into the public system ... And that was absolutely traumati[s]ing. We just had to watch her get sicker and sicker and sicker. And we're completely powerless to do anything about it. And that was a situation I hope no-one else ever gets into.[58]
>
> When my son goes off his medication and medicates himself with alcohol, life becomes very difficult and stressful ... at times it has been so bad that I have had to sleep in my car. There have been hundreds of nights with no sleep, and not being able to work because I was so exhausted and I had to care for my son.[59]

Personal story:

Aaron and Kristy Robinson

Aaron and Kristy* care for their 22-year-old daughter, Thea*, who has multiple diagnoses including borderline personality disorder, obsessive compulsive disorder and generalised anxiety disorder. Thea has been hospitalised several times due to numerous suicide attempts and a serious eating disorder.

Caring for Thea has a significant impact on Aaron and Kristy's lives, causing them carer fatigue and ongoing financial and relationship stress.

> We have had no carer respite whatsoever throughout the time we have been Thea's carers. The stress we have been under for the past 10 years has been horrific.

Aaron and Kristy note that being a long-term carer for someone 'places a soul destroying burden on families, and affects the ability of these families to keep working'. They would like better financial support for carers of people living with complex and long-term mental illness.

Kristy has stopped work to care for Thea, and Aaron now works part-time nearby so he can be called on when there is a crisis at home. The financial pressures caused by Aaron and Kristy's caring responsibilities adds to what is an already stressful situation.

According to Aaron and Kristy, Thea requires constant supervision to remain safe. At times Aaron and Kristy have felt that Thea has not received sufficient care in a hospital environment, so they now remain with her even when she is in hospital.

Aaron and Kristy said they are not able to go out together, as one of them must be with Thea at all times.

> As carers we are unable to go out as a couple to dinner, the movies or to see friends, because at least one of us always has to be with Thea. Even if two support workers are at home, a parent always has to be there as well.

Aaron and Kristy would like carers to be supported by trained staff providing better treatment for complex, suicidal patients, as well as regular respite for carers.

> This respite could either be from other highly trained compassionate support workers coming into the family home … or from Thea going somewhere outside of the home where she is looked after, in a caring safe way.

Source: *Joint Witness Statement of 'Aaron Robinson' and 'Kristy Robinson' (pseudonyms)*, 12 June 2020.

Note: *Names have been changed in accordance with an order made by the Commission.

Families, carers and supporters also need to feel safe as well as supported. There can be tensions between consumers and their families, carers and supporters, particularly during times of crisis. In a focus group the Commission held with carers about crisis responses, one parent described their experience of trying to help during a crisis, when their child was not able to be at their best, and feeling as though they were seen as an enemy.[60]

Another participant described her experience of caring for her son, who became aggressive and violent towards her, and her concerns for her own physical safety as well as that of her daughter. She told the Commission that police and hospital staff have at times been dismissive of her attempts to seek help for her son, including one occasion where she says police refused to attend her home.[61]

Caring for someone with a mental illness can be a lifelong commitment. Families, carers and supporters may need different supports at different times in their life as their own circumstances evolve, and their caring roles and responsibilities change.

Responding to these changing needs requires a whole-of-life approach. Mind Australia, a community-managed specialist mental health service, endorses the *Carer Life Course Framework*.[62] The framework outlines six phases that carers can go through, and provides information about each phase. The phases are:

- awareness that something is wrong
- confirmation of mental illness
- adjustment
- management
- purposeful coping
- end of active caring role.[63]

The phases are not linear and carers will go through different phases throughout the course of their caring role. Carers will also need different supports, such as education and respite, during different phases.

Families, carers and supporters also have different experiences and face different challenges based on the nature of the caring relationship they are in as well as their own stage of life. The Commission heard from people who had been caring before they were 10 years old, and others who were caring into their 90s. This is explored in Figure 19.2 and the following sections.

Figure 19.2: Different relationships of care and support

Different relationships of care and support

Adult children

'My dad was asking me to get involved and the mental health service wouldn't involve me'[1]

Siblings

'I was once told that I wasn't a young carer, I was just being a good daughter or a good sister. … I was really angry because they don't see the things that I go through'[2]

Parents

'Your role as a parent is to nurture your child. But sometimes a parent needs some help, to really help those around them'[3]

Young carers

'I know mum's mental health, and sometimes I know what's going on more than the doctors do, but I am not asked my opinion or involved when she is in hospital'[4]

Other relationships

'Because of confidentiality, carers are not often equipped with the right information to help their friends and family. Sometimes people don't realise their best support is their family and friends – their carers'[5]

Partners

'Speaking to the spouse is important, because I had been there for everything, and knew [him] and could describe how he was to them'[6]

Older people (parents, grandparents, partners)

'I am 65 years old; widowed. I wonder what will become of my son when i am dead. I wonder about supported accommodation later in his life, or if he can live at home, having a case worker who visits frequently'[7]

Source: 1. RCVMHS, *Werribee Community Consultation – May 2019*; 2. RCVMHS, *Young Carers Human Centred Design Focus Group – Melbourne*, 2019; 3. RCVMHS, *Pakenham Community Consultation – April 2019*; 4. *Witness Statement of 'Emily John' (pseudonym)*, 15 July 2020, para. 17; 5. RCVMHS, *Mildura Community Consultation – May 2019*; 6. *Witness Statement of Katerina Kouselas*, 15 July 2019, para. 7; 7. David Dunne, *Submission to the RCVMHS: SUB.0002.0002.0116*, 2019, p. 4.

19.6.1 Young carers

In its interim report, the Commission acknowledged some of the challenges that young carers face. These include adverse impacts on education and employment opportunities, normalisation of the caring role, difficulties being fully engaged in their childhood and education because of their caring role, and feeling excluded from services during a parent's hospital admission or discharge.[64]

Ms Piu told the Commission that long-term caring can have a range of adverse effects on young carers, including 'poor educational attainment, low self-esteem, difficult transitions into adulthood as well as developing their own experiences of mental health issues'.[65] Young carers can also face practical challenges, such as difficulties getting to school and support services if they are not old enough to drive or cannot afford public transport, the financial impacts on their family when a parent has a mental illness, and difficulties managing social activities.[66] Young carers might also feel extremely isolated, and may assume that no one will understand their experience:[67]

> Children and young people in caring roles can be viewed with pity, and easily feel patronised. In reality many of them are extremely capable, resourceful and skilled at navigating the health care systems, at the same time as feeling overwhelmed and burdened at times.[68]

The *Victorian Carer Strategy 2018–2022*, which sets the direction for government to support carers, also outlines some of the challenges faced by young carers, including that a '[l]ack of support during a person's formative years can have lifelong effects on cognitive and social development, learning and education, work opportunities, finances, emotional and mental health and physical health.'[69]

Young carers have shared their experiences with the Commission. In his witness statement, Mr Nathan Turner said he has had to be an adult since he was 16 years old.[70] Mr Turner described having to take on additional responsibilities in his early teenage years:

> My mum began to get sick and so I started to take on more responsibility for things around the house. … I started to have responsibility for doing the shopping and helping around the house. I just took it all on because I felt like I had to and I didn't want to ask any questions. It was a lot to take on at such a young age.[71]

Mr Jesse Morgan, witness, told the Commission he was unaware of the financial supports that were available to him[72] and described the continuing challenges he experiences into adulthood as a result of being a carer throughout his teenage years:

> My caring role for mum was always my first priority growing up, to the detriment of my own life and development. I dropped out of year 12 as the caring responsibilities and my own mental health issues all got too much to be able to manage the workload. I feel like it has set me back in life.[73]

Miss Denna Healy, witness, told the Commission that she became a young carer at 16, after her father attempted to take his life. She took on household responsibilities and was an emotional support for her family. Miss Healy said, '[t]here was a period of time where I forgot about myself for a while.'[74]

Personal story:

Justin Heazlewood

Justin Heazlewood grew up in Tasmania in the 1980s and 1990s, an only child who never met his father. Justin became aware that 'something wasn't right' at a young age.

> At seven I remember lying in bed while Mum wailed in the bedroom next to mine … I wanted the crying to stop. This is my first memory of monitoring Mum's illness, something I would spend a lifetime doing. I didn't know it then but I was a child carer.

Justin's mother lives with a diagnosis of schizophrenia. By age nine, Justin could see patterns forming in her behaviour. He recalls that she was well half the time and unwell half the time.

Justin describes his Nan and Pop as his main source of support. He would call them often in his early teenage years, as his mother cried uncontrollably, and ask his Nan to come and get him. She was reluctant to interfere, but told Justin he could call whenever he liked.

When he was 14, Justin secretly made an appointment with his mother's regular GP.

> I told her in detail how bad Mum was. The crying, the swearing, the violent episodes. The GP said something about doctor–patient confidentiality and that was that.

Justin says it is inconceivable to him now that a doctor listened to his story and didn't take any action. He describes this as an appalling result and says it discouraged him from seeking help again for a decade.

> When I look back on my experience I am struck by the complete lack of support I received. At school there was not a single lesson spent on educating us about mental illness or self-care. At no point was the role of the school counsellor adequately explained to us. I was never prompted to tell anyone about any of my problems at home. Meanwhile Nan was delivering the message that I had to remain strong and carry on. There was definitely a stigma around mental illness and our family kept a tight lid on the silence around Mum's story.

Having fretted over his mum for years, Justin has also experienced challenges to his own mental health, both in his teenage years and as an adult. He experienced what he describes as a nervous breakdown at age 33.

After years living interstate and a period in which he distanced himself from his family, Justin returned to Tasmania in July 2019. His mum was accepted into the National Disability Insurance Scheme in December 2019. Justin says he and his mum are now closer than they've ever been.

> I have accepted that I must carry the burden of being an only child who cares for his Mum. At least now I am able to do so with the support I've always needed.
>
> As Justin Heazlewood, son of Maureen Heazlewood, my whole life has been forged by schizophrenia. It has shaped and misshaped the person I am. The secret life of being a child carer has taken a personal toll on me. I now experience mild depression and generalised anxiety disorder as a result of my complex developmental trauma ... I continue to accept my limitations while believing that recovery is possible.

Justin is now an Ambassador for Satellite Foundation, a Melbourne-based not-for-profit that supports young carers with a range of peer support programs, workshops and respite through activities such as overnight camps.

Source: *Witness Statement of Justin Heazlewood*, 22 April 2020.

19.6.2 Older carers

Older carers may be caring for someone who is a spouse, an elderly parent, an adult child, a grandchild, a sibling or another relationship. This may include taking on multiple roles at once, such as caring for an adult child and a partner, as the carer experiences ageing and manages their own physical and mental health and wellbeing.

The Commissioner for Senior Victorians told the Commission '[t]here is a high risk of carer burnout, particularly for those who are older and [have] been a carer or support person for many years.'[75]

Evidence before the Commission suggests that many older carers are concerned about who will care for the person for whom they care and provide support when they can no longer do so,[76] and where the person they care for will live.[77]

Ms Piu told the Commission:

> I have observed that a huge fear of carers who are ageing grandparents, parents and siblings, is to who or what will fill the void when they are gone.[78]
>
> I have spoken to older carers who have explained this fear to me. One carer who is now 74 years of age, who began caring for her brother as a teenager said that she wanted to know that there were proper supports and plans in place for her brother after she is no longer around as a carer. Specifically, she wanted to know that someone would be available to check in on him and make sure he is okay.[79]

Personal story:

Jean

Jean* is 73 years old, and is the full-time carer for her 43-year-old son, James,* who lives with her. Jean saw a decline in James' mental health after some distressing experiences in his late teens. He has been diagnosed with schizophrenia and a number of other medical conditions. James has a long history of experiences with the mental health system, including spending time in psychiatric wards and on compulsory treatment orders.

Caring is a full-time role for Jean. As James' carer, Jean says one of her key roles as carer is coordinating her son's healthcare.

> Advocating for his medical and specialist services, dealing with the [National Disability Insurance Scheme], managing his diabetes supplies and records, podiatry, pathology, dental care all contribute to a full load.

Jean spent almost two years trying to put in place longer-term living arrangements for her son. Despite successfully applying for a permanent place in supported independent living, her son wanted to remain living with his mother.

> My son, in all seriousness, expects me to care for him until I'm in my nineties.
>
> [M]y son declined the offer and said he would kill himself if I made him live there.

Jean is concerned about who will care for James if she is no longer in a position to support him.

> What are the options for my son should I die or become unwell given there is no one in the family who could take over my carer role? … Recovery seems out of reach without significant input and support.

Jean highlights the importance of continuity of care and treating physical and mental health together and recommends providing comprehensive support for carers and families and including them as part of care and discharge plans.

Jean said she would like to see carer consultants work directly with carers, without session or time restrictions, as they try to seek help or navigate the complex mental health services.

Source: 'Jean' (pseudonym), *Correspondence to the RCVMHS*, 2019.

Note: *Names have been changed to protect privacy.

19.6.3 Aboriginal carers

The importance of family and community in Aboriginal communities in Australia is well established. In its interim report the Commission acknowledged 'the centrality of Aboriginal family and kinship connections to a person's mental health'.[80] The *Balit Murrup: Aboriginal Social and Emotional Wellbeing Framework 2017–2027* also explains this:

> The concept of Aboriginal health and wellbeing is different to the universal concept as it is regarded and recognised as a more holistic and whole-of-life view. It encompasses the social, emotional and cultural wellbeing of not only the individual, but the wider community thereby bringing about the total wellbeing of community.[81]

In a focus group the Commission held with Aboriginal carers, one participant said that as a carer and an Elder, he needed to show strength within the whole family unit, but there was no help for him. Participants also described a responsibility in Aboriginal communities to all families, not just immediate family members. This can mean helping families five or six nights a week.[82]

Another focus group participant talked about the importance of keeping family updated in Aboriginal communities and wanting services to do this, 'within our community, it's about sharing the lot. And it's about knowing what's best for our people'.[83]

Hands-on-Health Australia told that Commission that '[w]hile care giving can be beneficial for family members and care givers; there is also the potential for burn out, depression and other mental and physical issues',[84] and that this is prevalent within the Aboriginal community, where 'culture, language, emotions, family community, spirituality, ancestors need to be [part] of the carer profile'.[85]

19.6.4 Culturally diverse carers

Families, carers and supporters from culturally diverse communities can experience additional challenges when trying to navigate the mental health system and access support.

In her evidence to the Commission, Ms Kali Paxinos, who is in her 90s, told the Commission she was born in Australia to parents who had migrated from Greece. Ms Paxinos, who has cared for her now adult son, spoke of her experience supporting migrant communities and the difficulties people from culturally diverse backgrounds can face when 'coming to this country without the language, without people, without knowing anybody, without partnerships'.[86]

Ms Paxinos spoke about the difficulty of language barriers, and the need for professionals to use language and terms that can be understood by people for whom English is not their first language:

> So, I said, as professionals you've got to be very careful to understand that it's not a disgrace to use a simpler word when you're explaining something to people who don't speak English very well.[87]

The African Australian Communities Leadership Forum told the Commission that '[d]ue to fear of stigma and lack of knowledge of symptoms of mental illness, families keep people at home until crisis point'.[88]

The Multicultural Centre for Women's Health told the Commission that immigrant carers can have smaller family and support networks compared with people born in Australia, and this can place strain on families.[89]

The Ethnic Communities' Council of Victoria told the Commission:

> Responses to mental illness vary across communities, but in general in [culturally and linguistically diverse] communities family members and carers play a particularly important role in care provision. There are various reasons for this, including the underutilisation of mental health services by people from [culturally and linguistically diverse] backgrounds, their relative isolation from mainstream society, and the collectivist nature of many cultural groups, in which intra-group care is the norm.[90]

In his statement to the Commission, Mr Paris Aristotle AO, CEO of the Victorian Foundation for Survivors of Torture (Foundation House), outlined a need for processes that include the whole family of people who are newly settling in Victoria, and people with limited English and low incomes.[91] Mr Aristotle said, '[s]imply addressing the mental health problems of the person initially referred without understanding how they intersect within the home context, including what support others at home might need, makes it difficult to achieve positive long-term outcomes.'[92]

19.6.5 The impacts of COVID-19 on families and carers

The COVID-19 pandemic has been particularly challenging for many families and carers.

Caring Fairly, a national campaigning coalition led by unpaid carers and coordinated by Mind Australia, conducted a survey on the experiences of carers during the COVID-19 pandemic. The survey was open to carers from 21 April to 5 May 2020, and there were 471 responses.[93]

While the survey findings offer some insight into the impacts of the pandemic, Victoria continued to be under various restrictions for many months after the survey closed, and the effects of these extended restrictions are likely to be greater than those reported in April and May.

Results of the survey include:

- 60 per cent of respondents reported that the person they care for had reduced access to support services and 47 per cent reported having reduced access to support services for themselves[94]
- the proportion of carers who reported spending more than 45 hours per week on caring increased from 27 per cent before the pandemic, to 50 per cent[95]
- 81 per cent of respondents reported a deterioration in their mental health, and 88 per cent reported increased stress in their role as a carer[96]
- 71 per cent of respondents reported spending more on living costs, and 58 per cent reported spending more to support the person they care for[97]
- 38 per cent of respondents reported an increase in concern about their personal safety.[98]

19.7 Rebalancing the system's relationship with families, carers and supporters

In developing recommendations that respond to the needs of families, carers and supporters, the Commission aims to rebalance the relationship between the mental health system and families, carers and supporters. The future mental health and wellbeing system must be accountable to families, carers and supporters, as well as being accountable for including their needs and views as core considerations at both a system and service delivery level.

The Productivity Commission's *Mental Health Inquiry Report* also determined that this was an area requiring greater focus, stating, '[a]ll mental health services should be required to consider family and carer needs, and their role in contributing to the recovery of individuals with mental illness.'[99]

There is no single, simple strategy that will achieve this shift in the position of families, carers and supporters. A systemic approach is needed, including: establishing accountability for families, carers and supporters; embedding the expectation that mental health and wellbeing services will work with consumers' families, carers and supporters, including through government commissioning decisions; and providing dedicated supports for families, carers and supporters in their own right.

19.7.1 Establishing accountability for the involvement of families, carers and supporters

In the past decade, there has been increasing recognition of, and government policy mandate for, family and carer involvement in supporting mental health consumers. In several instances, this policy mandate has been enshrined in legislation, such as section 11(1) of the *Mental Health Act 2014* (Vic), which includes principles about involving carers (including children) of people receiving mental health services in decisions about assessment, treatment and recovery whenever possible, as well as recognising, respecting and supporting the role of carers.[100]

The policy position has been set out in relation to carers generally, as well as more specifically in the mental health context. Examples include:

- the *Carers Recognition Act 2012* (Vic), which includes a set of principles about the significance of care relationships, and specifies obligations for public care agencies and funded care agencies[101]
- the *Victorian Charter Supporting People in Care Relationships*, which reflects and supports the Carers Recognition Act. The charter encourages organisations and services to better respect the important role carers have in the community[102]
- the Mental Health Act, which provides for the disclosure of health information in general terms to a friend, family member or carer of the person to whom the information relates in certain circumstances[103] (discussed further at section 19.9.3)

- the *Victorian Carer Strategy 2018–2022*, which is the first Victorian whole-of-government strategy to support carers in their own right. The strategy sets the direction for government to support carers. Priority 5 in the strategy is that carers are recognised, acknowledged and respected[104]
- the *National Standards for Mental Health Services*, which aim to aid development and implementation of appropriate practices across a broad range of mental health services and includes standards in relation to working with carers[105]
- *Working together with families and carers: Chief Psychiatrist's guideline*, which provides advice to Victoria's publicly funded clinical mental health services in relation to involving families and carers in treatment, care and support.[106]

Despite these developments, the evidence examined above demonstrates a failure on the part of the mental health system to work effectively with families, carers and supporters. This failure is evident in the structural barriers and power imbalances that exist for families, carers and supporters.

The Commission's starting point is to establish clear accountability for involving families, carers and supporters across the system. Measures recommended or suggested elsewhere in this report to achieve this include:

- recognising the value of families, carers and supporters in the objectives or principles of the proposed Mental Health and Wellbeing Act, described in Chapter 26: *Rebalancing mental health laws—a new Mental Health and Wellbeing Act*
- establishing a new Mental Health and Wellbeing Commission, which will be responsible for promoting the role, value and inclusion of families, carers and supporters across the mental health system, described in Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*
- developing a new *Mental Health and Wellbeing Outcomes Framework* in consultation with families, carers and supporters to ensure the outcomes and measures reflect what is important to families and carers, described in Chapter 3: *A system focused on outcomes*
- establishing a new performance monitoring and accountability framework to improve the outcomes and experiences of families, carers and supporters, as well as a new approach to measure the effectiveness of mental health and wellbeing services from the perspective of families, carers and supporters, described in Chapter 28: *Commissioning for responsive services*
- including family, carer and community inclusive values and approaches in the future *Victorian Mental Health and Wellbeing Workforce Capability Framework*, described in Chapter 33: *A sustainable workforce for the future*.

Families and carers must also have opportunities to participate at senior levels within the system and its governance structures. This is the topic of the next section.

19.8 Family and carer leadership in the future mental health and wellbeing system

Families, carers and supporters have experienced some of the power imbalances in the mental health system. While families, carers and supporters are not subject to the mental health system in the same way as people with lived experience of mental illness or psychological distress many have their own experiences of being disregarded or made to feel invisible, while decisions are made that affect them.

In its interim report, the Commission committed to a redesigned system that puts people with lived experience of mental illness or psychological distress, their families, carers and supporters at the forefront, and listens to and values them as active contributors and leaders.[107] This is central to an inclusive, compassionate and humane mental health and wellbeing system. The Commission's vision is for a reformed mental health and wellbeing system where families, carers and supporters are valued partners who help drive reform and contribute to better outcomes.

To date, consultation with families, carers and supporters has largely taken place outside the current system's formal decision-making structures. For example, many different advisory groups with family and carer participation have been established over time to provide advice to the then Department of Health and Human Services and to individual services. These groups include the current Lived Experience Advisory Group, co-chaired by the department and the CEOs of the Victorian Mental Illness Awareness Council and Tandem, which is tasked with providing advice to the department and is also a key partner in implementing the Commission's recommendations.[108]

While this type of consultation dynamic can be effective and influential on particular projects, it means that families, carers and supporters have little say in budget allocation and service priority, performance and accountability decisions.

To rectify this, the Commission makes a number of recommendations to elevate the experiences, expertise and perspectives of families, carers and supporters, as it has with consumers, so that together, they are at the centre of the mental health and wellbeing system's governance and leadership structures.

In Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*, the Commission recommends the establishment of a new statutory authority—a Mental Health and Wellbeing Commission—to provide strong system oversight. Membership on the executive leadership of this new Commission will include one Commissioner with lived experience as a family member or carer.

The new Commission will be responsible for monitoring the performance of the mental health and wellbeing system and the Victorian Government's implementation of the Royal Commission's recommendations.

The Commissioner with family or carer lived experience will contribute to the functions of the Commission as a whole, particularly as they relate to the needs, experiences and outcomes of families, carers and supporters. The Commissioner with lived experience as a family member or carer could also be delegated responsibility for promoting the role, value and inclusion of families, carers and supporters in the mental health and wellbeing system.

Likewise, the Mental Health and Wellbeing Division within the Department of Health must employ people with family/carer lived experience in multiple and substantive leadership positions and throughout its internal structures. These positions will ensure leaders with family or carer lived experience have an enduring and influential role in government decision making that affects family and carer experience and outcomes, with particular regard to implementing the Commission's recommendations, for at least the initial four years, and related policy decisions.

Further, as established in Chapter 5: *A responsive and integrated system*, people with family or carer lived experience will also be represented across the recommended Regional Mental Health and Wellbeing Boards, where they will play a prominent role in decision making with respect to service and capital planning, commissioning mental health and other related services, workforce planning, and research and evaluation initiatives. These arrangements will ensure the views, experiences and perspectives of people with family and carer lived experience are at the heart of planning and resourcing decisions, driving progress towards a system that recognises and responds to the differing needs of families, carers and supporters.

Like all people in leadership and governance roles, families, carers and supporters must have opportunities to build and further strengthen their existing capabilities and skills so they can succeed in these roles.

At the individual service level, the Commission's recommendations in Chapter 28: *Commissioning for responsive services* include introducing new service standards that can be used to assess which providers to fund. The new service standards will improve service delivery, including through establishing accountability for family, carer and supporter involvement in treatment, care and support and in service planning, design, delivery and evaluation.

The National Mental Health Commission's *Sit Beside Me, Not Above Me* report highlights the importance of supporting people with lived experience to contribute effectively across all levels of the system. To complement this view, the National Mental Health Commission encourages a skills-based approach, noting that lived experience alone does not equate to expertise in policy and governance matters, and that capacity must be built in a broader range of areas to support greater participation.[109]

To put these principles into practice, the Commission recommends that the Victorian Government supports the Mental Health and Wellbeing Commission to develop and support leadership and governance capabilities of families and carers of people living with mental illness or psychological distress. This will be done through learning and development opportunities so they can participate in decision-making processes about policies and programs, in particular where these directly affect them.

These measures will ensure families, carers and supporters have an enduring role in decision making in the mental health and wellbeing system, and that there is an evolving group of family/carer leaders.

19.9 Working with families, carers and supporters is core business

Realising the Commission's vision for greater involvement of families, carers and supporters in the mental health and wellbeing system requires a comprehensive response. There are longstanding barriers, outlined in section 19.9.1, that must be overcome. This will only be possible through a consistent and coordinated response across the state that clearly establishes that government expects that mental health and wellbeing services will work with families, carers and supporters.

The Commission's recommended approach includes three key strategies to achieve this:

- ensuring that working with families, carers and supporters is an essential part of the commissioning of mental health and wellbeing services
- improving information sharing with families, carers and supporters, including developing standards for services and practitioners
- introducing system-wide training for the mental health and wellbeing workforce to facilitate working with families, carers and supporters.

This approach will be further strengthened by delivering a range of therapeutic interventions that involve families, carers and supporters, which is the topic of section 19.10.

19.9.1 Barriers and opportunities when working with families, carers and supporters

Despite the existing policy intent outlined in section 19.7.1, there are barriers at both the system and service levels to practices and models of care that support working with a consumer's family, carers or other supporters. These barriers include:

- **time and capacity**—limited resources mean the workforce is under pressure in challenging circumstances and an approach that includes a consumer's family, carers or supporters will not be given priority[110]
- **workforce training and capability**—some practitioners feel that working with a consumer's family, carers or other supporters is a speciality role they are not trained to do[111]
- **implementation**—implementing and sustaining change requires long-term commitment, including to workforce development and training; this can be difficult when there are many competing needs that practitioners face[112]
- **concerns about privacy**—concerns about risk and privacy leave many clinicians feeling uncomfortable working with family members and support networks,[113] and some may view client confidentiality as a barrier that prevents engaging with families, carers and supporters[114]
- **professional culture**—the current service culture is individualistic and has developed over a number of years, partly due to pressure on services[115] and partly because many professionals are trained to work one on one in their relationship with patients or clients[116]
- **accountability**—current standards for service providers about family-inclusive practice are voluntary, meaning organisations may not implement them.[117]

To respond to the barriers and embed a commitment to work with families, carers and supporters, the Commission draws on a range of levers across the system, including commissioning and funding, service standards, training, workforce culture and development, and the facilitation of information sharing. Improved accountability at the service and system levels will also be critical, as discussed in section 19.7.1.

This combination of approaches forms a system-wide strategy that was not previously available as a package of reforms to support the inclusion of families, carers and supporters. Family, carer and supporter-inclusive approaches will no longer rely on the priorities of individual services and practitioners.

19.9.2 Working with families, carers and supporters is an expectation of services

The Commission is satisfied of the need to provide 'a very clear message that family involvement is not an add-on, but is core business',[118] noting that this includes families of choice and broader support networks.

The Commission has recommended that the Victorian Government ensures that in commissioning mental health and wellbeing services, expectations are set for working with families, carers and supporters. Reporting on delivering these expectations will become part of the accountability measures in service agreements between service providers and the Department of Health.

This approach does not mean that all families, carers and supporters will have an automatic right to be involved in a consumer's treatment, care and support. But the system should presume that most people live with some form of relationship of care and support—relational approaches must be a central part of the approach to treatment, care and support and, when involved, families, carers and supporters must be supported in their caring role.

Dr Denborough told the Commission:

> The traditional approach in psychiatry is to focus … on finding out what is 'wrong' with a person. However, to improve effectiveness the focus needs to be listening more carefully to the perspectives and issues being experienced by the individual and their family. This allows assistance and help to be provided more efficiently and allows the person and their family to have greater involvement in treatment options which will lead to more positive outcomes.[119]

A consumer's relationships with family, carers or supporters may break down or be fraught for a range of reasons. Sometimes these breakdowns are irreparable, but they may also fluctuate and improve over time.[120] Clinicians and services need to keep this in mind, taking a holistic view of the consumer and their family, carers and supporters. As one participant at a community consultation session said:

> Staff taking the time to understand family and friends and carers is critical—they are more than a person with behavioural issues … staff can construct a 3D picture of that person.[121]

The Commission acknowledges that in some instances, such as where abuse has occurred or is occurring, involving the people in a consumer's social context, including their family of origin, in treatment, care or support is not appropriate and can be counterproductive.

Ms Indigo Daya, Consumer Academic from the Centre for Psychiatric Nursing at the University of Melbourne, gave evidence in a personal capacity, emphasising that families are not always supportive and can be a source of trauma for consumers.[122] But she also acknowledged that 'family can be the most helpful and supportive part of [a consumer's] recovery'.[123] Ms Daya also said that '[f]amilies/carers can be great advocates for our rights, will and preferences, and assist in supported decision making. Families/carers can also offer many very practical supportive resources.'[124]

In the event of a relationship breakdown, a consumer may still have other people in their support network who they want involved in their care, such as a different family member or a friend who could play a valuable support role. Dr Brendan O'Hanlon, Mental Health Program Manager of the Bouverie Centre at La Trobe University, told the Commission that friends can be excluded from involvement in care when, in some circumstances, they may be the most important relationship for a consumer.[125]

Dr O'Hanlon also told the Commission that in cases of relationship breakdown, services may not explore other potential relationships that could be involved in a consumer's care.[126] The question of relationships of care and support that consumers find helpful is one that should be revisited at different points during treatment because relationships evolve and vary over time.

When a consumer's views on involving their family, carers or other supporters do not align with those of the people in their support network, it can be challenging for both practitioners and families.[127] Dr O'Hanlon told the Commission that the way in which services and practitioners operate can have a considerable bearing on a consumer's openness to the involvement of their social context:

> If practitioners are talking about the possibility of family involvement with consumers from the outset, and seeing it as a natural and normal part of the work that they do, it is likely that more families will be included. Some of the understandable and legitimate issues a consumer might have about having their family being involved can also be worked through with a clinician who is open to family involvement.[128]

Part of the Commission's vision is a mental health and wellbeing system better equipped to deal with these complexities and where early connections with families, carers and supporters may help to limit the extent and frequency of relationship breakdowns.

19.9.3 Information sharing

Effective information sharing is important for working with families, carers and supporters.

Information exchange was one of the key concerns raised by families and carers throughout the Commission's work. Ensuring that families, carers and supporters have the information they need to carry out their caring role is a central aspect of a system that values and supports families, carers and supporters.

Families and carers have consistently told the Commission that they struggled with a lack of access to information about the treatment, care and support of the person they care for. The Commission considers that this matter must be dealt with while also acknowledging adult consumers' right to privacy and choice about who, if anyone, their information is shared with (unless disclosure is otherwise permitted by law).

The broader role of information management in the redesigned mental health and wellbeing system is explored in more detail in Chapter 35: *New approaches to information management*, including new approaches to support consumers to access their own information, effective and safe information sharing between services, and consent approaches in the future system.

Tandem told the Commission, '[f]amilies and friends almost universally report being denied basic information, which would aid them to care, build stronger relationships, or just understand what's going on.'[129] In her witness statement, Ms Piu said, '[c]arers continue to meet resistance when trying to access information vital to the carer relationship, and involvement in care planning and discharge. This must change.'[130] One carer told the Commission:

> The discharge summary should come to you as the consumer and the carer where that's appropriate. And where the person doesn't have capacity or lacks cognition, the carers role [is] very much about keeping that person alive and without adequate information. That makes it very difficult.[131]

In her witness statement, Ms Christine Thomas told the Commission about the difficulties she faced while caring for her husband, who was suicidal. Ms Thomas said 'I was constantly asking to speak with doctors but nobody was ever available, they tried to shut me out of meetings and in general I was given the run around.'[132]

The importance of two-way information sharing has also been raised with the Commission. Practitioners and services should seek and value information that families, carers and supporters can provide. One carer told the Commission:

> How can the counsellor help a person without knowing the wider context of what is going on, and only know the information presented by the patient? Why is it that a child requires a responsible adult but once a person turns 18yo their family is locked out of the treatment process due to privacy regardless of the vulnerability of that person's clinical presentation? Including the family in the treatment can be important to a positive outcome.[133]

Evidence indicates that this is not a problem limited to a particular age group of consumer. While the child and youth mental health system typically takes a more inclusive approach to family involvement, as examined earlier, Orygen reported that:

> A young person's privacy and confidentiality is often cited as a barrier to family inclusion and a key factor in family dissatisfaction with services. Legislation can also determine the amount or type of information a clinician can share with a family. Families report feeling particularly distressed when confidentiality is cited as the reason for not sharing information.[134]

The complexity of information-sharing arrangements makes it challenging for professionals in many instances. Research suggests that mental health professionals often 'do not have sufficient guidance as to how to balance the protection of confidentiality and the disclosure of information'.[135] There is also acknowledgement in the literature of the difficulty practitioners may have navigating this matter, including that 'the complexity of Australian laws relating to confidentiality makes it difficult for lawyers to identify and understand them, let alone health practitioners'.[136]

This is not a challenge limited to Victoria, nor indeed the mental health sector. The 2005 *Paving the Way: Review of mental health legislation in South Australia* report states, '[c]onfidentiality should not be interpreted as a barrier to proper sharing of information in the best interests of consumers'.[137] The review recommended both legislative change and professional development of mental health staff to overcome this barrier.[138]

The Royal Commission into Family Violence also examined the complexities of information sharing, finding that both legislative change and an information-sharing culture were required to respond to barriers in the system.[139]

The evidence before this Royal Commission suggests that the ambition of the Mental Health Act to provide clarity in this area has not been realised. This matter is also examined in Chapter 26: *Rebalancing mental health laws—a new Mental Health and Wellbeing Act*, including the underlying intentions of the current Mental Health Act and the distress that families, carers and supporters can experience in the absence of effective communication. For example, the provisions in the Act about disclosing health information allow service providers to reveal health information about a consumer if it is disclosed in general terms to a friend, family member or carer of the consumer and the disclosure is not contrary to the consumer's views and preferences.[140] That is, providers can share information of a general nature with families, carers and supporters that will help them to carry out their caring role—for example, what medication someone has been prescribed—provided that the information is not shared against the consumer's wishes. However, families, carers and supporters have consistently told the Commission that they do not receive this type of general information.

These provisions also allow the disclosure of a patient's health information to a carer if the information is reasonably required to provide care to a patient, and only if the patient's views and preferences are taken into account.[141] Such disclosure does not require consent. There is a distinction that these provisions apply only to a 'patient', a term defined in the Act to only include people subject to compulsory treatment (including orders under the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* (Vic)),[142] so this provision does not apply to all consumers.

The Act also introduced nominated person provisions, which allow a patient to nominate someone from their support network to provide support, receive information, be consulted with, and represent their interests.[143] *Victoria's Mental Health Services Annual Report 2019–20* notes that only 2.55 per cent of adult consumers had a nominated person recorded (compared with 2.60 per cent in 2018–19 and 2.44 per cent in 2017–18).[144]

Evidence before the Commission about the difficulties families, carers and supporters have with accessing information suggests that these provisions have not been effective and may be poorly understood by the workforce, consumers, families, carers and supporters.

In Chapter 26: *Rebalancing mental health laws—a new Mental Health and Wellbeing Act*, the Commission outlines its recommendations for rebalancing mental health laws, including enacting a new Mental Health and Wellbeing Act. The objectives or principles of the new Act should include the recognition and promotion of the value of the role of families, carers and supporters. The Commission has further identified that simplifying provisions about information sharing with families, carers and supporters is an essential change required to the legislation.

The Commission considers that the biggest improvement in information-sharing practices with families, carers and supporters will be achieved through both legislative change and the practice and culture changes outlined throughout sections 19.9 and 19.10. To support new cultures of information sharing, the Victorian Government should articulate expectations in law about how information should be shared with families, carers and supporters.

Following legislative change, the Victorian Government should develop clear and consolidated standards to guide the sharing of appropriate information with families, carers and supporters.

The standards should reflect the new Mental Health and Wellbeing Act as recommended in Chapter 26: *Rebalancing mental health laws—a new Mental Health and Wellbeing Act*, once it is enacted (by the end of 2021 and no later than mid-2022). They should also be informed by the new consent approach to information sharing recommended in Chapter 35: *New approaches to information management*.

The Commission acknowledges there are existing guidelines for professionals in this area. An example is *Working together with families and carers: Chief Psychiatrist's guideline*, which includes a section about open communication with consumers, families and carers about privacy, confidentiality and information sharing.[145]

Despite the existence of such guidelines, the evidence before the Commission suggests that little appears to have been achieved in practice. Ms Piu told the Commission that despite recent acknowledgement of mental health carers, families and friends, including in the Chief Psychiatrist's guideline, 'these are only guidelines and [have] only limited scope to change practices in relation to identifying, including and supporting the consumer and their family and friends or support network services on the ground'.[146]

In making this recommendation for new standards, the Commission acknowledges that a range of measures are required to achieve a change in practice cultures. But as part of an overarching suite of reforms aimed at acknowledging the vital role of families, carers and supporters in care and recovery, major cultural change can be achieved.

Once developed, these standards will form part of the professional development training in working with families, carers and supporters that is detailed in section 19.9.4. This training will be critical to ensure understanding of the standards, as well as consistent and effective application.

The Commission supports the proposition that successful implementation and sustainability of work that involves a person's family, carers and supporters must include staff being trained 'in best practice in privacy, confidentiality and information-sharing'.[147] This includes asking families, carers and supporters for information about the person they care for or support, as appropriate, as well as sharing information that enables people to be effective in their caring role.

The Commission believes that conversations with consumers about who they may want to receive information about their treatment should start early in the therapeutic relationship and be ongoing. As noted by Dr Leggatt, when a person becomes acutely unwell, a failure to ask their family for information may lead to inadequate treatment, deterioration or escalated measures such as police involvement or involuntary hospitalisation.[148]

19.9.4 Training for the mental health and wellbeing workforce to facilitate work with consumers' families, carers and supporters

Mr Angus Clelland, CEO of Mental Health Victoria, told the Commission that many service providers do not feel adequately trained to work in a way that involves a consumer's social context.[149]

Dr O'Hanlon told the Commission, '[i]f clinicians in their undergraduate training have not had exposure to working with families (which is very often the case as the focus is on one-on-one interventions) the idea of having more than one person in the room is often quite daunting.'[150]

Dr O'Hanlon also considered that while the emphasis on family involvement in training varies from profession to profession, it transcends disciplines.[151]

The Commission recommends that the Victorian Government includes training in working with consumers' families, carers and supporters as part of continuing professional development requirements across the mental health workforce. This training will include coverage of the information-sharing standards outlined in section 19.9.3. The Victorian Government should also strongly advocate for including training in working with consumers' families, carers and supporters in both undergraduate and postgraduate tertiary-level mental health workforce qualifications.

In addition to this dedicated training, being family-, carer- and community-inclusive will be built in as a core value and approach of the mental health workforce, and working with families, carers and supporters will be a priority capability for the future system, as outlined in Chapter 33: *A sustainable workforce for the future*. These priorities will guide the broader system approach to workforce development.

Dr O'Hanlon told the Commission that 'there is a tendency to 'bolt on' new specialist programs in response to apparent need rather than to integrate them within existing services … There has been a lack of action in ensuring translation of admirable policies into actual practice.'[152] The Commission's recommendation for workforce training should be viewed as a supporting element of its broader recommendation that work with families, carers and supporters will be a built-in expectation of Victorian Government–funded mental health and wellbeing services.

Given the considerable practice and culture change required in the adult and older adult mental health and wellbeing system, practitioners from services within this system should also be given the opportunity to draw on secondary consultation and advice from the Bouverie Centre as a specialist family service.

The Bouverie Centre is a service that 'combines clinical family therapy, academic teaching … research, workforce development and community education in one integrated service'.[153] Its mission is 'to improve the lives of individuals and families through relationship focused services'.[154] It currently offers services including discrete one-off 'case-based' discussions, facilitation of reflective practice sessions, professional advice about building 'working with families' capacity within a team, program or organisation, and other professional support.

The capacity of the Bouverie Centre will be expanded to undertake this role in the future system.

19.10 Expanding models of care that involve families, carers and supporters

New accountabilities and expectations for mental health and wellbeing services to work with families, carers and supporters must be supported by a new approach to ensure more widespread availability of inclusive therapy models. This will be achieved through increased capacity and capability for service providers alongside a strengthened family and carer peer workforce.

As outlined in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*, Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will provide comprehensive, integrated treatment, care and support that is proportionate to the person's needs, including through family therapies and other approaches that consider a person's relational context. This will ensure these supports are available more equitably across rural, regional and metropolitan Victoria.

Family inclusion in the infant, child and youth mental health and wellbeing system is discussed in more detail in Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing* and in Chapter 13: *Supporting the mental health and wellbeing of young people*.

Across the mental health and wellbeing system there will be strong models of care across all age group services that will involve families, carers and supporters.

19.10.1 Ensuring the availability of inclusive therapy models

In addition to building in work with a consumer's social context as part of standard practice, there are a range of existing therapy models that specifically include families, carers and supporters. These models have varying intensities and require different levels of training in order to practise. Some of these models are currently used in the Victorian system, albeit with inconsistent availability.

The Commission's intent is that the capacity and capability of services across the state will be boosted to deliver these models more consistently, with additional support and/or secondary consultation (a consultation between clinicians without the consumer or family member(s), carer(s) or supporters present) available as required to provide more specialised support.

Several models are briefly explored below. This is not an exhaustive list, and the Commission notes that there are a range of well-researched models of family-inclusive practice. It is not the Commission's intent to be prescriptive about the particular models that service providers adopt; rather, the expectation is that they will be used and must provide capacity for meaningful inclusion of families, carers and supporters.

Single-session family consultation involves a consumer's social context and is a model that could have more widespread use across both the adult and older adult, and infant, child and youth mental health and wellbeing systems. Single-session family consultation was developed by the Bouverie Centre and combines family consultation with single-session therapy to maximise outcomes.[155]

In *From Individual to Families: a Client-Centred Framework for Involving Families*, the Bouverie Centre describes single-session family consultation as 'a time limited and structured process for meeting with a client and the family and is focused on achieving realistic and negotiated goals'.[156] The Bouverie Centre defines family as including 'family, significant others and social networks'.[157] According to the Bouverie Centre, single-session family consultation can create greater understanding of problems and their impacts on individuals and families, help families understand how they can best support the consumer, and provide clarity about how the consumer's network may be involved in their treatment.[158] Training in single-session family consultation can be completed in two days, making it cost-effective if training large groups of staff.[159] Alfred Health told the Commission that it provides single-session therapy based on the Bouverie Centre's model, and that young people and their families both value these sessions.[160]

Open Dialogue is another approach. Originating in Finland, the model helps people and their families feel 'heard, respected and validated'.[161] Its principles include providing immediate help (within 24 hours of first contact), social network inclusion, a flexible approach including often meeting in the consumer's home, the care team being responsible for treatment, care and support for as long as is necessary, and building an environment where all parties feel safe.[162]

Research indicates that as an alternative to treatment within a hospital, Open Dialogue can be associated with reduced likelihood of involuntary treatment, and small-scale studies suggest it may produce better outcomes than conventional treatment.[163]

Open Dialogue's 'largely non-institutional and non-medicalizing approach'[164] aligns with a human rights-based approach to treatment, care and support:[165]

> Its fundamental network perspective facilitates a contextual and relational understanding of mental well-being, as it is postulated by contemporary human rights approaches.[166]

Alfred Health currently uses the Open Dialogue methodology in its Youth Early Psychosis Program.[167] In its submission to the Commission, Alfred Health said that Open Dialogue:

> provides a set of values and techniques that seek multiple perspectives and client strengths ... Staff across the program received extensive training in the dialogic approach. After the technique was implemented, further training and supervision were provided ... The technique has now evolved, in response to differences experienced ... The approach to care continues to emphasise a collaborative adaptive network approach, which is shaped by family engagement and support.[168]

'Multiple family groups' is an example of a more intensive family-inclusive engagement model. It is a family psychoeducational intervention that brings multiple families together, including consumers, to support each other. These groups generally meet fortnightly for six to 12 months.[169] Multiple family groups provides an effective and efficient intervention because it only requires a small number of staff to support a broad group of families.[170] There are two such programs currently operating in Victoria—at the Inner West Area Mental Health Service and at Jigsaw Youth Mental Health Drugs and Alcohol Services at Barwon Health.[171]

Multiple family groups provides information to families while also creating a social network and a form of mutual support for families where they may otherwise feel isolated.[172] Research suggests that multiple family groups has specific benefits for consumers, including reduced relapse and readmission, and improved participation in rehabilitation and employment.[173] There is also evidence indicating that multiple family groups improves family functioning.[174]

19.10.2 The role of family and carer peer workers

The family and carer peer workforce helps services work effectively with families, carers and supporters.

As the Commission recognised in its interim report:

> Lived experience work will be a central pillar of the future mental health system: new lived experience roles will be established and supported, spanning service design and delivery, service and system leadership, research and evaluation, and system accountability and oversight.[175]

The current system includes only a limited number of family and carer peer workers. In 2017 there were 341 occupied lived experience positions in Victoria's public mental health services (amounting to 187 fulltime-equivalent positions).[176] Of the total number of positions, 102 worked from a family–carer perspective.[177] Chapter 33: *A sustainable workforce for the future* examines the lived experience workforce in more detail.

In its interim report, the Commission recommended that the Victorian Government expands the consumer and family and carer lived experience workforces and enhance workplace supports for their practice. To achieve this it recommended, among other things, learning and development pathways, education and training opportunities and a statewide approach to organisational readiness training[178] to ensure all agencies receiving government funding for mental health services are equipped to support lived experience workforces.[179] Promoting and understanding the value of lived experience expertise and perspectives at all levels of an organisation is integral to the 'introduction, ongoing support and sustainability of lived experience work'.[180]

The Commission sees existing family and carer peer workers as critical to the future mental health and wellbeing system. Many of the current family and carer peer roles help services to work with and support families, carers and supporters. These roles must continue and be expanded to deliver on the Commission's vision. The Commission makes specific recommendations for an increase in family peer workers elsewhere in this report. For example, in Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing*, the Commission recommends that the service stream of Infant, Child and Family Area Mental Health and Wellbeing Services significantly increase the number of family peer workers they employ. Chapter 13: *Supporting the mental health and wellbeing of young people* similarly recommends that family peer workers are employed across the service stream of Youth Area Mental Health and Wellbeing Services.

19.11 Establishing a statewide program of supports for families, carers and supporters

Families, carers and supporters make an enormous contribution to the system as well as the people they care for, often at the expense of their own wellbeing. They are a critical part of sustaining the system. Therefore, in designing the future mental health and wellbeing system, the Commission has considered two fundamental aspects of supporting the needs of families, carers and supporters—better support to help them carry out their role, and support in their own right as individuals with their own needs who are taking on a challenging role.

In recognition of this, the Commission recommends establishing a statewide program of supports for families, carers and supporters that consists of four central elements:

- eight family- and carer-led centres, one in each region across the state
- access to increased financial support to help with immediate practical needs (brokerage)
- a statewide peer call-back service for families, carers and supporters caring for people experiencing suicidal behaviour
- tailored online information for families, carers and supporters.

19.11.1 Family- and carer-led centres

The Carers Recognition Act sets out that '[a] carer should be respected and recognised as an individual with his or her own needs'.[181] As demonstrated throughout this chapter, the mental health system does not adequately recognise or respond to family and carer needs.

Tandem told the Commission that a 'system that recognises that family and friends are a critical part of the recovery journey [must] consequently [acknowledge they] are entitled to respect, kindness, information and support'.[182] The Commission agrees with this proposition.

The Commission therefore recommends that eight regional family- and carer-led centres be established by the end of 2022. Each centre will have a physical location (opportunities for co-location with existing community service settings should be explored) and an online presence, which could be provided via a central hub for all centres that also includes access to region-specific information. The centres will all have consistent branding to help families, carers and supporters find support more easily. The centres will:

- provide families, carers and supporters with tailored information about supports and services available in the region (online, face-to-face and telephone contact options)
- offer after-hours access
- work with families, carers and supporters to identify their needs and connect them to the supports that will best respond to those needs, including providing one-on-one support

- take a personalised strengths-based approach to needs identification and planning including coverage of health and wellbeing, practical, financial, employment/education and the social needs of the families, carers and supporters
- provide access to brokerage funding to help with immediate practical needs, which may include opportunities for rest or temporary alternative care options (short-term planned respite)
- support carers with additional needs and cultural diversity, including Aboriginal people, people from culturally diverse backgrounds, people with disabilities, people with coexisting mental and physical health conditions, young people (up to and including 25 years), older Victorians (people aged 65 years or older) and LGBTIQ+ people
- support older carers with transition planning
- provide clear referral pathways to help families and carers seek support and services, including to the primary health system, counselling and peer support groups
- deliver support and mentoring for volunteer-based family and carer peer support groups in the region.

The Commission's recommendation is that the Victorian Government commissions either a single non-government organisation or multiple organisations to deliver a network of centres. Each centre will work closely with mental health and wellbeing services in their region, which will have a role in raising awareness of the centres and helping people to connect to them. Tandem, through its existing Support and Referral Service, can also play a valuable role in connecting people to the centres. Families, carers and supporters will be able to use the centres without a formal referral.

A minimum of eight fulltime-equivalent support worker positions should be funded in each family- and carer-led centre to directly support families and carers.

It is expected that, over time, most workers in the family- and carer-led centres will be family and carer peer workers. Workers in the centres should be supported by a statewide coordinator who is a family and carer lived experience worker. This coordination role will work in a similar way to the Families where a Parent has a Mental Illness (FaPMI) program, where coordinators are supported by a statewide coordinator located within the Bouverie Centre,[183] and the Risk Assessment and Management Panel, where family violence coordinators are supported by a development officer who undertakes a statewide coordination role within Domestic Violence Victoria (the peak body).[184] As such they will facilitate collaboration across the regional centres and provide additional supervisory support.

In establishing the centres, lessons can be drawn from the New South Wales Family and Carer Mental Health Program described in Box 19.3.

19.11.2 Financial support

Carers can experience significant financial hardships associated with their caring roles. The Productivity Commission's *Mental Health Inquiry Report* stated that '[i]n 2018, 41% of primary carers of people with mental illness reported difficulty meeting everyday living costs as a result of caring (compared with 30% for other primary carers)'.[185] These hardships can arise from both reduced income and costs associated with caring.

Box 19.3: New South Wales Family and Carer Mental Health Program

The New South Wales Family and Carer Mental Health Program is a statewide program funded by the New South Wales Government. The program is delivered in a partnership that includes local health districts and five specialist community organisations, and is delivered across 35 sites.[186]

The program aims to 'improve the wellbeing of families and carers of people with mental health conditions, and the people they support'.[187] Services offered include education and training packages for families and carers, information, resources and one-on-one support, health promotion activities and clinical services.[188] Supporting carers from diverse backgrounds and carers with additional needs is another important service offered. This includes Aboriginal people, people from culturally diverse communities, LGBTIQ+ people, people with a disability, young people and older people.[189]

Mental Health Carers NSW describes the program as 'one of the sole reliable sources of individual carer advocacy and one on one support in NSW and MHCN [Mental Health Carers NSW] routinely refers carers to the program for support. Although the program has not been comprehensively evaluated, the feedback which we have received from carers is that the support provided by the program is highly valued'.[190]

The weekly median income of carers is reported to be 42 per cent lower than that of non-carers.[191] The Productivity Commission reported that 32 per cent of employed carers worked reduced hours due to their caring role, and 44 per cent of carers who were not working would like to work.[192] Lower labour force participation has flow-on consequences for levels of income and, later in life, superannuation.

Ms Anna Wilson illustrated the individual impact of reduced income in her witness statement:

> Since Harold's illness, my whole career has gone out of the window. My annual income is down from around $50,000 to about $5,000. I have been too busy, stressed and exhausted from fighting and caring for my son to be able to work.[193]
>
> For Centrelink, there are all these rules and regulations around what you can and cannot claim. For example, you cannot claim travelling expenses, but travelling is a lot of what I do as a carer, whether it is to visit Harold in hospital or drive him to appointments.[194]

The practical costs associated with caring can also be broad ranging. For example, in their witness statement Aaron and Kristy Robinson said their daughter:

> struggles to access treatment and regularly runs away (at least once per week on average and more often recently) from home and treatment centres and attempts suicide.
>
> This generally involves breaking windows and climbing the fence when escaping from home ... Between replacing broken windows and having to put in fence extensions, we have spent about $4,000 in the last month. We don't have endless pockets of money and the National Disability Insurance Scheme ... seems reluctant to reimburse us for these costs.[195]

Some carers can access limited financial support from the Commonwealth Government. The Commonwealth Carer Payment is a fortnightly income support payment for carers of a person with a severe disability or medical condition or who is frail due to old age. As at 20 September 2020, the maximum rate was $944.30 for a single person per fortnight or $1,423.60 for a couple.[196] The Carer Allowance is an income supplement in recognition of the costs of caring and was $131.90 per fortnight as of 16 December 2020.[197] The Carer Supplement is an annual lump sum payment of $600 to assist with the costs of caring.[198]

In its interim report, the Royal Commission acknowledged concerns raised by families, carers and supporters about the Commonwealth's Carer Allowance and Carer Payment.[199] When considering similar concerns, the Productivity Commission's *Mental Health Inquiry Report* found there was 'some evidence to support claims that mental health carers are less likely to receive these payments than carers of people with a physical condition'.[200] The Royal Commission supports recommendation 18 from the Productivity Commission's *Mental Health Inquiry Report*, which suggests that the Commonwealth Government 'should amend the eligibility criteria for the Carer Payment and Carer Allowance to reduce barriers to access for mental health carers'.[201] In particular, the Productivity Commission recommended amending the eligibility criteria to reflect:

> the nature of care provided for someone with mental illness is not necessarily as 'constant' as that for a physical illness, can vary substantially from day to day, and is less likely to relate to the care recipient's 'bodily functions'. To provide more flexibility for the carer in undertaking their own economic and social activity, the restriction on hours that the carer can work should be evaluated over a month rather than each week, and the restrictions on study and volunteer activity should be removed.[202]

At the state level, the Royal Commission recommends changes to existing brokerage funding arrangements to provide families and carers with access to funds that support immediate practical needs.

Currently, families and carers can get modest brokerage funding through the Victorian Government–funded Mental Health Carer Support Fund, which has been administered by Tandem since 2009. To be eligible for funding the family member or carer applying for assistance must be supporting a person who is receiving services from an area mental health service.[203] The funding can be used for expenses such as transport, carer education programs, respite, educational and vocational opportunities, counselling, wellbeing activities and activities for groups of carers.[204]

In the 2018–19 financial year 3,427 applications to the Carer Support Fund were processed.[205] Based on the Commission's estimate that there were more than 58,000 carers of people living with mental illness in Victoria in 2018–19,[206] this means that, at most, just under 6 per cent of carers received support from the fund. Each application has a recommended cap of $850 per application with a maximum of $1,100 including GST per financial year.[207] In her statement to the Commission, Dr Melissa Petrakis, Chair of Tandem, said '[t]he reality is that in the 2019-20 financial year so far, the average amount per application has been $474.70'.[208]

Submissions made to the Commission indicate that the Mental Health Carer Support Fund is a well-used resource, and some submissions have advocated for an increase in its funding.[209] Dr Petrakis described the fund as 'effective at providing practical assistance for carers connected with [area mental health services] who are most likely to be experiencing the most acute economic, social and emotional distress'.[210] Dr Petrakis also told the Commission that Tandem has recommended that the Victorian Government reviews the level of support provided by the Carer Support Fund and increases the funding from $1.6 million to $2.6 million.[211] The Commission supports an increase to the Carer Support Fund but considers that a more substantial increase is required to meet its vision for greater supports for families and carers, as well as improved access pathways to the funding.

The Commission recommends that the Carer Support Fund be available through family- and carer-led centres as well as through Infant, Child and Youth Area Mental Health and Wellbeing Services and Adult and Older Adult Area Mental Health Services because these will become critical support points for families and carers in the future. Eligibility criteria should also be amended so that eligibility does not depend on supporting a person who is receiving treatment, care or support from a mental health and wellbeing service. Whether or not the person they care for is using services does not reflect the needs of families and carers.

The Commission considers that the Victorian Government should increase the fund to $4.2 million per annum by the end of 2022. This represents the $2.6 million sought by Tandem plus the equivalent of $200,000 per family- and carer-led centre.

While this total funding pool will be available via different pathways (through services and through the family- and carer-led centres), Tandem should retain its overall administrative role to provide a degree of oversight and consistency, as well as ensuring a streamlined application process for families and carers. The Victorian Government should also consider the resourcing implications for Tandem in administering a larger fund with a broader scope.

In practical terms, the substantial increase in brokerage funding available to carers across the state will allow families, carers and supporters greater access to respite and inreach supports. Respite for families and carers can take many forms including in-home support and a range of activities that allow families and carers to take a break, connect with others and look after their own wellbeing. Chapter 10: *Adult bed-based services and alternatives* provides details of the Commission's recommendations for investing in a range of time-limited, flexible and non-clinical respite services for consumers that are designed, delivered and evaluated by people with lived experience.

The Commission also recommends that brokerage funding available to young carers be substantially increased and made available to assist with the specific circumstances and needs of young carers (for example, general household supports such as cleaning, transport costs or tutoring).

The former Department of Health and Human Services estimated that in 2020 there were 9,000 young carers in Victoria.[212]

Coordinators under the FaPMI program currently provide access to a limited brokerage pool that is available to young people. According to departmental guidelines brokerage is incorporated into the program funding, with each area mental health service receiving $16,000 each year.[213] This level of funding would equate to an average of $195 per annum to 20 per cent of young carers.

The *Families where a Parent has a Mental Illness (FaPMI) Program Guidelines* stipulate that this brokerage funding can be used for 'goods and services to address a need and/or for the prevention of an emerging situation for which no alternative response is available'.[214] There are exceptions where support is not readily available and needs are assessed as urgent, such as food, clothing and transport.[215]

This funding should be increased to a minimum of $2.2 million per annum statewide and be made available through the new young carer support workers outlined in section 19.12.2. This would provide for average funding of $1,222 for 20 per cent of young carers per annum.

The Commission has concluded that young carers can experience particular disadvantage and that strong support when carers are young could substantially improve wellbeing, including mental health, and longer term engagement in education and employment.

Brokerage funding administered by Tandem and via young carer support workers should be reviewed every five years.

19.11.3 A statewide peer call-back service for families, carers and supporters caring for people experiencing suicidal behaviour

Many families, carers and supporters of someone experiencing suicidal behaviour shared their experiences with the Commission. Their caring experience often involved long-term psychological distress, hypervigilance, lack of sleep, practical strategies to keep the person they are caring for safe, and desperation in their efforts to get help for the person they cared for:

> I had to lock everything up at home, sleep on the floor of her room for 4 months and give her 24/7 attention. She was so suicidal she tried to jump out of cars.[216]
>
> We were not even told how to support someone who had attempted suicide, and they were just discharged.[217]

Ms Susan Trotter, witness, described caring for her son who first attempted suicide when he was 19 years old and who attempted suicide another 25 times before he died at age 33.[218] Ms Trotter said that 'for me it was a roller coaster and hospitals after hospitals'[219] over many years.

Families, carers and supporters play an important role supporting people who are experiencing suicidal behaviour, or following a suicide attempt. There are both system- and individual-level benefits to better supporting families, carers and supporters to perform this valuable role.[220]

Even with improved access to mental health and wellbeing services, families, carers and supporters will still carry most of the responsibility of the day-to-day caring and emotional support for people who are experiencing suicidal behaviour. Recognising how personally taxing this can be and the potential impacts on the families, carers and supporters, it is important that they themselves are supported.

Families, carers and supporters told the Commission of a need for better supports for people who are caring for someone who has suicidal thoughts.[221] The National Suicide Prevention Taskforce's *Interim Advice Report* to the Commonwealth Government also acknowledges the need for '[b]etter supports for family and caregivers – including those supporting someone through a suicidal crisis'.[222]

There is limited research on family and carer experiences of caring for someone who is experiencing suicidal behaviour. However, Australian research undertaken in 2019 that involved 758 people providing care to a family member or friend after a suicide attempt indicates that 65 per cent of respondents did not receive any information from the treating health professional about how to care for their loved one, and only 18 per cent felt supported to provide care.[223] Many sought information online, from support groups or relied on their own psychological supports.[224]

The Commission acknowledges the particular effects of long-term stress and hypervigilance on families, carers and supporters, and the need to provide tailored supports and information to help people in these circumstances with their caring role as well as their own wellbeing.[225]

In its interim report, the Commission recommended the full rollout of the HOPE (Hospital Outreach Post-suicidal Engagement) initiative's support and assertive outreach services to all area mental health services across the state.[226] The HOPE program is designed to support people after they are discharged from hospital following a suicide attempt or people who express suicidal ideation or repeatedly intentionally self-harm but who do not meet the threshold for entry to specialist clinical mental health services.[227]

While HOPE does provide support to a person's family, carers and supporters, its primary focus is on the person who has attempted suicide. The support that families, carers and supporters might receive from the HOPE program is limited and is provided in the context of how they might support the person they are caring for.[228]

In Chapter 9: *Crisis and emergency responses* the Commission outlines its vision for a reformed approach to crisis response. Acknowledging that families, carers and supporters are themselves often deeply affected when someone they care for is experiencing a mental health crisis, services will consider the specific needs of families, carers and supporters in crisis responses. Wherever possible, dedicated peer worker roles should be established for families and others involved in the crisis.

In addition to these measures, and acknowledging the considerable strain on families, carers and supporters experiencing long-term stress and hypervigilance, the Commission also recommends that the Victorian Government establishes a statewide peer call-back service for families, carers and supporters caring for people experiencing suicidal behaviour.

At a prearranged time that suits the family member, carer or supporter, a peer worker will provide emotional support delivered by telephone or online, as well as supporting the person's capability to look after the person they are caring for. This might include practical strategies drawn from evidence and the peer worker's own experience. The peer worker will also support the family member, carer or supporter in their own self-care and mental health and wellbeing.

Peer workers will be available at times that best suit families, carers and supporters, including after hours, and will consider the diverse needs of the community, including people from culturally diverse backgrounds and LGBTIQ+ people.

According to the Black Dog Institute, '[p]eer warm line models, where those with lived experience answer calls, reflects community demand for telephone based support'.[229] This new service will not be a crisis line. Instead, the warm line model is 'designed to support people who are in distress and need support before reaching an immediate crisis need'.[230] The service will differ significantly from existing services such as Lifeline (which provides 24-hour crisis support) and the Commonwealth Government–funded Suicide Call Back Service (which provides 24-hour access to a professional counsellor for people with suicidal ideation) in that it will connect families, carers and supporters with peer support that is specific to suicidal behaviour and to their role in caring for someone with suicidal behaviours. It will be delivered by families, carers and supporters with a lived experience of caring for someone experiencing suicidal behaviour rather than by peers with lived experience of mental illness more broadly. This is important because caring for someone with suicidal behaviour can be substantially different from caring for someone with other mental health and wellbeing challenges.

The service will also differ from the HOPE initiative, which is currently only available once a person has attempted suicide. The call-back service will be open to families, carers and supporters of people experiencing any form of suicidal behaviour. It will reach a much wider range of families, carers and supporters and offer more intensive and personalised support than the HOPE program does. Families, carers and supporters involved in the HOPE program can opt to be connected with the call-back service so they can receive dedicated support in their own right from people who have been in similar situations to them.

The peer call-back service draws on evidence about the effectiveness of peer support. The Commonwealth Government's guidance on the role of the peer workforce in mental health and suicide prevention highlights the important role peer workers can play:

> Peer workers draw on their lived experience to play unique roles in encouraging and supporting the recovery of people experiencing mental health issues by:
>
> - Offering hope and supporting … carers to develop a recovery-oriented perspective
> - Supporting … carers to develop important life skills
> - Supporting … carers to move beyond being a … carer to develop a personal sense of empowerment
> - Empathising with … carers from a position of experience.[231]

The service will provide a call-back following appropriate peer matching. Peer matching means that callers will be matched with someone with a similar experience—someone who has walked in their shoes and has had to make similar decisions or lived through similar periods of stress. For example, a parent caring for a teenager who has suicidal thoughts will be able to speak with another parent who has been in that position. This approach will ensure practical advice and supports tailored to the circumstances of the family can be provided.

The call-back element of the service recognises that caring for someone who is experiencing suicidal behaviour can be time consuming and requires flexibility as to when the person in the caring role can access help. The family member, carer or supporter can choose a time that best suits them—for example, it may be at night when the person they are caring for is sleeping. The remote delivery of the service means the person in the caring role does not have to physically leave the person they are caring for alone and can stay in the comfort of their home.

The Commission's recommended approach of a peer-led call-back service draws on a pilot program from Roses in the Ocean, an organisation 'committed to developing a national lived experience workforce to inform, enhance and lead initiatives and services within suicide prevention'.[232] Roses in the Ocean is currently trialling a suicide prevention 'Peer CARE Connect warm line service' for people affected by suicide.[233] The service will provide callers with the option of a response within 48 hours via either phone call, email or text message.[234]

This pilot program from Roses in the Ocean builds on its existing peer program (by providing the pilot call-back service), which provides 'a 'light touch' scaffolding of support to people impacted by suicide experiencing heightened emotions in times of adversity [delivered by] peers [who] are trained specifically to address this very specific and significant need within our communities'.[235]

Another example is Queensland's Peach Tree peer-led perinatal mental health call-back service established in 2020. Peach Tree supports perinatal resilience and recovery with individuals and families, and its peer call-back service offers emotional support to people parenting children aged 0–5 years. The service is designed to support parents who feel they are not coping with life and parenting, have low mood, heightened anxiety or are unsure about how to get help and support. Peach Tree has been offering face-to-face peer support for the past nine years, and the introduction of the peer call-back service was in response to the COVID-19 pandemic.[236]

Victoria should build on these emerging models.

The Commission has also made a separate set of recommendations on suicide prevention and response, which are explained in Chapter 17: *Collaboration for suicide prevention and response*. The recommendations in Chapter 17 will better support families, carers and supporters, including through a statewide postvention bereavement support program.
The grief following a loved one's suicide can be profound and the emotions experienced, particularly when people experience stigma and isolation because of the way a loved one died, can differ considerably from the grief felt following other types of deaths. All Victorians bereaved by suicide should have access to evidence-informed services to reduce their risk of suicidality and poor mental health and, in the future, all people bereaved by suicide will be automatically referred to postvention bereavement support.

19.11.4 Tailored online information for families, carers and supporters

Families, carers and supporters, including young carers, have told the Commission that they often struggle to find information about supports available to them.[237]

A 'one-stop shop' with information for families and carers is difficult to achieve in practice, partly because the Commonwealth and Victorian governments are responsible for different services and supports.

Currently, information is spread across government, peak body and service provider websites. This situation could be vastly improved with better coordination and central delivery and management of online information (including the necessary resourcing to achieve and maintain this). A central website with statewide information will be established with links to other sources where relevant—for example, Commonwealth programs.

The Commission recommends that the Victorian Government be responsible for ensuring there is information for families, carers and supporters, such as on the new statewide mental health website outlined in Chapter 8: *Finding and accessing treatment, care and support.* These recommendations should be implemented alongside each other to ensure efficiencies in digital infrastructure and resourcing.

The online information should be co-designed with people with family and carer lived experience and will include:

- information and details for the eight family- and carer-led centres
- information for families, carers and supporters who are caring for someone who may be experiencing suicidal thoughts
- tailored information about supports available (including financial assistance and eligibility criteria) for young carers and other children and young people who have a family member experiencing mental illness or psychological distress.

Information should also be available in accessible formats.

The Commission also encourages the Commonwealth Government to improve its online information for mental health carers (as well as ease of navigation), including the Carer Gateway and guidance about federal financial supports available to young carers (such as eligibility criteria and application processes). The Commission notes that this aligns with findings from the Productivity Commission's *Mental Health Inquiry Report*, which made recommendations for the Commonwealth Government to evaluate and publicly report on how well the Carer Gateway:

- meets the needs of mental health carers relative to other types of carers
- meets the needs of young carers, Aboriginal carers and culturally diverse carers.[238]

19.12 Supporting young carers and children and young people who have a family member experiencing mental illness or psychological distress

As examined earlier in this chapter, young carers who take on formal caregiving responsibilities face particular disadvantage. However, all children in families where a parent, other family member or carer experiences mental illness or psychological distress can be affected by the experience. This includes being likely to obtain poorer education outcomes than their peers, experience social isolation and take on caring and household responsibilities beyond expectation for their age.[239]

Research suggests that approximately 25 per cent of children live with a parent who has a mental illness[240] and that:

> These children have an increased [likelihood] to experience additional adversities due to their family circumstances, which for some, may lead to negative long-term difficulties, in addition to substantial lifelong impacts for individuals, governments and the wider community.[241]

One limited study of the experiences of siblings concluded that '[a]ll participants had been greatly affected by the onset of the psychosis in their brother or sister. Most siblings did not identify themselves as carers, although most played a significant part in their brother's or sister's life.'[242]

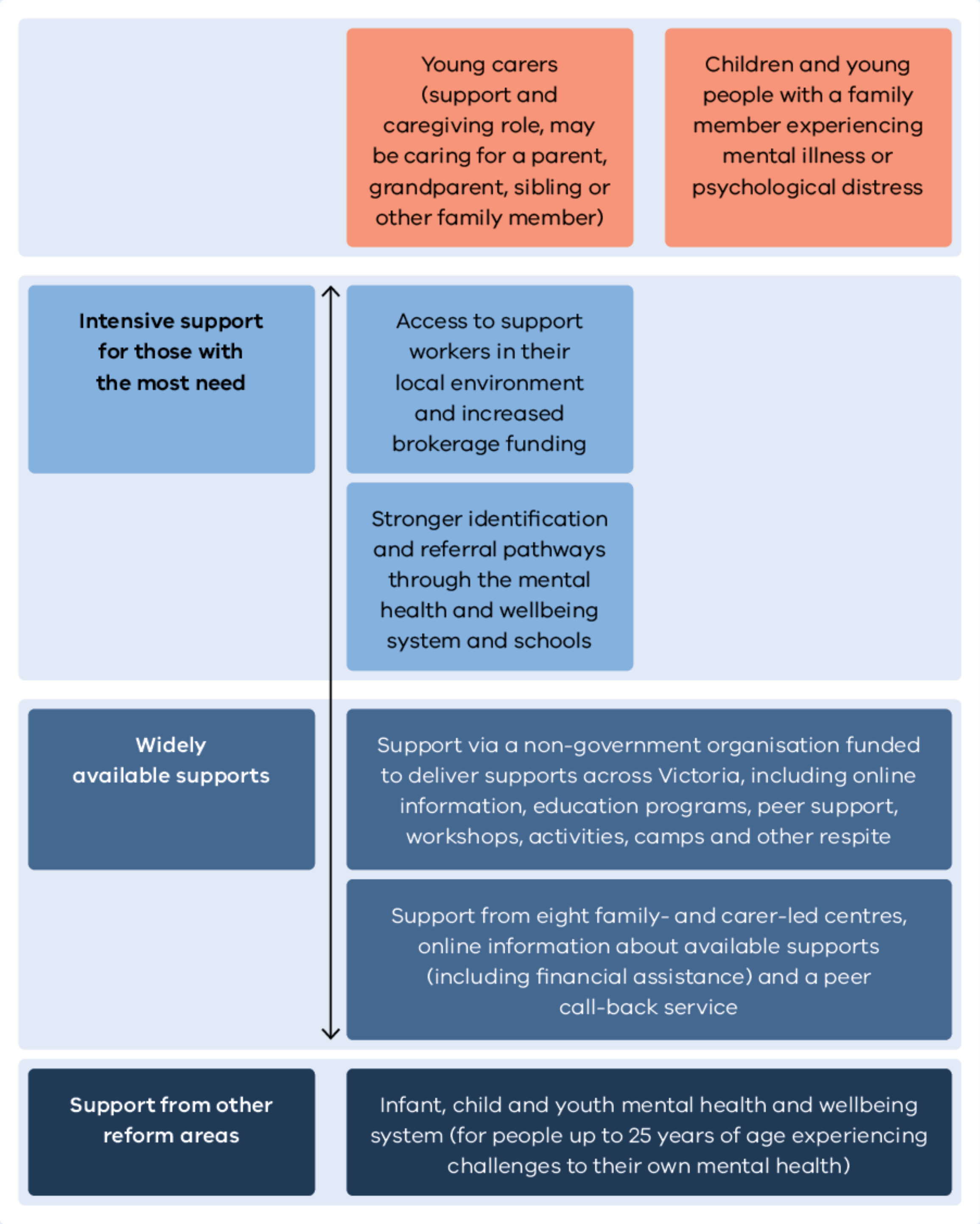
Research from Orygen, the National Centre of Excellence in Youth Mental Health, suggests growing recognition of the need to support siblings of young people experiencing mental illness, alongside support for parents and caregivers. Orygen stated that '[t]he experience of siblings includes mixed emotions of resentment and guilt stemming from reduced parental focus, the need to be more self-reliant, overcompensating for their own behaviour and unmet needs for parental support. Alongside this experience they can also feel as if they have "lost" their sibling.'[243]

The Commission acknowledges the need to provide dedicated support to young carers and children and young people who have a family member experiencing mental illness or psychological distress to mitigate what can be lifelong impacts.

The level of support needed will vary, depending on the circumstances of the young person and their family, and the nature of any caregiving role. A flexible approach is therefore recommended, with a range of supports available not only to young carers but also other children and young people who have a family member experiencing mental illness or psychological distress. Intensive supports, tailored to the needs of young carers, will be available to young people with caring responsibilities. This flexible approach is outlined in Figure 19.3.

Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing* and Chapter 13: *Supporting the mental health and wellbeing of young people* outline the Commission's recommended approach to mental health and wellbeing for people up to and including 25 years of age. The recommendations in these chapters will also benefit young carers and children and young people who have a family member experiencing mental illness or psychological distress, and who experience challenges with their own mental health. It is also noted that some young parents experiencing mental illness or psychological distress will be accessing support through the youth mental health and wellbeing service stream and that their children will have access to the supports outlined here.

Figure 19.3: A graduated program of supports



19.12.1 A range of supports for children and young people

Young carers have told the Commission of the importance of being able to connect with other young people with similar experiences. This was highlighted during the Commission's focus groups with young carers:

> This focus group has made me feel very validated and shown me that I need to go and try and find more young carers because my experience with carers has … been with older carers so I just didn't reali[s]e the extent of what it would do for me and how great of an opportunity it is for me …[244]
>
> knowing that there are … other people who experience what I experienced. And it's been so wonderful to hear what everyone's talked about … I really, really need to try and … meet other young carers or join some sort of support, because this has been really good for my mental health.[245]

The Commission recommends that the Victorian Government funds a non-government organisation such as Satellite Foundation to creatively co-design and deliver, by the end of 2022, an expanded range of supports that will be available across the state to both young carers and other children and young people who have a family member experiencing mental illness or psychological distress.

While there are several networks to support young carers—the Carer's Australia Young Carers Network and Little Dreamers being two notable examples—these networks offer a range of programs, activities and support to young carers broadly, not just mental health carers. The Commission believes, however, that there is a need for supports dedicated to the needs of young mental health carers and children and young people who have a family member experiencing mental illness or psychological distress. This is due to the particular challenges they may experience (and the distinct nature of the mental health caring role) including the impact of stigma, the level of emotional support provided and intergenerational effects on mental health and wellbeing.

Supports and programs will cater for a range of age groups up to and including 25 years. The supports offered will be co-designed with children and young people with lived experience as a young carer or having a family member experiencing mental illness or psychological distress and will include:

- online information, education programs, resources and supports, including peer support
- face-to-face peer support, workshops, activities, camps and other respite
- creative responses through a positive and supportive environment
- creative educational programs and materials that can be delivered in and shared with schools
- programs that support children and young people in rural and regional areas (including face-to-face programs)
- programs that respond to diverse needs, including those of Aboriginal communities, culturally diverse communities and LGBTIQ+ people.

The funded non-government organisation should also:

- actively engage with schools and mental health service providers to build referral pathways
- build partnerships to expand collaborative research opportunities.

According to Ms Rose Cuff, State-wide Coordinator of FaPMI and Executive Director and co-founder of Satellite Foundation, young carers can feel extremely isolated and may assume that no one will understand their experience.[246] Supporting children and young people who have a family member experiencing mental illness or psychological distress to come together in a welcoming and positive environment will be an important way to help combat these feelings of isolation.

Satellite Foundation (refer to case study) is an organisation that operates on a small budget with the support of volunteers. Young carers have told the Commission about their positive experiences with Satellite Foundation, including people who are now adult ambassadors.[247]

In her statement to the Commission, Ms Cuff described Satellite Foundation as an organisation that 'develops programs that enable children and young people to focus on their hopes and dreams for their future whilst connecting them with others who may have similar experiences'.[248]

The remit of the funded non-government organisation will include co-designing creative programs that can be delivered across Victoria (in partnership with schools) that encourage conversations about mental health and its impacts on young carers and other young family members (refer to section 19.12.3). This should receive a dedicated funding stream within the overall program funding.

As an example of a creative program, Satellite Foundation launched It's A Mad World in November 2020, 'an online showcase of different perspectives on mental health, created by those with lived experience and the Satellite Foundation. Using different mediums, we share stories of the funny and the sad, the happy and the mad, when navigating the complex world of mental health'.[249] Originally planned as a live performance project, It's A Mad World was adapted to a two-week online exhibition due to COVID-19.

19.12.2 Providing young carers with access to support workers

The mental health system must be responsible for actively supporting young carers.

Many young carers do not reach out for support, and some actively try to stay under the radar of services. As the Productivity Commission observed, young carers may not self-identify as carers, or may hide their caring role because they 'are concerned about intervention from child protection services'.[250]

Mr Morgan said that although his mother had case managers, he and his brother did not engage with support services.[251] Part of the reason for this was that his family 'lived in a constant fear of being separated from each other … I felt like engaging in help and telling people the extent of what was going on, that threat would be realised'.[252]

Case study:

Satellite Foundation

Satellite Foundation (Satellite) is a not-for-profit organisation founded in Melbourne in 2009. Co-founder Ms Rose Cuff said it was established in recognition that 'approximately 250,000 children and young people in Victoria live with a parent or carer who has a mental illness'.

> Satellite Foundation seeks to contribute to positive outcomes for children, young people, their families, and communities, where a parent has a mental illness or mental health challenges.

Satellite's range of creative programs and activities aim to offer safe and welcoming spaces for connection and peer support, strengthening skills and sharing ideas.

Satellite seeks to provide young people with opportunities to share their experiences and create ongoing connections. Ms Cuff said:

> These young people need experiences other than their caring role, and need to feel supported and connected in order for them to be optimistic for their future—to see a 'solution-enabled' future for themselves.

Satellite provides a range of free programs to children and young people aged 8–25, and has increased its offering of online programs in response to COVID-19. Satellite's programs include the following:

- **Satellite Connect** is a free online six-week program for people aged 17–23 years. The program includes a range of workshops designed to support adolescents and young adults to recognise their strengths and realise their potential. There is a weekend retreat at the end of the program.
- **Satellite Connect Youth** is an adapted version of Satellite Connect for adolescents aged 14–17 years.
- **At Home with Satellite** provides a selection of activity-based, self-care packs and online workshops for children and young people aged 8–16 years. It includes opportunities for creative expression, storytelling and peer connection.
- **Satellite Camps** provide three-day overnight programs for young people aged 10–15 years. The aims of the camp include providing respite for children and young people, reducing isolation through peer support, promoting healthy coping strategies, and encouraging longer-term interactions between participants.
- **Music, art and song writing workshops** are three-day, in-person programs for young people aged 11–14 years that provide supported opportunities for creativity and collaboration in a fun and safe space.

- **Photography workshops** are one or two-day, in-person programs for young people aged 10–16 years (approximately). The workshops provide a space for young people to explore different experiences, including mental health and wellbeing, and a chance to use creative practice to explore how they see the world.
- **It's a Mad World** is an online exhibition where people with lived experiences can share different perspectives on mental health, creating a space to talk and laugh freely.

Satellite operates on three principles—connect (recognising the importance of belonging and fostering a sense of community), support (providing supportive and safe environments), and empower (putting young people at the heart of its work).

A recent graduate of a Satellite Connect program described her experience:

> I do not have the right words to accurately articulate how wonderful and amazing this program has been and how much this program has touched my life. I feel like I have made more progress in the past six weeks with Satellite Connect, than I have in eight years seeing psychologists on and off. I am so grateful for everything that the Satellite Foundation has blessed my life with.

Satellite has support from Emerging Minds, an organisation dedicated to advancing the mental health and emotional wellbeing of Australian infants, children, adolescents and their families. Satellite also works closely with a number of community, mental health and arts-based organisations, providing opportunities for research and collaboration. In June 2020, Satellite received funding from the Commonwealth Government to boost its supports for children and young people during the COVID-19 pandemic.

Source: Satellite Foundation, <www.satellitefoundation.org.au>, [accessed 18 October]; *Witness Statement of Rose Cuff*, 2 July 2019; Rose Cuff, Correspondence to RCVMHS, 2020; The Honourable Greg Hunt MP, Commonwealth Minister for Health, Media Release: COVID-19: Support for Children and Young People, 17 June 2020, <www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/covid-19-support-for-children-and-young-people>, [accessed 9 September 2020]; Emerging Minds, Who we are, <www.emergingminds.com.au/about/who-we-are>, [accessed 14 December 2020].

To provide more intensive support for young carers, the Commission recommends that the scope of the FaPMI program be broadened by the end of 2022, including by enabling each Adult and Older Adult Area Mental Health and Wellbeing Service to employ new workers who will be dedicated to providing support to young carers in their local environment and increasing the amount of brokerage funding available to help young carers with practical needs (refer to section 19.11.2).

The Commission's recommendation for dedicated support workers draws on a current research project based in Austria—the Village Project—which is outlined in Box 19.4.

Box 19.4: The Village Project

The Village Project is a four-year research project that seeks to improve development and wellbeing outcomes for children of parents with a mental illness. The Village Project has two core elements—improving how children in that situation are identified and strengthening child-focused support networks.[253]

As well as early identification of children in families affected by mental illness, the project is seeking to ensure children have a range of informal and formal supports available to provide them with the support that they need and want.

The project's approach to early intervention includes the 'collaborative village approach' to strengthening child-focused support networks.

> According to the project concept, for installing the support network within the [collaborative village approach], informal support sources will be activated as a primary source, and supplemented by formal support, where needed. The project draws on community-capacity building approaches, developing a supportive network of allies around a person.[254]

An important part of the project methodology is the concept of 'child voice' to ensure the child is at the centre of their own care and supported to identify their own formal and informal support networks.[255]

The research group is supported by a 'competence group'. This group consists of six lived experience experts—adolescents and young adults who have a parent with a mental illness.[256]

FaPMI is a Victorian Government–funded program launched in 2007. The program recognises the impact of mental illness on family members, particularly dependent children. Program delivery is via adult area mental health services.[257] One of the program's objectives is to '[e]stablish and strengthen service networks in partnership with consumers and carers to provide a coordinated and collaborative response to the needs of families where a parent has a mental illness.'[258]

A statewide coordinator for FaPMI sits within the Bouverie Centre, and Victorian Government funding enables one fulltime-equivalent coordinator position to be employed in each adult mental health service. The coordinators 'offer a range of services including secondary consultations, and joint consultations with the parent/family to enable conversations with clients and families about the potential impact of mental illness, especially on children.'[259] The coordinators are also involved in building resources and workforce development initiatives and building collaborative practices between sectors.[260]

FaPMI plays an important role in supporting families and improving services' responses to families where a parent has a mental illness. However, the Commission considers that more intensive supports, focused primarily on the everyday and long-term needs of the young carer, are needed in addition to the existing scope of the FaPMI program.

The scope of the FaPMI program will be broadened to include support workers for young carers across the state. At least 32 fulltime-equivalent support workers for young carers should be based across the 22 mental health and wellbeing adult and older adult service areas. Support to young carers will be provided by Adult and Older Adult Area Mental Health and Wellbeing Services on an outreach basis in the young carer's local environment (these workers will be in addition to the FaPMI coordinator role currently located in each adult area mental health service). Each Adult and Older Adult Area Mental Health and Wellbeing Service will have at least one support worker, with the Commission recommending an additional 10 workers given some areas will have additional resourcing requirements based on geographic and demographic need. Access to a support worker will be available to young carers in a variety of relationships of care and support, such as a sibling or grandparent, not just people caring for a parent.

The role of support workers will include:

- supporting young carers, including through active follow-up and outreach
- working with the young carer to identify their existing informal support network (which could include grandparents and other relatives, friends and neighbours) and identify gaps that could be filled with more formal supports (for example, tutoring or transport to school if a parent is unwell)
- identifying how existing support gaps can be filled and facilitating meetings with the young person's existing network as well as formal supports to plan how to collectively support the young person
- connecting young carers to other forms of support (including in liaison with existing FaPMI coordinators), including brokerage and helping them to apply for other forms of financial assistance.

The aim of the Commission's recommendation is not only to fund support workers for active follow-up and outreach but also to help young carers to develop strong support networks of their own that they can draw on for support long term, as needed.

Importantly, the ability to get help from a support worker will not be limited to circumstances where a family member is actively connected with a mental health service as a consumer. Young people may require support even when a family member experiencing mental illness or psychological distress is not accessing treatment, care and support themselves. Given that many young carers in need of help from a support worker will be under the age of 18, it will be critical for the support workers to establish a relationship with the young carer's parent/s, guardian, or other family member/s as well, depending on the individual circumstances. Delivery of this program will be based on individual as well as local needs, noting that young carers in rural and regional areas may have quite different support needs from those in metropolitan areas. An appropriate change to the program name should be considered to reflect this change in scope.

While funded as part of an existing government program, this new approach to support will require creativity. The expanded FaPMI program should explore new ways of proactively engaging with young people to ensure they feel safe, supported and understood.

19.12.3 Strengthening identification and referral pathways through the mental health and wellbeing and education systems

In addition to actively supporting young carers, the mental health and wellbeing system must play a stronger role in identifying young carers and referring them to supports. The education system can also play an important role given it is a consistent and non-stigmatised service in the lives of most children and young people.

The Commission recommends that the Department of Health improves identification and referral pathways through the mental health and wellbeing system and works with the Department of Education and Training to strengthen these pathways in the education system.

In the mental health system, research indicates that clinicians do not 'routinely engage with their clients about parenting, children's needs, or family functioning'.[261] The Commission's recommendations in this chapter intend to rectify this. There is also often a gap in identifying the needs of children and young people outside of a parent–child relationship, such as siblings, grandchildren, nieces and nephews.

In the future mental health and wellbeing system, it will become more common to engage with consumers not just as individuals but by taking into account their family and other relationships as well. This will play an important role in identifying more young carers and other children and young people in a family who may need support.

Personal story:

Emily John

Emily* is 18 years old and has been a carer for her mother her whole life. Emily was 13 when her mother experienced her first mental health crisis and was admitted as an inpatient.

> I remember the ward seeming old and outdated, so it was really scary.

Emily has been the primary support for her mother since that crisis. However, she finds there is little consistency in how hospitals involve family in treatment and has generally found that 'no matter what age, they never really listen to what I have to say'.

> I am a big advocate for my mum. I have done it all my life. It was difficult when I was underage and lived at home by myself when my mum was admitted. I didn't want to tell the hospital I was home by myself because I felt that it was going to get other people involved.

Following her mother's first inpatient admission, the Families where a Parent has a Mental Illness (FaPMI) program connected Emily with young carer support services. This support provided Emily with respite away from her caring role as well as a supportive environment where she could learn more about mental illness with other young people going through the same experiences.

> When I was in the young carers program I'd get movie tickets and they would organise outings for us. They took me out of my situation and gave me a little bit of respite.
>
> FaPMI gave me a lot of opportunities both as a carer and a kid that has a parent with a mental illness. They ran programs over the school holidays for kids living with parents who have a mental illness to help us understand mental illness more. The programs are fun and you feel supported because everyone there has a parent with a mental illness.

Emily credits FaPMI with providing her with the skills and support to explore opportunities as a peer support worker.

> FaPMI also gave me the opportunity to become a peer support leader. I have developed a voice because of the opportunities they have given me over the last six years. I have sat on panels and participated in a forum discussion with case workers and others working in the mental health system.

Source: *Witness Statement of 'Emily John' (pseudonym)*, 15 July 2020.

Note: *Name has been changed in accordance with an order made by the Commission.

The *FaPMI Program Guidelines* include the following guidance:

- 'Ensure consumers who are parents, and their children, are routinely identified.'[262]
- 'Dependent children and young people whose parent has a mental illness will have their own support needs recognised by their parent's mental health service or other participating service, therefore having their own mental health optimised.'[263]

The improved approach to identification must become a routine part of contact with new youth and adult mental health clients, with referrals and supports then offered to children and young people as needed (including to the new support workers and family- and carer-led centres). Practitioners should engage with consumers in a way that includes their family and important relationships, including children and young people in their care.

In relation to the education system, the Commission welcomes the recent work of the Department of Education and Training to support young carers, such as developing a policy and guidance for schools (published in November 2020) on identifying and supporting young carers. This guidance includes the ability to record the status of a student as a young carer in school record-keeping systems.[264] The Department of Education and Training has also partnered with Little Dreamers and PROJECT ROCKIT to 'build the capacity of school staff to recognise and support young carers to stay engaged in school'.[265] However, as established throughout this chapter, the role of caring for someone living with a mental illness is distinct from other types of caring roles. Young carers of a family member experiencing mental illness or psychological distress have reasons to try to avoid identification by services, largely driven by experiences of stigma and discrimination, and the fear of statutory child protection involvement.

The Commission has therefore determined a need to go further to ensure the education system becomes an environment where young mental health carers feel safe to disclose their circumstances and can be connected with supports.

Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect* outlines in more detail how education settings are priority environments where mental health and wellbeing can be promoted. It also establishes that supporting children and young people to get help and providing inclusive environments where students are encouraged to participate is critical to supporting better long-term outcomes.

There is a significant opportunity to build awareness of the needs and circumstances of young mental health carers into new and existing programs for mental health support in schools. The Commission notes that some Victorian Government programs have recently been boosted, and in some instances rollout brought forward, in light of COVID-19.[266]

It is recommended that the Department of Health partners with the Department of Education and Training to explicitly build young mental health carers into existing and future programs focused on the mental health and wellbeing of students. For example, staff training and school mental health and wellbeing officer roles could be expanded to include training in how to identify young mental health carers and to talk to them about their challenges and support needs; how to engage with parents and families of young carers; as well as how to provide up-to-date information about available support services and networks.

As well as expanding existing mental health programs in schools to include young mental health carers, a non-government organisation will be funded to co-design creative programs that can be delivered in partnership with schools, as discussed in section 19.12.1. These programs will encourage conversations about mental health and its impacts on young carers and other family members.

Mr Justin Heazlewood, a witness before the Commission, said that adults must assert a duty of care towards young carers, rather than waiting for children to make the first move to ask for help.[267] The education system is a critical setting for this type of outreach. In his witness statement, Mr Heazlewood shared his ideas for creatively reaching out in schools:

> There should be an increase in targeted education of children from primary school age about mental illness. This should coincide with a proactive attempt to identify any children who may be caring for parents with a mental illness. This could be done through a questionnaire or interviews. A special performance or talk could be created with the express purpose of educating children and encouraging them to come forward at the end of the session and nominate that they may be in a position of needing help. (Similar to the Life Education vans, we need a mental illness "mothership" which could trundle from school to school and be unusual and exciting in its design, like a huge alien brain.) Again, it would be devised solely for the purpose of educating about mental illness, mental health and self-care.[268]

It is the Commission's intent that through a stronger focus on early identification of young carers via both the mental health and wellbeing system and the education system, young carers will be able to get the supports they need (including support workers and brokerage funding) in a more supportive and timely way than is currently the case.

19.13 Families, carers and supporters across the Commission's recommendations

Finally, the Commission acknowledges that many of the matters families and carers raised during its inquiry were problems that stem from the consumer experience. Seeking to make things better for consumers in the future mental health and wellbeing system, as well as in broader community settings, has been a natural extension for many families, carers and supporters of their focus on the needs of the person for whom they care.

The Commission has made recommendations on a wide range of matters raised by families, carers and supporters throughout this report. These reforms are interconnected and should be considered as a whole.

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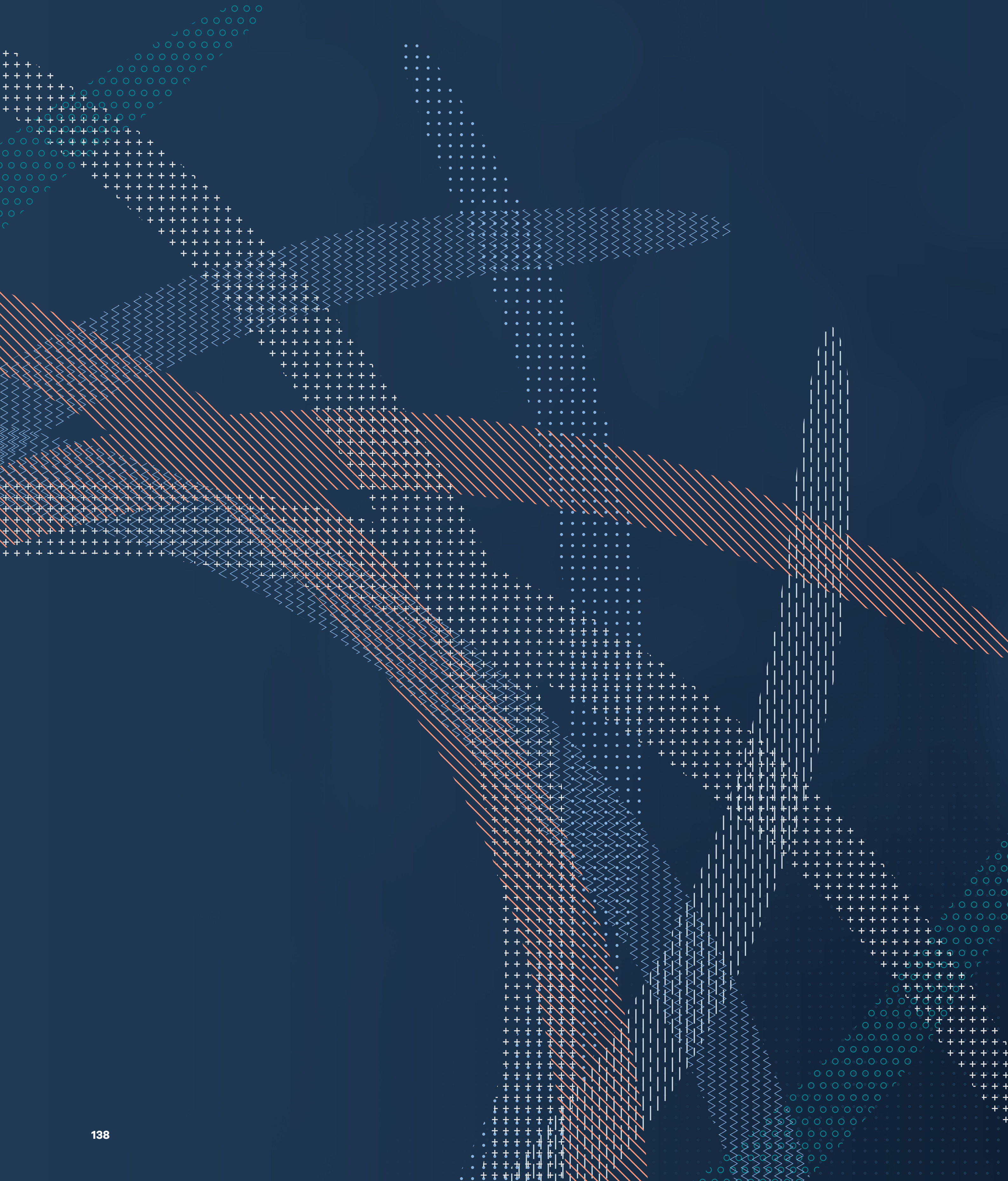


Chapter 20

Supporting Aboriginal social and emotional wellbeing

Recommendation 33:

Supporting Aboriginal social and emotional wellbeing

The Royal Commission recommends that the Victorian Government:

1. build on the interim report's recommendation 4 to support Aboriginal social and emotional wellbeing, and resource the Social and Emotional Wellbeing Centre to establish two co-designed healing centres.
2. resource Infant, Child and Youth Area Mental Health and Wellbeing Services to support Aboriginal community-controlled health organisations by providing primary consultation, secondary consultation and shared care.
3. resource Aboriginal community-controlled health organisations to commission the delivery of culturally appropriate, family-oriented, social and emotional wellbeing services for children and young people.
4. resource the Victorian Aboriginal Community Controlled Health Organisation, in partnership with an Infant, Child and Youth Area Mental Health and Wellbeing Service, to design and establish a culturally appropriate, family-oriented service for infants and children who require intensive social and emotional wellbeing supports.

20.1 Aboriginal social and emotional wellbeing

Social and emotional wellbeing means being resilient, being and feeling culturally safe and connected, having and realising aspirations, and being satisfied with life.[1] Witnesses and submissions from Aboriginal people and community-controlled organisations made clear to the Commission the courage and strength of Aboriginal communities, and the protective role of culture, identity and connection to country for social and emotional wellbeing.[2]

In the face of significant challenges stemming from invasion, dispossession and ongoing systemic racism and marginalisation,[3] Aboriginal communities remain resilient. The Commission recognises the leadership and ingenuity of many Aboriginal Elders, communities and community-controlled organisations in supporting better social and emotional wellbeing outcomes for Aboriginal people.

The Commission is grateful to the many Aboriginal people and organisations who have invested their trust in the Commission and shared their individual and collective experiences of pain, trauma and resilience. The Commission agrees with evidence before it that Victoria's mental health system has failed to meet the needs of Aboriginal people.[4] The mental health system has failed to genuinely recognise or reckon with the many ways in which it has excluded Aboriginal people, and it has failed to acknowledge the ways in which it has contributed to or exacerbated mental illness.[5] Perhaps most devastatingly, it has failed to change.

The Commission also acknowledges the significant contribution of the Victorian Aboriginal Community Controlled Health Organisation, which developed the *Balit Durn Durn* report to support the Commission's deliberations. In the report, CEO, Jill Gallagher described the 'direct relationship between poor mental health and wellbeing, and loss of land, culture, identity, self-worth and the breakdown of traditional kinship structures and roles' within Aboriginal communities.[6] Speaking about the community consultations undertaken in the development of the report, Ms Gallagher noted:

> Despite the levels of loss, grief, health anxieties and racism felt in Aboriginal Communities, many interviewees were incredibly passionate about their work and optimistic about the future. Interviewees showed a deep commitment to their own and their family's healing and social and emotional wellbeing.[7]

Ms Gallagher also discussed the devastating impact—felt worldwide—of the death of African American man George Floyd in the United States of America, while being arrested:

> Floyd's death triggered demonstrations and protests globally that also had enormous reverberations in Victoria and across Australia. It reminded us how we must be prepared to address the injustices and ongoing impacts of colonisation if we ever wish to see improved health and wellbeing outcomes in Aboriginal Communities.[8]

The Royal Commission into Victoria's Mental Health System follows many royal commissions and inquiries—spanning several decades—that have highlighted the systemic failure of government agencies and social institutions to discharge their responsibilities to Aboriginal people and communities. The breadth and depth of this failure is more than adequately documented in multiple royal commission reports.[9] These shortcomings are frequently compounded by a failure to fully implement the resulting recommendations or to adequately evaluate the impact of recommendations that are implemented.[10]

In recognition of both the urgent need for reform and the efficacy of taking a social and emotional wellbeing approach to mental health, the Commission's interim report recommended a suite of reforms to support Aboriginal community-controlled health organisations to provide comprehensive care for Aboriginal consumers (refer to Box 20.1).[11]

Building on, and consistent with, the reforms described in the interim report, the additional reforms in this chapter are founded on the principles of self-determination—'that Aboriginal Victorians hold the knowledge and expertise about what is best for themselves, their families and their communities.'[12]

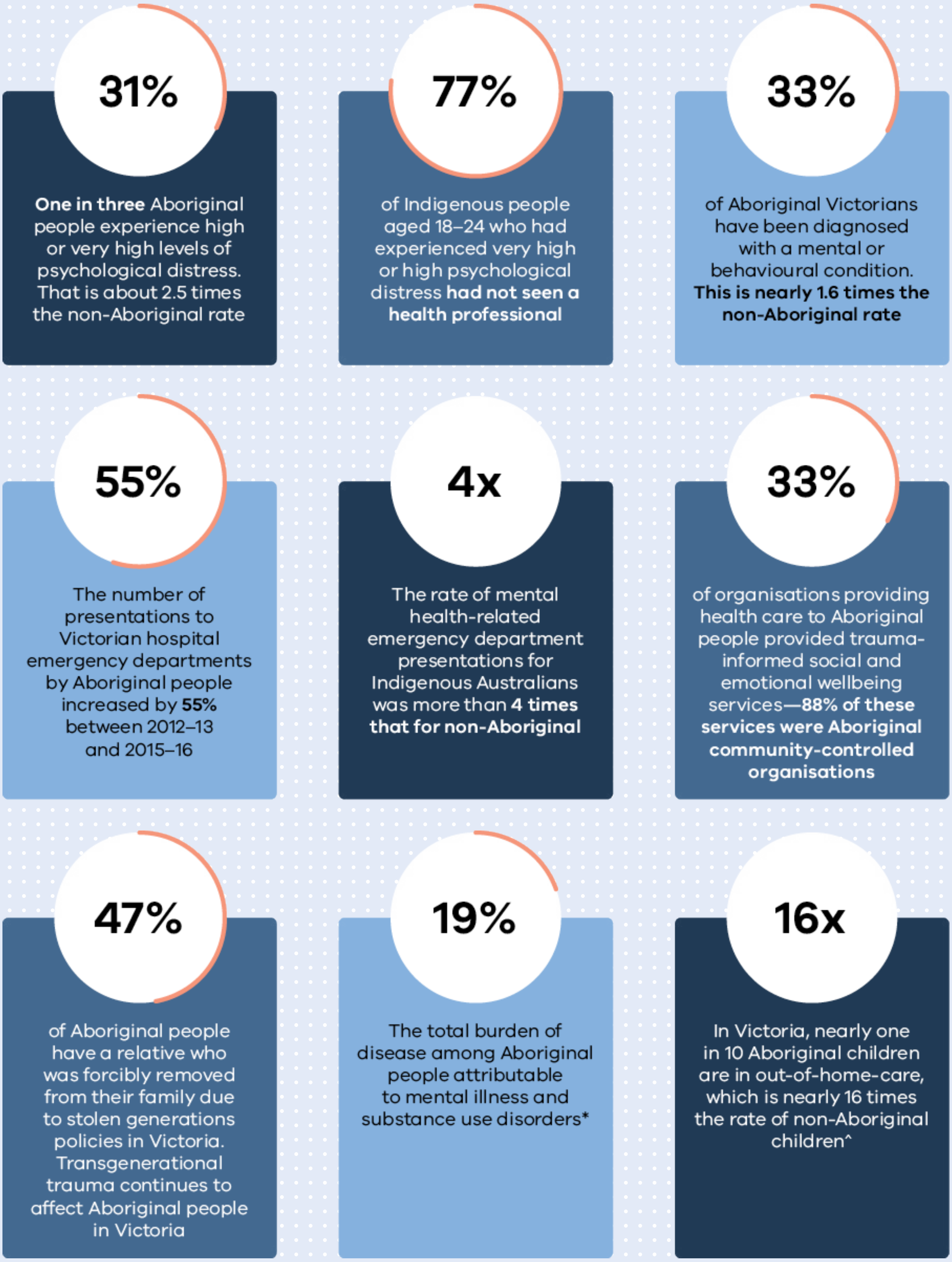
The recommended reforms include funding for the delivery of healing centres to complement the social and emotional wellbeing services delivered by Aboriginal community-controlled health organisations. The focus on healing marks a further shift away from the crisis-driven care that characterises much of the state's current response to mental illness.[13]

The chapter also includes a suite of reforms to provide children and families with early, culturally safe and flexible support through Aboriginal-led organisations in partnership with mental health services. Aboriginal children and young people will be able to access specialist mental health services, family-oriented therapeutic treatment, care and support and intensive multidisciplinary care delivered within community settings. These reforms focus squarely on treatment, care and support being delivered through Aboriginal organisations.

The Commission also recognises that many Aboriginal people access mainstream mental health services for treatment, care and support.[14] It is therefore incumbent on the mental health system to provide culturally safe, responsive and inclusive mental health and wellbeing services.[15] This chapter describes how reforms to increase the safety, responsiveness and inclusiveness of mental health and wellbeing services for all consumers will recognise and provide tangible benefits for Aboriginal consumers.

The Commission's aspiration is for a mental health and wellbeing system where Aboriginal self-determination is respected and upheld in the design and delivery of treatment, care and support, and where Aboriginal people can choose to receive care within Aboriginal community-controlled organisations, within mainstream services or a mix of both. Irrespective of where treatment, care and support is delivered for Aboriginal people, communities and families, it is fundamental that it is safe, inclusive, respectful and responsive.

Figure 20.1: The current state of Aboriginal mental health and the case for change



31%

One in three Aboriginal people experience high or very high levels of psychological distress. That is about 2.5 times the non-Aboriginal rate

77%

of Indigenous people aged 18–24 who had experienced very high or high psychological distress **had not seen a health professional**

33%

of Aboriginal Victorians have been diagnosed with a mental or behavioural condition. **This is nearly 1.6 times the non-Aboriginal rate**

55%

The number of presentations to Victorian hospital emergency departments by Aboriginal people increased by **55%** between 2012–13 and 2015–16

4x

The rate of mental health-related emergency department presentations for Indigenous Australians was more than **4 times that for non-Aboriginal**

33%

of organisations providing health care to Aboriginal people provided trauma-informed social and emotional wellbeing services—**88% of these services were Aboriginal community-controlled organisations**

47%

of Aboriginal people have a relative who was forcibly removed from their family due to stolen generations policies in Victoria. Transgenerational trauma continues to affect Aboriginal people in Victoria

19%

The total burden of disease among Aboriginal people attributable to mental illness and substance use disorders*

16x

In Victoria, nearly one in 10 Aboriginal children are in out-of-home-care, which is nearly 16 times the rate of non-Aboriginal children^

Source: Adapted from VACCHO, Balit Durn Durn, Strong brain, mind, intellect and sense of self, 2020, p.19; *Australian Institute of Health and Wellbeing, Indigenous Health and Wellbeing <www.aihw.gov.au/reports/australias-health/indigenous-health-and-wellbeing>, [accessed 14 January 2021]; ^Department of Health and Human Services, Wungurilwil Gapgapduir: Aboriginal Children and Families Agreement, 2018, p. 19.

20.2 Aboriginal social and emotional wellbeing in the interim report

The Commission's terms of reference directed the Commission to consider how to improve mental health outcomes, taking into account best practice and person-centred treatment and care models for people from Aboriginal and Torres Strait Islander backgrounds.[16]

The interim report discussed the ways in which colonisation, racism, discrimination, marginalisation and compounding intergenerational trauma have had a profound and enduring impact on mental health outcomes for Aboriginal people.[17]

Mental health outcomes and suicide rates among Aboriginal people are confronting:

- Poor mental health and substance use disorders have been estimated to account for as much as 14 per cent of the health gap between Aboriginal and non-Aboriginal people.[18]
- Research indicates that one in three Aboriginal people experience high or very high levels of psychological distress—almost three times the rate for non-Aboriginal people.[19] One study found that twice as many Aboriginal adolescents as non-Aboriginal adolescents (aged 18–24 years) experience considerable psychological distress.[20]
- The national suicide rate for Aboriginal people is estimated to be twice the rate of the general population;[21] suicide among Aboriginal people generally occurs at a much younger age.[22]
- Aboriginal children and young people accounted for 30 per cent of all suicide deaths by Australian children and young people in 2016; this is despite Aboriginal children and young people only representing 3–4 per cent of children and young people overall.[23]
- Aboriginal people aged 15–24 years are estimated to be over five times more likely to die by suicide than their non-Aboriginal peers.[24]

As discussed in Chapter 32: *Reducing compulsory treatment*, Aboriginal people are also over-represented in relation to compulsory treatment orders in comparison to the rest of the Victorian population, making up approximately three percent of clients placed on compulsory treatment orders.[25] While the causes of this over-representation are unclear, international analysis indicates that people from culturally diverse, marginalised and economically disadvantaged backgrounds are more likely to be treated compulsorily.[26] Consequently, the over-representation of Aboriginal people on compulsory treatment orders should be understood in the context of the effects of '(inter)generational trauma, racism, discrimination, marginalisation and disadvantage' on the health and wellbeing of Aboriginal people.[27]

The interim report also discussed the protective role of Aboriginal people's connection to country and culture,[28] which is a source of strength in the face of ongoing oppression.[29] It described the centrality of Aboriginal family and kinship connections to an Aboriginal person's mental health and the need for a holistic approach to understanding health and social and emotional wellbeing in Aboriginal communities:

> We need holistic responses that are developed and led by Aboriginal people and community organisations in partnership.[30]

Mainstream biomedical explanatory and treatment models for mental illness are considered at odds with Aboriginal cultural understandings of mental health, which are based on beliefs about the inextricable connections between the physical, emotional and spiritual wellbeing of a person, their community and the environment.[31] These domains of life are believed to be closely interconnected and explained by understanding the whole. As highlighted in the *Ways Forward: National Aboriginal and Torres Strait Islander Mental Health Policy National Consultancy Report*, for Aboriginal people:

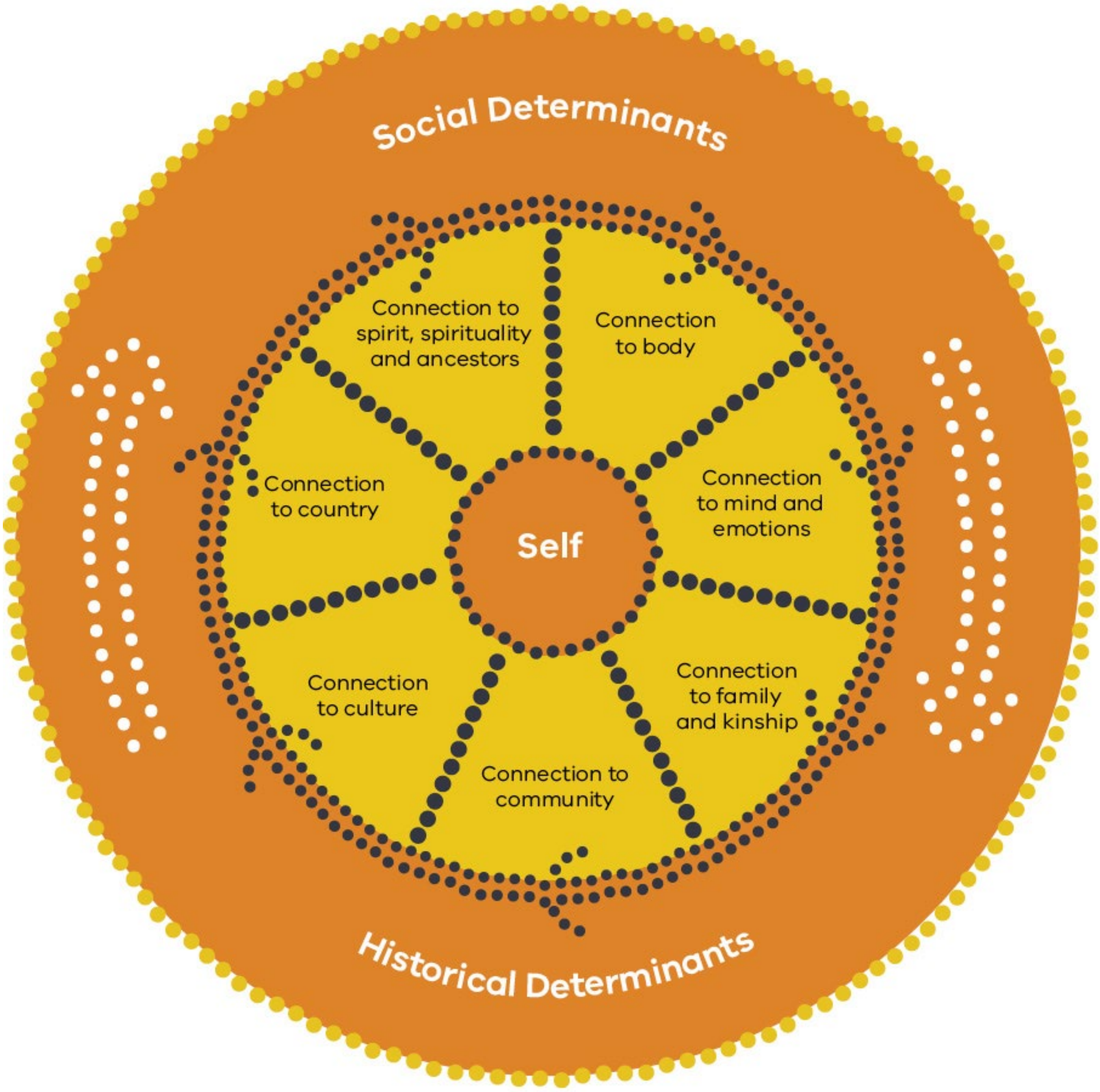
> Health does not just mean the physical well-being of the individual but refers to the social, emotional and cultural well-being of the whole community. This is a whole of life view and includes the cyclical concept of life-death-life. Health care services should strive to achieve the state where every individual can achieve their full potential as human beings and thus bring about the total well-being of their communities.[32]

The shorthand term 'social and emotional wellbeing' describes this understanding of mental health. Dr Graham Gee, Clinical Psychologist and Senior Research Fellow at the Murdoch Children's Research Institute, explained:

> Social and Emotional Wellbeing (SEWB) is a complex term that for many Aboriginal people refers to a holistic view of health that includes mental wellbeing and mental health disorders—but importantly, it links the mental health of individual and families, and the wellbeing of whole communities, to more than physical, emotional and mental wellbeing. SEWB from an Aboriginal perspective, recognises that mental health is also shaped by connections to culture, land, extended kinship, the ancestors, and spirituality. The other important part of SEWB that distinguishes it from conventional understandings of mental health is that these connections are influenced not only by social determinants of health, but also by historical, political and cultural determinants. Historical, political and cultural factors shape the presentation and meaning of how mental health symptoms are understood for Aboriginal clients, in many different ways.[33]

As Figure 20.2 shows, this holistic view is not limited to connections between the mind and the body: it also captures Aboriginal people's connections to land, spirit, spirituality and ancestors, culture and community, family and kinship.[34]

Figure 20.2: Aboriginal social and emotional wellbeing



This conception of self is grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community.

Source: Reproduced from Graham Gee and others, 'Chapter 4: Aboriginal and Torres Strait Islander Social and Emotional Wellbeing', in Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (Canberra: Commonwealth of Australia, 2014), pp. 55–68.

The interim report acknowledged the urgent need to address mental illness in Aboriginal communities and the central role of self-determined Aboriginal social and emotional wellbeing services in promoting Aboriginal social and emotional wellbeing.[35]

The Commission received several proposals from Aboriginal witnesses and community-controlled organisations advocating for the expansion of multidisciplinary models of care that apply the Aboriginal concept of social and emotional wellbeing. The Commission consequently recommended in its interim report, the expansion of Aboriginal social and emotional wellbeing services, supported by a new Aboriginal Social and Emotional Wellbeing Centre (refer to Box 20.1).

Box 20.1: Aboriginal social and wellbeing recommendation from the interim report

The Royal Commission recommends that the Victorian Government, through the Mental Health Implementation Office, expands social and emotional wellbeing teams throughout Victoria and that these teams be supported by a new Aboriginal Social and Emotional Wellbeing Centre. This should be facilitated through the following mechanisms:

- dedicated recurrent funding to establish and expand multidisciplinary social and emotional wellbeing teams in Aboriginal community-controlled health organisations, with statewide coverage within five years
- scholarships to enable Aboriginal social and emotional wellbeing team members to obtain recognised clinical mental health qualifications from approved public tertiary providers, with a minimum of 30 scholarships awarded over the next five years
- recurrent funding for the Victorian Aboriginal Community Controlled Health Organisation to develop, host and maintain the recommended Aboriginal Social and Emotional Wellbeing Centre in partnership with organisations with clinical expertise and research expertise in Aboriginal mental health. The centre will help expand social and emotional wellbeing services through:
    - clinical, organisational and cultural governance planning and development
    - workforce development—including by enabling the recommended scholarships
    - guidance, tools and practical supports for building clinical effectiveness in assessment, diagnosis and treatment
    - developing and disseminating research and evidence for social and emotional wellbeing models and convening associated communities of practice.

Source: Royal Commission into Victoria's Mental Health System, *Interim Report*, 2019 p. 46.

20.3 The impact of intergenerational trauma, colonisation and systemic racism

Colonisation, racism, discrimination, marginalisation and the compounding impact of intergenerational trauma have had a profound and enduring impact on mental health outcomes for Aboriginal people.[36]

Aboriginal Victorians experience higher rates of poor mental health than non-Aboriginal Victorians.[37] In its submission, the Victorian Aboriginal Child Care Agency described the effect of intergenerational trauma:

> Aboriginal peoples conceptualise 'trauma' as a way of understanding and describing the effects of interpersonal and collective forms of violence on their peoples. The term collective trauma considers the incidence and effects of individual traumatic events as well as the social and psychological trajectories in which the consequences of colonisation are aligned with the deterioration of social norms, values and cultural practices of a community. Aboriginal community members often share experiences of trauma, resulting in entire communities managing symptoms simultaneously, shifting cultural norms and breaking down social relations and traditional roles within families and communities.[38]

Some Aboriginal people are at higher risk of experiencing the intergenerational effects of trauma and mental illness. Among the most disadvantaged are members of the Stolen Generations, children in out-of-home care and those with a history of incarceration.[39] Almost half (47 per cent) of Aboriginal people in Victoria have a relative who was forcibly removed under Stolen Generations policies.[40] About 40 per cent of people of the Stolen Generations aged 50 years or older experience poor mental health attributed to the trauma of removal.[41]

Victoria, along with Western Australia and South Australia, consistently have the highest proportions of their populations born before 1972 who, in multiple surveys conducted from 2002 to 2014–2015, report being forcibly removed.[42] As the Healing Foundation submitted to the Commission, Aboriginal people in Victoria carry the legacy of trauma caused by the forcible removal of children from Aboriginal families.[43]

A first-of-its-kind study commissioned by the Healing Foundation provided comprehensive data to illustrate the direct link between the removal of Aboriginal children and symptoms of trauma in families and their descendants. The study also documented higher levels of health, economic and social disadvantage in the affected families and the consequences of the trauma experienced.[44]

Aboriginal organisations told the Commission:

> The prevalence of [poor] mental health within Victorian Aboriginal communities can be directly related to the loss of land, culture, identity, self-respect, self-worth and the breakdown of traditional roles within communities. Systemic racism has been a significant factor in ensuring Aboriginal communities remain fragmented and disjointed and has supported the social isolation, trauma and depression of many Aboriginal communities' members.[45]
>
> It is important for the Royal Commission to understand that colonial violence is not a stagnant piece of history. Intersecting systemic racism and systemic sexism keep Aboriginal and Torres Strait Islander women trapped in violent situations and cycles of trauma. The mental health system can present as yet another form of violence.[46]

Post-invasion policies not only disrupted family attachments, but severed Aboriginal peoples' attachment to their land, cultures and identities. The historical trauma experienced by Aboriginal people can have intergenerational impacts across entire communities as well as on individuals and families.[47] The intergenerational nature of trauma has significant implications for the mental health and wellbeing of children and young people in particular,[48] and requires culturally appropriate service responses to address the needs of these communities.[49]

The 'devastating impact' of trauma on Aboriginal culture and health also limits Aboriginal people's access to mainstream support services.[50] Many Aboriginal communities face challenges, such as alcohol abuse and forms of violence, that did not exist before colonisation.[51] Lack of access to early support for trauma, plus social or cultural determinants of health, can result in a 'cascade of problems',[52] which compound intergenerationally (as described in Chapter 15: *Responding to trauma*).

The Commission agrees that responding to these experiences requires a mental health workforce that understands how intergenerational trauma affects Aboriginal people's trust of services and willingness to seek help,[53] as well as the 'intersections between systemic racism, family violence, trauma and mental health stigma'.[54] Mr Andrew Jackomos PSM, Executive Director, Aboriginal Economic Development, Department of Jobs, Precincts and Regions, a Yorta Yorta man, told the Commission:

> The issues that impact on the health and well-being for our community is complex, inter-related and driven by a range of environmental factors. The legacy of intergenerational trauma is still very present in past, present and subsequent generations. Isolated reforms that happen in one pocket of the service system will not effectively address these complex issues.[55]

Dr Gee described the interplay between historical, political and cultural determinants that influence Aboriginal social and emotional wellbeing in addition to social determinants:

> historical determinants include the impact of past government policies and cultural displacement that has been experienced by whole of cultural groups and communities, or conversely, the extent to which communities have managed to maintain cultural continuity. Political determinants include sovereignty, unresolved issues of land and control of resources, and self-determination. These are not abstract concepts. They effectively shape the environments and circumstances into which Aboriginal children are born. They heavily influence the types of coping skills and resources that people can draw upon, including the community and relationship networks that are central for recovery.[56]

The effect of intergenerational trauma and the associated social and economic disadvantage is evident across multiple domains, such as in the criminal justice, prison, family violence, child protection and mental health systems.[57]

As discussed in the interim report, the Commission has heard considerable concerns from Aboriginal organisations and experts about the intersections between the mental health and justice systems for Aboriginal people.[58] Systemic racism and intergenerational trauma contribute to the over-representation of Aboriginal people in the Victorian justice system—Aboriginal children and young people are 14 times more likely than their non-Aboriginal peers to be under youth justice supervision,[59] and adults are 12 times more likely to be in prison or community corrections.[60]

The Victorian Aboriginal Legal Service described the effect that interactions with the justice system can have on Aboriginal Victorians:

> The impact of the legal system on mental health is particularly acute for Aboriginal peoples, given the lack of cultural safety and ongoing discrimination and racism within the system. This is even more aggravated for Aboriginal people in contact with the criminal justice system, where the impacts for social and emotional wellbeing are devastating, particularly for Aboriginal people in custody.[61]

Aboriginal people make up 10 per cent of the homeless population, despite comprising less than one per cent of the Australian population. Aboriginal Housing Victoria noted that 17 per cent of the Aboriginal population in Victoria had contact with homeless services in 2018.[62] Children and young people make up more than half of the Aboriginal people in contact with homeless services in Australia.[63] Research indicates that approximately one-third of young people become homeless within a year of leaving care; the over-representation of Aboriginal children in care may therefore go some way to explaining the high rates of homelessness among Aboriginal young people.[64] One in 10 Aboriginal children are in out-of-home care—which is nearly 16 times the rate of non-Aboriginal children.[65] There is noticeable overlap between out-of-home care and contact with the justice system; research suggests 64 per cent of Aboriginal young people in the criminal justice system were also in contact with child protection.[66]

The *Always Was, Always Will Be Koori Children* report by the Commission for Children and Young People, an investigation into the circumstances of Aboriginal children and young people in out-of-home care in Victoria, noted the following:

> The trajectory from out-of-home care to youth justice is a disturbing reality for many young people. This is particularly the case for Aboriginal young people. Research has found that Aboriginal young people are particularly vulnerable to becoming immersed in a cycle of contact with the criminal justice system. The cycle is intensified by contributing factors such as limited education and employment opportunities, drug and alcohol dependence and insecure accommodation.[67]

Evidence suggests that parental mental illness is a contributing factor to children being placed in out-of-home care. The *Always Was, Always Will Be Koori Children* report indicated that more than 60 per cent of the children reviewed as part of the report's Taskforce 1000 investigation 'came to the attention of child protection as a result of parental mental health issues in combination with other risk factors', and that parental mental illness was also the reason many children could not be returned.[68] The report pointed to the cycle of out-of-home care within many Aboriginal families, stemming from poor outcomes for Aboriginal young people leaving care, including unresolved trauma and abuse, children being dislocated from their families, culture and identity, homelessness, the trajectory into the justice system, poor education outcomes and limited employment opportunities.[69] The report stated:

> It was quite clear that many parents of the 980 children we saw [during the report's Taskforce 1000 investigation] had been in the care of the state and the state pushed them out of the door ill-prepared. The same thing sadly seems to be happening to the current generation of Koori kids leaving care.[70]

Always Was, Always Will be Koori Children also found high rates of mental illness in Aboriginal children in out-of-home care, with more than one in five children in the Taskforce 1000 investigation experiencing mental illness. The report noted that eight per cent of children who were identified as experiencing mental illness were under five years old.[71] The report's findings reflect those of the Victorian Auditor-General in its 2019 *Child and Youth Mental Health* report, which found that children in out-of-home care had up to five times higher rates of mental health problems and double the rate of suicide attempts compared with the general population.[72]

These findings align with research indicating that exposure to repeated trauma and prolonged adversities experienced during childhood—especially during particular developmental periods—increases the risk of developing mental illness.[73] Trauma experienced at an early developmental stage can affect a person's 'sense of self, safety and trust' and has the 'strongest connection to adult mental health issues, illness, self-harm and suicide'.[74]

Experiences of intergenerational trauma may also act as a barrier to accessing services. As noted by witness Mr Adam Burns, Senior Mental Health Clinician at Melbourne Health's Wadamba Wilam:

> The historical trauma experienced by many communities, families and individuals contributes to a distrust of all mainstream support services and a reluctance to access any services that may assist with SEWB [social and emotional wellbeing]. Additionally, the experiences of historical and intergenerational trauma have robbed people of many of the key elements of SEWB and they do not feel comfortable in accessing culturally specific services and supports. Historical and intergenerational trauma is all-pervasive and influences every interaction with support services and systems.[75]

For example, distrust of mainstream services stemming from historical trauma can leave parents reluctant to seek out support services, including mental health treatment, care and support, for fear that to ask for support may result in child notifications and contact with child protection.[76] This may lead to families failing to get necessary or timely health, mental health and social supports. It also points to the need for Aboriginal organisations to be adequately resourced in order to provide comprehensive mental health and wellbeing services for children and families.

20.4 Lack of cultural safety and cultural responsiveness in mainstream services

Ms Helen Kennedy, Chief Operations Officer of the Victorian Aboriginal Community Controlled Health Organisation, told the Commission about the 'profound distrust' many Aboriginal people have of mainstream services.[77] The Victorian Aboriginal Health Service highlighted the 'misinformed assumptions, negative judgement, overt and covert racism and a total lack of cultural understanding from mainstream services'[78] that many of its clients are exposed to. The service also noted that these experiences can mean that people might only seek out services once a crisis occurs.[79]

In a study involving 755 Aboriginal people in Victoria, nearly one-third of participants reported that they had experienced racism in health settings. This included being a target of racist names, jokes or teasing, being told they 'didn't belong in Australia', or hearing comments based on stereotypes of Aboriginal Australians, in health settings in the preceding year.[80] Research also indicates that experiencing racism in health settings is associated with increased psychological distress.[81] The Commission is aware of the negative impact of racism on Aboriginal people's mental health. An Aboriginal community-controlled organisation staff member described the work they do advocating for clients due to racism within mainstream settings:

> The real issue is institutional racism. It is really, really sickening. We have to continuously advocate for Community members while they are at mainstream services and its very time intensive, that's when resources come into it. We get a different response, if we are accompanying them, especially if it's by a registered nurse or someone with authority, they don't get the same response that an Aboriginal person presenting by themselves would.[82]

In addition to overt racism, the day-to-day practices and policies of health services can be culturally unsafe for Aboriginal people. The Commission has been told that the approach of many mainstream mental health services is problematic for Aboriginal communities.[83] Research indicates that the failure of health professionals to recognise and respond to cultural differences and communication gaps can reduce positive health outcomes for Aboriginal consumers, or even increase the risk of life-threatening outcomes.[84] Research also indicates that communication barriers between health professionals and Aboriginal people undermine relationships, and may result in Aboriginal people feeling alienated and disengaging from healthcare.[85]

Witnesses and submissions described the ways in which the mental health system is insensitive to the needs of Aboriginal people and Aboriginal spirituality is misunderstood. Aunty Nellie Flagg, witness, respected Elder and a Taylor-Charles, told the Commission:

> The [mental health] system does not understand Aboriginal spirituality … My family has been afraid of people judging them for their mental health issues. They have been afraid to talk about it for fear of being labelled mental or being unable to hold a job.[86]

Ms Tamara Lovett's personal story describes her experiences within mental health services.

Personal story:

Tamara Lovett

Tamara Lovett is a Gunai and Gunditjmara woman who has lived in Melbourne her whole life. She has experienced mental health challenges since she was young.

During her first pregnancy, Tamara established a good relationship with a GP, whom she felt she could be open and honest with. She asked for a referral to a psychiatrist as a way of protecting her mental health during her pregnancy, but she had a negative experience when she saw the psychiatrist at a hospital.

> A lot of the time when I have tried to access help it is not culturally safe. Sometimes I can get help but it doesn't fit. They automatically jump to a diagnosis. My mental health makes sense when you listen to my life story.

After her child was born, Tamara was facing homelessness due to a stressful living situation. She connected with Wadamba Wilam, a program that supports Aboriginal people who are experiencing homelessness and require support around their social and emotional wellbeing. She says that along with her GP, Wadamba Wilam has been her only source of help.

> Wadamba [Wilam] works from a strengths based approach and were able to help me see things in a more positive light. They believed my journey and didn't try and diagnose me or blame me for my past. My case workers listened and took my journey on board.

Tamara is not comfortable using mainstream services, as she believes that workers don't understand or respond to her cultural needs.

> They are just fixed on a diagnosis and also on medications, but that's not the therapy I wanted. They are also limited on time, rushed and don't listen. And you never see the same people, which means you have to keep re-telling traumatic events over and over again.

Tamara has since worked at Wadamba Wilam as a lived experience case manager, and as an Aboriginal Mental Health Outreach Worker within community health services. In the future, Tamara would like to see more services that are culturally safe, and more funding for Aboriginal-specific workers in clinical settings.

> We need more Aboriginal people working in both mainstream and Aboriginal mental health services.

Source: *Witness Statement of Tamara Lovett,* 16 July 2019; *Wadamba Wilam: Renew Shelter*, <assets.neaminational.org.au/assets/Resources/Services/1e24a31933/Booklet_WadambaWilam_V2.2_DIGITAL.pdf>, [accessed 21 December 2020].

20.5 Self-determination as the foundation of reform

The right to Aboriginal self-determination is enshrined in international law.[87] In 2009, the Commonwealth Government indicated support for the United Nations Declaration on the Rights of Indigenous Peoples, which provides a framework for action with self-determination at the core.[88] A vast number of policies and programs developed over several decades at the national level have highlighted the importance of redressing the historical and ongoing inequities in health, social and economic outcomes for Aboriginal people. However, most have failed to genuinely adopt principles of self-determination, and thus have failed to effect genuine change in mainstream services.[89] More than two decades ago, Aboriginal leader Rob Riley described this as 'administrative genocide'.[90] He linked the mental health status of Aboriginal people to the fact that 'they have not been empowered to make decisions about their lives and the lives and futures of their children', but instead have been forced into a 'co-dependency between the community and the bureaucracy'.[91]

Perhaps the most significant of these policies, in terms of missed opportunity, is the Closing the Gap initiative. The Australian Medical Association noted that the Closing the Gap initiative was considered ground-breaking when it was established in 2007, but its weakness was that 'Aboriginal and Torres Strait Islander people themselves were not part of the decision-making process'.[92] It said:

> The unacceptable progress against the Closing the Gap targets is reflective of the need to better incorporate the knowledge of Aboriginal and Torres Strait Islander people into policies and programs and include them in the negotiating process. This has long been called for.[93]

In its 10-year review, the Closing the Gap Steering Committee noted the failure to meet health targets for Aboriginal people and urged policy makers to re-orient their approach, rather than cancel funding for the initiative. In particular, the Steering Committee recommended focusing on the underlying structural factors shaping health, ensuring better cooperation between governments, and respecting 'Indigenous people's right to self-determination in efforts to improve their health'.[94]

In response, a new Partnership Agreement on Closing the Gap 2019–2029 has been established as an agreement between the Coalition of Aboriginal and Torres Strait Islander Peak Organisations and the Council of Australian Governments.[95] The objectives of the agreement include sharing 'ownership of, and responsibility for, a jointly agreed framework' as well as advancing Aboriginal and Torres Strait Islander 'involvement, engagement' and autonomy through equitable participation, shared authority and decision-making'.[96]

Recently, the Productivity Commission highlighted the need to ensure genuine self-determination in relation to Aboriginal policies and programs. Research undertaken in the development of the Productivity Commission's *Indigenous Evaluation Strategy* found minimal input by Aboriginal people into evaluations, with only 30 per cent of evaluations of Aboriginal specific policies and one of the 56 evaluations of mainstream policies and programs involving Aboriginal people in evaluation planning and decision making.[97] Concerningly, the research also noted 'more than half of the mainstream policy or program evaluations that mentioned or provided results for Aboriginal and Torres Strait Islander people did not report engaging with Aboriginal and Torres Strait Islander people.'[98]

At the state level, the current Victorian Government has made a strong commitment to self-determination through the treaty process driven by the First Peoples' Assembly of Victoria and supported by a truth and justice process (refer to Box 20.2). The Commission recognises the profound harm that has been caused to Aboriginal peoples throughout Australia's history. It shares the view that an equitable and reconciled society can only become a reality once the injustices committed against Aboriginal people are publicly acknowledged and remedied. The Commission therefore lends its full support behind the truth and justice initiative introduced by the Victorian Government working in partnership with the First People's Assembly of Victoria.

Box 20.2: Victoria's truth and justice process

In July 2020, the Victorian Government announced that it will be establishing a truth and justice process to formally acknowledge the past and present-day injustices committed against Aboriginal Victorians.[99] The government will work with the First People's Assembly of Victoria—a democratically-elected body made up of Aboriginal leaders—to develop the terms of reference for the process and ensure Aboriginal communities are heard in all stages of its planning, design and implementation.[100]

Victoria's truth-telling process is an historic move, being the first of its kind in Australia. It will make Victoria the only Australian jurisdiction to action the 'treaty' and 'truth' elements of the *Uluru Statement from the Heart*, the proposal for constitutional reform signed by Aboriginal people from all over Australia in 2017 to recognise and support their sovereignty.[101]

The establishment of a truth-telling process in Victoria is modelled on similar reconciliation initiatives overseas—such as truth commissions held in Canada and New Zealand—where public hearings established the scale and impact of human rights abuses committed against First Nations peoples, and made the findings of those inquiries a permanent and unassailable part of the public record.[102]

Truth-telling is a fundamental aspect of efforts to heal the wounds of the past and achieve reconciliation in Australia.[103]

In the words of The Hon. Gabrielle Williams, Minister for Aboriginal Affairs:

> There is nothing more powerful than the truth. Because with honesty comes healing. It's going to take courage from all sides to uncover the truths of our past and understand ongoing impacts – establishing this process brings us one step closer to genuine reconciliation.[104]

For Aboriginal peoples, Australia's colonial history is characterised by violence and overt racism, consisting of massacres, land dispossession, the forced removal of children from families, the failure to pay workers' wages, and incarceration and deaths in custody.[105] These events have had a devastating impact on the lives of many Aboriginal people, causing trauma and disadvantage that has carried across generations.[106]

While many Australians have become aware of these wrongs, they do not have a proper understanding of their details and ramifications.[107] Other Australians have difficulty accepting that they occurred at all.[108] This public ignorance and denial has diminished the grief, loss and sense of injustice that Aboriginal people feel.

By aspiring to uncover past and present mistakes, Victoria's truth-telling process is a chance to acknowledge and redress the injustices that stand in the way of reconciliation, not only in Victoria, but also in Australia more broadly. It is an opportunity to open up a debate on prejudice, discrimination and racism, and to lay the ground for change that increases the inclusion of Aboriginal people in the political, economic and cultural spheres of society.

Furthermore, Victoria's truth-telling process is a means to building greater understanding among future generations with a view to ensuring the same wrongs are never repeated. As Reconciliation Australia, the national body on reconciliation, has put it:

> We cannot change the past but we can learn from it. We can make amends and we can ensure mistakes are never repeated. Our nation's past is reflected in the present and unless we can heal historical wounds, they will continue to play out in our country's future. Reconciliation can only truly evolve when the Australian community and our major institutions acknowledge and repair the wrongs of the past, understand their effects—and make sure that these wrongs, or similarly damaging actions, are not occurring today and are never repeated in the future.[109]

The Victorian Government has embedded self-determination into key Aboriginal policies, including the *Victorian Aboriginal Affairs Framework 2018–2023*, which commits government to achieve systemic and structural transformation to enable self-determination, and thereby support better outcomes for Aboriginal Victorians (refer to Box 20.3). Self-determination is also a fundamental requirement under the Victorian Government's Aboriginal health, wellbeing and safety strategic plan 2017–2027, *Korin Korin Balit-Djak*. It states that self-determination:

> **means that rather than Aboriginal people merely being 'engaged' or 'consulted' as 'advisors' or 'co-designers' of services and policies, they are authorised and empowered to own, direct and make strategic decisions.**[110]

It says that Aboriginal decision making should apply to the 'values and motivations on which a policy or program is based, strategic intent, policy or program design, funding and allocation of resources, implementation and operations, evaluation measures and definitions of success'.[111]

Box 20.3: Victorian Aboriginal Affairs Framework 2018–2023

In 2018, the Victorian Government refreshed the *Victorian Aboriginal Affairs Framework 2018–2023* in partnership with Aboriginal Victorians through broad and inclusive engagement. The framework is Victoria's overarching strategic framework for working with Aboriginal Victorians to drive improved outcomes.

The framework includes goals, indicators and measures to guide and track government progress to achieve positive outcomes for Aboriginal Victorians across six domains:

- children, family and home
- learning and skills
- opportunity and prosperity
- health and wellbeing
- justice and safety
- culture and country.[112]

The framework commits government to advancing Aboriginal self-determination. In doing so, the framework builds on and goes beyond previous government approaches, by recognising that to improve outcomes for Aboriginal Victorians, government must enable self-determination through systemic and structural transformation. The framework also requires that the government report on its efforts to enable self-determination in the annual *Victorian Government Aboriginal Affairs Report* and commits to establishing an Aboriginal-led evaluation and review mechanism to track government's progress against the framework.

The framework identifies four self-determination enablers as priority action areas:

- prioritise culture
- address trauma and support healing
- address racism and promote cultural safety
- transfer power and resources to communities.

It is envisaged that these enablers will help to eliminate structural and systemic barriers experienced by Aboriginal Victorians, so that they are empowered to own and drive change. The resulting quality and accessibility of services will lead to more Aboriginal Victorians using those services and experiencing improved outcomes.[113]

In the interim report, the Commission noted that self-determination in the context of mental health 'means transferring power and resources to Aboriginal communities to design and deliver their own mental health services while drawing on the skills and expertise of others where needed'.[114] This is consistent with evidence that programs encouraging self-determination and community governance show promising results for Aboriginal social and emotional wellbeing.[115]

Australian and international evidence suggests that self-determination is crucial to achieving lasting improvements in health and social outcomes for Aboriginal people.[116] This can include the positive effects for Aboriginal people from personally participating in self-determination processes, such as an increased sense of control and the subsequent impact on mental health and wellbeing.[117] The Victorian Aboriginal Children and Young People's Alliance recommended the Commission '[r]einforce the role of self-determination as the foundation of improving the health and wellbeing of Aboriginal people in Victoria.'[118]

The implementation of the Commission's reforms will require the Victorian Government to apply the principles of self-determination towards improving outcomes for Aboriginal people. Ms Kennedy stated that:

> **There is an opportunity to support real self-determination as part of implementing the recommendations of the Royal Commission.**[119]

Mr Jackomos told the Commission that '[w]herever government comes into contact with the Aboriginal people and community, there is a place for self-determination' and highlighted that the Victorian Government's commitment to self-determination includes every area and level of government.[120] This means that self-determination must be at the core of the work undertaken by the agencies and departments implementing the Commission's recommendations.

Adhering to the principles of self-determination will help to ensure the process of implementing the reforms is as beneficial to mental health and wellbeing as the reforms themselves.[121] As Ms Kennedy explained:

> Given the legacy of institutional injustice, how governments work with Aboriginal communities is just as important as what actions governments take to improve mental health outcomes for Aboriginal people and communities.[122]

The Commission has identified key areas for reform to support social and emotional wellbeing for Aboriginal people based on the evidence presented by Aboriginal organisations and communities, and others. The Victorian Aboriginal Community Controlled Health Organisation noted that:

> The system-wide changes and self-determining principles that are proposed in the Interim Report offer a transformational opportunity to deliver meaningful outcomes for Aboriginal people.[123]

As described later in this chapter, the Commission's reforms focus on two areas: (1) supporting healing and (2) improving child and family mental health and wellbeing. However, the design and the delivery of these reforms should be determined by Aboriginal organisations and communities, with support from the Victorian Government.

Mr Jackomos also spoke of the importance of Aboriginal self-determination and involvement in relation to service design, implementation and monitoring, and just as importantly, in building the cultural competence and cultural safety of mainstream and other mental health and wellbeing services.[124] The Commission strongly suggests that the Victorian Government take note of his advice regarding the main enablers for compliance with the principles of self-determination. This includes the advice that:

- the service/program/initiative is identified by the community or is equally owned by the community
- community stakeholders are involved from the very start, rather than other parties designing a response and seeking endorsement for a model that has already been developed
- community members are central to the development, implementation and evaluation of the services
- the resources for service provision are transferred to the community for decision making, and service delivery is undertaken in a Koori-friendly location
- the services are managed and delivered by Aboriginal people where possible, with significant resources provided for personal and career development.[125]

20.6 The need for healing approaches

The Commission heard '[h]istorical and intergenerational trauma is all-pervasive and it influences every interaction with support services and systems.'[126] Abundant evidence before the Commission attests that '[r]econnection to culture is healing and is not supported in the current mental health system'.[127] Healing practices are recognised internationally for their 'effectiveness in addressing intergenerational trauma, improving wellbeing and reducing rates of suicide, incarceration, domestic and family violence and drug and substance abuse'.[128]

Ms Kennedy told the Commission:

> It is now broadly recognised, as described by the Healing Foundation, that unresolved trauma is directly related to the policies of past governments, resulting in the legacy of the stolen generations. Many of the problems prevalent today, such as substance abuse, mental illness and family violence are themselves rooted in a cycle of trauma. As described by the National Healing Foundation, healing involves the application of existing cultural knowledge, as well as the development of new ways to practice this in a contemporary context, in order to address trauma stemming from colonisation. Healing needs to be an intricate part of the processes of prevention as well as the treatment of mental health issues, supporting recovery and improving social and emotional well-being.[129]

The extensive and pervasive trauma that many Aboriginal people live with every day is profound, and it affects individuals, families, carers and supporters and broader communities.[130] Often, the impacts of historical and intergenerational trauma limit the extent to which Aboriginal people can receive social and emotional wellbeing support.[131] These impacts are highly varied and can have life-long consequences on people.[132] In complex cases, some trauma experiences—such as historical or intergenerational traumas—can lead to Aboriginal people falling 'through the gaps of standard service provision',[133] as explained in Chapter 15: *Responding to trauma*. Mr Burns told the Commission:

> Addictive behaviours such as heavy, problematic AOD [alcohol and other drug] use and gambling often prevent people from accessing the healing and enriching parts of culture, community, country, spirituality, ancestry and family. Another key factor that detrimentally impacts SEWB [social and emotional wellbeing] relates to people not having their basic needs of housing, food, safety and belonging met. Exposure to and experiences of all types of violence and abuse, in addition to the lack of sense of agency, also often forms a major barrier to positive intervention, healing and support.[134]

Aboriginal organisations and witnesses have called on the Commission to promote and embed healing practices in social and emotional wellbeing services in Aboriginal communities.[135] Further, submissions have called for increased investment in healing centres or places. Such programs would support people to address the impact of trauma on themselves, families, carers and supporters.

As Ms Kennedy told the Commission:

> My plea is that we focus more on supporting our communities, individuals and families to address that underlying trauma and in the context of preventative responses. I am a big advocate for us to have a much greater focus on providing support services that focus on healing models.[136] … Healing needs to be an intricate part of the processes of prevention as well as the treatment of mental health issues, supporting recovery and improving social and emotional well-being. No amount of conventional Western mental health approaches will be enough without concurrent investment and focus on traditional and contemporary healing.[137]

It is the Commission's position that healing approaches are fundamental to supporting the mental health of Aboriginal people.[138] Focusing on healing gives Aboriginal people a platform to strengthen and support their resilience, healing, and trauma recovery through fostering connection to Country, kinship and culture.[139]

20.6.1 The role of healing

The historical and continuing trauma within many communities requires healing practices to support Aboriginal social and emotional wellbeing. In its submission to the Commission, the Healing Foundation described healing as:

> the process by which people come to a stronger sense of self-identity and connection and through this are able to address the distress that they experience changing how they are able to interact. Healing involves a holistic and ongoing approach that is deeply rooted in culture and addresses physical, social, emotional, mental, environmental and spiritual wellbeing.[140]

The concept of healing is critical in the context of intergenerational traumas and for people experiencing ongoing adversities. As noted in Chapter 15*: Responding to trauma,* acknowledging trauma and its impacts on people can be fundamental to long-term recovery:

> An understanding of an individual's story of trauma is critical to the healing journey, and is interwoven with the stories of that person's family and community. Victim survivors, including children, need to have their stories heard and acknowledged so that they can commence or continue their healing journeys.[141]

Healing can be a 'lifelong process' of seeking to find 'a balance between the good and the bad things in one's life'.[142] Healing enables mental health to be recognised as part of a holistic and interconnected Aboriginal view of health; embracing 'social, emotional, physical, cultural, and spiritual dimensions of health and wellbeing'.[143] Critically, this approach does not focus on 'symptom reduction', but instead works to strengthen culture, community connection, reduce social disadvantage and build empowerment.[144]

Healing approaches are underpinned by four pillars of recovery (refer to Figure 20.3). 'These pillars can improve outcomes across a range of health and wellbeing domains, especially in terms of mental health'[145] and include:

> - 'safety—creating safe spaces, healing places and identifying safe people to support healing
> - identity—building a strong cultural identity by reconnecting to our cultural values and practice
> - reconnection—rebuilding our relational support systems with family, community and services that can support us
> - trauma awareness—learning about the impacts of trauma on our minds, bodies and spirits so we can find paths to healing'.[146]

20.6.2 Healing practices

Engaging in healing practices can be highly therapeutic for individuals, families and groups. Healing practices are deeply entwined with self-determination, with healing being a part of a 'collective process of self-determination [that] enables Aboriginal and Torres Strait Islander people to identify and deal with the underlying causes of trauma'.[147]

Healing can be delivered in many forms, including programs,[148] services,[149] or centres.[150] Healing centres, for example, 'incorporate traditional and Western practices, operate with Aboriginal and Torres Strait Islander spirituality and culture at their core, and may be situated on custodial land or a site of local significance'.[151]

Traditional healing practices can include talking circles, sweat lodges, smudging, drumming, traditional crafts and dancing, bush medicine, healing songs and healing ceremonies. Collectively, these processes '[reinstate and reconnect] Aboriginal and Torres Strait Islander communities to their core cultural value systems, where obligations and reciprocity were central to community survival'.[152]

Participation of Elders is a key element of traditional healing practices. Elders may impart important cultural knowledge to young people through storytelling, walking through country identifying native plants and discussing their uses.[153] Aunty Nellie Flagg described her vision for a healing program that incorporated Elder wisdom to support early parenting:

> I have a fantasy of 'Aunty's Places' where families can go to live, learn and be themselves. We could teach parenting skills and help them learn how to do things they aren't good at. They could learn to cook and also learn to understand issues they have with their children and each other. If the kids are naughty, we can teach them how to be respectful.[154]

Figure 20.3: Four Pillars of Indigenous Trauma Recovery

Source: Healing Foundation with M Adams and others, ‘Towards an Aboriginal and Torres Strait Islander violence prevention framework for men and boys’, 2017.

Evidence shows the profound value of healing centres in capturing, restoring and retaining cultural knowledge. Building this knowledge forms the cornerstone of healing; enriching culture, connection to community and country, spirituality, ancestry and family.[155] As one stakeholder told the Commission via the *Balit Durn Durn* report:

> My perfect scenario would be a healing space for us, whether it was land or a multi-purpose building that allowed cultural practice to occur; fire pits, yarning circles, specific areas where you have environmentally friendly therapeutic areas. That is the absolute dream. We need an Aboriginal Knowledge Place.[156]

In addition to traditional healing practices, some Western approaches are often incorporated. One-on-one or group sessions covering problems at school and at home, peer pressure, anger management, and sexual abuse can be used in tandem with traditional healing approaches.[157] The Commission understands that while traditional and Western approaches differ, '[b]oth approaches have their merits and should be part of a collaborative approach that seeks the best outcome for the person seeking help'.[158] In the *Balit Durn Durn* report, one woman told the story of her experiences of grief, trauma and healing through a combination of counselling and traditional healing practices. These excerpts are a small part of that story:

> A friend referred me to a neuro-psychotherapist and counsellor who specialised in childhood trauma and brain development. The thing that helped me – the area she specialises in – was helping me to understand how the way brain develops, from when we are growing in the womb, when we are born, and the crucial first weeks and months of our life ... My counsellor helped me realise my flight or fight response and that what worked for us when we were little, could no longer work for us as adults. We couldn't just hide in the closet or under the bed anymore ...
>
> It was then that I decided, I need to do something more ... I decided I needed to go home, back to Country ... I went back to the desert. There is a special place, for women only in our tribe. In the middle of nowhere there is this green place with gum trees, green bushes, bush foods, and water holes. My Aunties took me there and showed me that it was a special place for women to heal ... My five Aunties did a special ceremony for me. They had coals already heated covered in fresh gum leaves, so it was safe to lie on them. We have a lot of sandalwood trees out there; it has been part of our culture for thousands of years and it is a part of who we are. They used the sandalwood oil and ochre and covered my body in ochre and oil and sang in language about me being home ...
>
> The most beautiful thing about it as a grown woman, is that it felt like I was a little girl. I had a lot of my childhood taken away from me. To have that love and nurturing. It was being passed to me, that has been done to our women, for generations. These people who love you and want you to be better and want you to heal ...
>
> I had Western counselling and that has helped me. And my Aunties told to keep that connection back to Country...
>
> I realised that it was more than just one element that I needed. To heal from my past, my trauma, and my grief. I realised that I needed to go and seek all those elements to help me feel normal again.[159]

20.6.3 Outcomes of healing

Evidence indicates that there are many benefits of healing programs in the restoration and recovery from historical and intergenerational traumas experienced by Aboriginal people. Mr Jackomos said:

> I know from what I have witnessed over my lifetime and particularly in the last twenty years, that connectedness to culture, country and community is the foundation stone for building stronger individual and collective identities. I cannot over stress the importance of strong culture in building positive self-esteem, resilience and improved outcomes across the other determinants of health, including education, economic stability and community safety.[160]

This was echoed in the *Balit Durn Durn* report, where one young person described how, for young people who are not connected to Country, 'there's something that's inside that you know is missing. When you don't have that strong connection, it makes you vulnerable'.[161]

Healing practices strengthen a sense of self, 'such as self-worth, positive core beliefs and values, and coping skills that are related to things like being able to managing difficult emotions and strategies to cope with stress and adversity'.[162] These outcomes, alongside building connection to culture, community and peers, provide critical protection against mental illness arising from trauma.[163] Some studies suggest 'that empowerment programs have positive impacts on long-term health status and lead to a decrease in health disparities'.[164] Further, healing programs that establish or renew cultural identity have also been linked to decreased suicide rates among Aboriginal young people.[165]

Research indicates that healing programs that establish a strong sense of cultural identity can be protective against the development of mental illness:

> It has been shown that a strong sense of cultural identity can be protective against the development of psychiatric morbidity. It is likely that Aboriginal people who have strong family connections, know about their Aboriginal heritage, including their tribal group and traditional lands, and continue to live an Aboriginal lifestyle (the nature of which varies between Indigenous groups) are similarly protected.[166]

Further, healing supports the development of coping strategies that can be positive for the individual, family and community re-experiencing trauma or adversity. As Mr Burns explains:

> The key factors that protect SEWB [social and emotional wellbeing] are having access to community and community resources, awareness of cultural history, family and country, spending time on country, access to specific cultural groups (such as women and men's groups), contact with family and engagement in meaningful activity. The factors of SEWB can be utilised to promote healing and resilience from trauma, allowing the person to proactively manage their mental health and well-being using coping strategies that are positive for the individual, family and community.[167]

A review of social and emotional wellbeing programs (which include a focus on healing) found programs led to 'participants developing resilience, confidence and self-esteem, better recognising the causes of problems, and building communication, conflict management and negotiation skills.' The review also noted that '[h]ealing came as the result of dealing with grief and loss'.[168]

A 2016 Victorian evaluation of 13 gathering places (which undertake healing practices) found that increased social and emotional wellbeing is a major benefit of gathering places because they 'clearly support the development of social support networks and social connection'.[169] The evaluation also found 'physical health benefits from community members' attendance and participation in community health checks, chronic disease screening and specific health programs'.[170] Food security was a major theme across most gathering places.[171] From an Aboriginal holistic view, gathering places are crucial hubs for people to engage.[172]

International evidence also indicates the success of locally owned healing programs in Indigenous communities in Canada, New Zealand and the United States.[173] For example, the recent *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction* in New Zealand found that some Māori communities have made substantial gains in reducing fragmentation between services by forming community collectives to provide frontline mental health functions, including mental health assessment, triage, early intervention, respite care and ongoing support.[174]

20.6.4 Contexts for healing

In Victoria, successful healing programs, services and centres share several common characteristics. These include being Aboriginal-led and designed, promoting healing and wellbeing, and being culturally safe.[175]

Figure 20.4 depicts the core characteristics of Indigenous healing.

Figure 20.4: Core characteristics of Indigenous healing

Indigenous ownership, design and evaluation of services	Informed by an Indigenous, not a Western, worldview and using culturally sensitive screening and assessment tools
Holistic and multidisciplinary approach	Addressing mental, physical, emotional and spiritual needs with a focus on familial and community interconnectedness, as well as connectedness to the environment and the spiritual realm
Centrality of culture and spirituality	Cultural renewal is seen by some as an essential precursor to healing
Informed by history	Being cognisant of the historical source of trauma, rather than focusing too strongly on the individual pathology
Adopting a positive, strength-based approach	Recognising and promoting the resilience of Indigenous people
Preventative and therapeutic strategies	Rather than reactive responses that merely seek to reduce symptoms
Commitment to healing	As a process—a journey that takes time rather than a one-off event
Commitment to adaptability, flexibility and innovation	Programs must be inclusive to ensure they reach people who may not have strong cultural ties and to incorporate localised practices
Utilisation of particular approaches best suited to the Indigenous context	Programs to include approaches such as narrative therapy, group processes and a combination of Western and traditional practices, such as the use of traditional healers or Ngangkari

Source: Aboriginal and Torres Strait Island Health Foundation, 'Healing Centre, Final Report–21 December 2012'. Adapted from Catherine Caruana, C Family Relationships Quarterly No.17, Healing Services for Indigenous People <aifs.gov.au/cfca/publications/family-relationships-quarterly-no-17/healing-services-indigenous-people>.

Case study:

Wulgunggo Ngalu

The Wulgunggo Ngalu Learning Place (Wulgunggo Ngalu) is a joint initiative of the Aboriginal community and the Victorian Government under the Victorian Aboriginal Justice Agreement. It opened in 2008 in Yarram, Gippsland.

Wulgunggo Ngalu is a residential learning place, accommodating up to 18 men. The program offers voluntary attendance; however, people may be directed to attend by the courts. Shaun Braybrook ACM, General Manager of Wulgunggo Ngalu, said:

> [Wulgunggo Ngalu] is a place that helps Aboriginal men understand what it means to be an Aboriginal today. Through the use of culture we support the men to address their offending behaviours and the effect these behaviours have on them, their families and our communities.

Aboriginal Elders provide leadership and communicate traditional cultural values, in keeping with the name 'Wulgunggo Ngalu', from the local Aboriginal language, Gunai/Kurnai. 'Wulgunggo' means 'which way' and 'Ngalu' means 'together'.

Mr Braybrook said Wulgunggo Ngalu places issues of culture and identity at the centre of its operations and promotes cultural connection at multiple levels, including with the physical environment, with the staff, through the cultural content of programs and activities and with community.

He noted that Aboriginal values and physical protocols are reflected in Wulgunggo Ngalu's environment; for example, its bush location, firepit, dance circle, multiple shared living spaces and accommodation for Elders and visitors. The physical building was designed by an Aboriginal architect to reflect the blue wren, a totem of the local Aboriginal community.

Mr Braybrook explained that all core staff at Wulgunggo Ngalu are Aboriginal men who act as strong role models and '[w]eave into the fabric of [Wulgunggo Ngalu] Koori ways of communicating and doing business'.

The program provides an opportunity to engage in a range of activities, such as education, community work and learning new skills, many of which are directed at increasing cultural knowledge and strengthening identity. These include the Aboriginal Cultural Immersion Program, Koori Art and Design (an on-site TAFE program) and ceremony activities. Mr Braybrook said Wulgunggo Ngalu also includes cultural elements in its other programs wherever possible, such as in its family violence programs.

Photo credit: Wulgunggo Ngalu Learning Place

The vocational and recreational activities at Wulgunggo Ngalu also provide residents with opportunities to interact positively with the local community, such as by performing dance ceremonies at local events.

Uncle Warren Marks, a member of the Stolen Generations and participant of the program, said the program was a turning point in his life.

> It was a start of a new journey … If you let them teach you and listen to what they say … you realise who you are, where you come from and what you stand for. You know how you got here but how you can fix yourself up and make your family proud.
>
> You come here just as a black fella, I left here as a black fella who had become an elder, somebody who had learnt about his culture as well.

Another participant in the program said.

> [Wulgunggo Ngalu] is a special place to finally be able to heal from the life I was so caught up in which was so toxic, the life I thought I would never get out of, the ultimate success I needed in order to grow and change my life forever.

A qualitative evaluation of the program was completed in 2013, and one of its many findings was that the program had improved its participants' cultural identity. The evaluation also stated that the program creates 'an environment that encourages men to reflect, share stories, discuss issues and bond with other men, laying critical foundations for any process of change'.

The program was awarded a prestigious International Corrections and Prisons Association (ICPA) award in October 2010.

Source: Shaun Braybrook ACM, *Correspondence to the RCVMHS*, 2020; Corrections Victoria, Community Programs, <www.corrections.vic.gov.au/community-corrections/community-programs/community-programs>, [accessed 30 November 2020]; *Wulgunggo Ngalu Learning Place*, Final Evaluation Report, May 2013; Vimeo, Warren Marks_WNLP2019_V2, <www.vimeo.com/350095550>, [accessed 18 December 2020].

Healing programs and centres have diverse contexts, settings and functions, including but not limited to:

- **education**: Ms Kennedy described to the Commission an effective and 'economically efficient' example of a healing program in an education setting, the Murri School program:

> The Murri program is a holistic educational framework that consists of a range of activities such as counselling and healing camps, which are designed to address the intergenerational trauma experienced by Aboriginal children at a [Queensland] school. Though the cost per individual student is slightly higher than the state average, the net benefit far outweighs the initial outlay. For every added dollar invested in the Murri Healing program, there was a return of $8.85. Kids had lower rates of mental illness, had less contact with the justice and child protection systems, and achieved a higher educational standard, all whilst saving an estimated 6.5 million. This was for only 230 students, indicating the opportunity for significant saving.[176]

- **health and physical lifestyle**: Some healing programs incorporate a diverse range of social and emotional wellbeing approaches, including a focus on health and physical lifestyle. The availability of different approaches can be particularly beneficial when whole families are involved. As Mr Gee told the Commission:

> combining exercise, healthy lifestyle and cultural activities were associated with increases in resilience and decreases in psychological distress, without specifically addressing mental health as a topic in the program. These types of programs can take a whole of family approach (e.g., where the whole family participates) and may provide opportunities for health checks, and mental health awareness that results in counselling and support later.[177]

- **drugs and alcohol**: Some healing services relate specifically to drug, alcohol and rehabilitation needs of Aboriginal people. For example, Wadamba Wilam provides 'a small but significant service offering to people who have fallen through the gaps in standard service provision'. This healing program is 'unique in that it has multi-agency involvement and provide holistic, intensive, long-term support for their multiple healthcare, cultural, social and housing needs'.[178]
- **family violence**: Some healing services are delivered in the context of supporting people experiencing family violence or to support perpetrators to stop using violence. The Commission has heard that healing approaches to family violence are holistic and 'sensitive to the trauma and impact of family violence on individuals and families as well as the accumulated trauma experienced by Aboriginal people and communities as a result of colonisation'.[179]

The diversity of healing practices across these different settings and contexts provides meaningful support for Aboriginal people in critical life stages, including support to people experiencing trauma. Witness, Daniel Bolger, a proud Noonuccal Aboriginal man and founder of Got Ya Back, described his experience at the Bunjilwarra Koori Youth Healing Centre:

> I went to Melbourne Magistrates' Court for a bail hearing. The judge indicated I could get bailed to the Bunjilwarra Koori Youth Healing Centre. The Koori Youth Healing Centre is an Aboriginal youth rehab centre. Andy Brigham, a worker from there, came and talked to me in a visiting area. That was the first time for a while that I had normal conversation. He knew everything about the system. He did the assessment straight away, he explained the process and didn't make any promises … It was a real special place. I finally had workers around me that I got along with and that cared about me. To me, the place was run perfect.[180]

20.6.5 Supporting healing practices in Victoria

The Commission concurs that supporting healing is essential to improved Aboriginal social and emotional wellbeing and recognises that the Aboriginal Social and Emotional Wellbeing Centre is best placed to co-design and deliver an initial two healing centres with communities. These new healing centres will be developed based on local Aboriginal needs.[181] Further, the new healing centres may seek to:

- provide a place for Aboriginal-led trauma-informed healing that integrates traditional and contemporary practice
- restore language, knowledge systems, kinship and Aboriginal customs
- create paid employment opportunities for Elders who will play a critical role in the healing of young people and communities.[182]

This approach is in line with the Healing Foundation's identification of ownership, design and evaluation by Aboriginal people as a core characteristic of healing centres (refer to Figure 20.4).

These healing centres could also include:

- residential services, allowing time for healing in a culturally appropriate and trauma-informed environment
- access to and the provision of wellbeing supports
- treatment options that both prevent and support people experiencing crisis
- community services to inreach and contact a person for follow-up in the community on discharge.

The Commission believes there is enormous opportunity to embed and align healing practices through the Commission's reformed mental health and wellbeing system. In considering how the system will embed healing within its services, the Commission encourages future programs to heed evidence underpinning effective healing programs. This includes healing centres:

> - '[being] developed to address issues in their local communities
> - [being] driven by local leadership
> - [being] based upon well-developed evidence and theory base
> - combining both western methodologies and traditional healing in their treatment theory base
> - [being] informed about and understand[ing] the impact of colonisation and intergenerational trauma and grief
> - building upon individual, family and community capacity through the acquisition of knowledge and skills
> - incorporating strong evaluation frameworks
> - [having] a proactive rather than reactive focus'.[183]

Healing centres are also delivered through a multidisciplinary workforce, which comprises teams 'with a mix of clinical and non-clinical workers and Aboriginal and non-Aboriginal staff', providing 'culturally responsive, coordinated clinical and practical supports in the one place'.[184] This may include lived experience and peer support workers.

The Commission has heard that central to establishing healing centres is equipping and supporting staff to deliver trauma-informed treatment, care and support[185] and that '[t]rauma-informed and healing-based approaches should be the cornerstone of all care practices' for Aboriginal people.[186] Thus, the Statewide Trauma Centre (as described in Chapter 15: *Responding to trauma*) will be critical to support Aboriginal people attending the centres and the workforce.

As one staff member from an Aboriginal organisation told the Commission via the *Balit Durn Durn* report:

> My days are filled with high complexity and high trauma from listening to people's stories. Sometimes I just have to leave the office. I wish we had a place at the office where I could just curl up. Sometimes I need time to recover and I don't want to take sick pay, because I'm not sick. I don't want to have to go and get a doctor's certificate for something that's part of my role, I would like an understanding around that. I would like the policy makers to know, it's not us making an excuse, sometimes you can't take on anymore, you can't even look people in the face, you are done – I would like for there to be some respect around that.[187]

Practitioners have also stated that further investment and evaluation of healing approaches is essential to 'help families stay safely together'.[188] This is because the efficacy of healing approaches can be difficult to determine, given that (as this chapter has identified):

> - 'healing practices are diverse
> - the goals of healing are diverse
> - clients have diverse reasons for seeking healing
> - success can occur at different levels—individual, community, environment, cosmos
> - healing is ongoing and long term by nature'.[189]

The reforms proposed throughout this chapter recognise the profound effects of historical and intergenerational traumas on Aboriginal people. The Commission acknowledges the critical need for further investment in healing centres to support people experiencing complex and pervasive adversities. It is the vision of the Commission that through these reforms, and others identified in this chapter, the mental health and wellbeing system will create a paradigm shift supporting 'intergenerational healing and resilience'.[190]

20.7 Supporting Aboriginal children and young people

Victoria's Aboriginal population is relatively young; the 2011 census data reported that the median age for Victorian Aboriginal people was 22 years of age, compared with 37 years of age for non-Aboriginal Victorians. The data indicated that more than half of Victoria's Aboriginal population were less than 25 years old.[191]

Aboriginal children and young people are disproportionately represented in the mental health system; 2.5 per cent of child and youth mental health service clients identified as Aboriginal, despite making up only 1.4 per cent of all Victorians aged 0–24.[192] Aboriginal children are also nearly three times as likely to experience high or very high levels of psychological distress than non-Aboriginal children; however, it is unclear whether the reported rates of mental health service access for Aboriginal children and young people matches the need for care.[193] Only one in four Aboriginal children experiencing traumatic life events are accessing appropriate services.[194]

Aboriginal children and young people may face considerable challenges related to intergenerational trauma and associated disadvantage that leave them at risk of experiencing childhood adversity and mental illness.[195] Trauma and adversity in childhood has been closely linked with negative physical, social and mental health outcomes in childhood, adolescence and adulthood.[196] Research indicates that adverse childhood experiences—such as abuse and neglect, exposure to family violence and having a parent with lived experience of mental illness requiring high-intensity supports, alcohol and or substance use, or history of engagement with the criminal justice system—increase the risk of mental illness.[197] Within Aboriginal communities, research indicates that childhood and family adversity has a substantial effect on mental health and wellbeing; Aboriginal children are exposed to multiple risk factors for mental illness, such as exposure to violence, living in households with drug and alcohol use and addiction, not living with both parents and being bullied.[198] As identified by the Commission for Children and Young People:

> Like other First Nations children, Aboriginal children and young people continue to be disproportionately impacted in their developmental years by negative outcomes in key domains such as maternal, physical and mental health, homelessness and intergenerational trauma.[199]

Dr Tim Moore, Senior Research Fellow at the Murdoch Children's Institute, giving evidence in a personal capacity, described to the Commission a range of risk and protective factors that affect infant development. These include:

- the social and physical conditions in which families conceive and raise young children—the social determinants of health that 'shape health and wellbeing'
- socioeconomic status— 'from the point of conception, the higher a person's socioeconomic status, the healthier they (and their children) are likely to be throughout their life'
- transgenerational risk factors— 'risks that can be transmitted from one generation to the next'.[200]

Dr Moore described two ways risks can be transmitted across generations:

> The first form of transmission is genetic: when parents have been exposed to adverse experiences (including nutrition, environmental toxins, nurturing behaviour and social stress) that have produced changes to their epigenome, these changes can sometimes be passed onto their children, even if the children develop in optimal conditions themselves. … The second mode of transmission is environmental: children often 'inherit' the same social and environmental conditions (including poverty or trauma) that have created physical or mental health problems for their parents, thereby increasing the children's risk of physical and mental health problems.[201]

The Commission recognises that improving the social and emotional wellbeing of Aboriginal children and young people requires genuine acknowledgement and engagement with the legacy of trauma that continues to negatively affect families and communities. This includes recognising that experiences of mental illness in children and young people cannot be considered in isolation from the social and emotional wellbeing of parents and families, and that solutions must focus on both children and young people and their families and communities. Dr Moore emphasised to the Commission that 'while services are important for giving infants the best chance of good health and wellbeing, the social conditions in which they and their families live have a greater impact on their health and development'.[202]

Similarly, Professor Helen Milroy, Professor of Child and Adolescent Psychiatry at the University of Western Australia, Commissioner on the National Mental Health Commission, and a descendant of the Palyku people of the Pilbara region, told the Commission:

> The mental health system has been set up with a framework that has better application to physical health, trying to deal with symptoms as they present rather than dealing with the underlying causes for poor mental health. A child's best chance at having good mental health is to be born healthy, grow up in a loving and supportive family and community with good access to services, education and support as needed throughout development.[203]

Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing* emphasises the importance of delivering developmentally appropriate care to infants and children and the need to support the mental health and wellbeing of parents, particularly during the perinatal period (prospective or new parents from conception until 24 months after birth).[204] As outlined in that chapter, experiences of mental illness and psychological distress may negatively impact on a person's adjustment to parenting and their capacity to care for a newborn, disrupting the parent-infant relationship.[205] This disruption can then affect an infant's development, behaviour and relationships,[206] which may also negatively impact on transition into early education. The reforms outlined in that chapter focus on providing developmentally appropriate mental health and wellbeing treatment, care and support for young children and their families. The Commission recognises the additional challenges many Aboriginal children and families face.

The Commission also acknowledges the role of intergenerational trauma in the continued disproportionate representation of Aboriginal children and young people in out-of-home care in Victoria, and the impact of out-of-home care on the social and emotional wellbeing of children, families and communities.[207] The Victorian Aboriginal Children and Young People's Alliance told the Commission:

> The removal of an Aboriginal child from their home, community and culture affects the whole community—and without allowing us to do the work our community needs, the approach of the current system is inflicting further harm on families, children, carers and our workforce.[208]

The *Always Was, Always Will Be Koori Children* report made it clear that the child protection system too often fails to preserve, promote and develop cultural safety and connection for Aboriginal children in out-of-home care.[209] It highlighted:

> non-compliance with legislative and practice requirements for cultural planning and inadequate inclusion and engagement with Aboriginal family, programs and community in decision-making, [which] have resulted in the dislocation from culture and family for large numbers of Aboriginal children in out-of-home care.[210]

The Commission heard that parents need support to address experiences of mental illness that have resulted in children being removed.[211] The Aboriginal community-controlled organisation, Djirra, described an expectation that mothers will 'fix their mental health with no real support to do so'.[212] The organisation argued for a 'shift towards providing or linking parents, particularly mothers, with meaningful support and services to address their mental health issues, not punishing them'.[213]

The Commission is encouraged by the Victorian Government's announcement in late 2020 of funding to support the reform of out-of-home care services and to support Aboriginal children and family services. This includes funding to ensure Aboriginal community-controlled organisations have case management control for Aboriginal children, in accordance with *Wungurilwil Gapgapduir: Aboriginal Children and Families Agreement*, and for the piloting of Aboriginal family support teams.[214] The Commission also recognises that long-term, multisector reform is required to respond to the over-representation of Aboriginal children and young people experiencing mental illness in out-of-home care, in contact with the justice system and at risk of homelessness. This multisector approach is the foundation of the Commission's recommendation to develop a *Mental Health and Wellbeing Outcomes Framework* to drive collective responsibility and accountability for mental health and wellbeing outcomes across government portfolios described in Chapter 3: *A system focused on outcomes*.

20.7.1 Early intervention

Aboriginal organisations and experts emphasised the importance of early intervention to support the mental health of children and young people. Ms Kennedy told the Commission of the need for early intervention to help deal with the impacts of intergenerational trauma:

> I believe that the impact of trauma on Aboriginal children and families is a major undetected, underestimated and misunderstood determinant of the poorer mental health outcomes seen in the adult Aboriginal population. Given the high prevalence of mental illness and a large, rapidly growing population, there is an urgent need to address this with new solutions and better, more accessible culturally responsive services and initiatives. In other words, we must prioritise and strengthen early intervention and prevention approaches for Aboriginal children.[215]

Early intervention is identified as one of the most effective ways to reduce the occurrence or impact of adverse childhood experiences. In particular, this includes support for parents within the first two years of their child's life.[216] Early intervention crosses multiple service systems. Professor Frank Oberklaid AM OAM, a paediatrician at The Royal Children's Hospital and Co-Group Leader of Child Health Policy, Equity and Translation at the Murdoch Children's Institute, told the Commission of the 'need to build the capacity of the universal services accessed by parents and children—childcare, schools, local doctors and nurses and other community-based services—to identify and deal with problems early.'[217] He also told the Commission:

> Many of the children currently seen by tertiary mental health services have problems that could and should have been dealt with at an earlier stage in the community before they deteriorated. There is hardly a child I see in my practice that does not make me wonder why I did not see that child sooner.[218]

The Victorian Aboriginal Children and Young People's Alliance spoke about the central role of Aboriginal communities in supporting children and families to prevent the break-up of families:

> It really does take a village to raise a child, and through building relationships with families we can see the ongoing protective role of culture and community that will continue throughout families lives. Despite this – there is a significant lack of investment in early intervention – and very little of it goes to Aboriginal families and those that need it most.[219]

Evidence to the Commission identifies a need for Aboriginal children and young people to have 'access to culturally safe, therapeutic family strengthening services and early intervention',[220] and 'well-resourced Aboriginal community controlled health services'.[221] The Commission for Children and Young People identified these services as vital, noting that in the '[a]bsence of easily accessible, culturally appropriate support services to strengthen the capacity of families to provide optimal care, the trajectory to child protection intervention is increasingly the outcome for many Aboriginal children and their families'.[222]

The interim report recommendation for the expansion of social and emotional wellbeing teams across Victoria's community-controlled health organisations is designed to encourage the early detection of mental illness and provide social and emotional wellbeing services within communities. The functions of the teams, which include linking into support services, engaging with families and communities and providing assertive outreach services such as home visits, will support early intervention within Aboriginal communities.

As noted in the interim report, the social and emotional wellbeing teams will initially focus on Aboriginal adults (aged 16 years or older), and the Aboriginal Social and Emotional Wellbeing Centre will continue to build the evidence base for best practice and clinical effectiveness in working with Aboriginal children and younger people.

The Commission acknowledges that the current mental health system does not provide the necessary early intervention and therapeutic care to support Aboriginal children and families. As the Victorian Aboriginal Child Care Agency told the Commission:

> We contend that the social and emotional wellbeing needs of our children, young people and families are not currently being met by the mental health service system, it is not responsive to the specific needs of the Victorian Aboriginal community. Aboriginal children and young people are vulnerable to a lifetime of social and emotional wellbeing concerns due to the early exposure to risk factors creating a pathway into poor mental health and mental illness.[223]

The Commission recognises the need for immediate reforms to provide mental health and wellbeing supports for children and families while the Aboriginal Social and Emotional Wellbeing Centre develops models of care for children and young people. The following reforms are designed to support Aboriginal organisations to deliver a range of clinical and therapeutic services for children and families, to support early intervention, family healing and provide wrap-around multidisciplinary care for children and families most in need.

20.7.2 Partnering with child and youth mental health and wellbeing services

The interim report identified the need for and benefits of Aboriginal people being able to access culturally appropriate mental health services through Aboriginal community-controlled health organisations. It is the Commission's position that Aboriginal children and young people should be able to access the same level of culturally appropriate services. Professor Milroy noted that understanding 'cultural norms is essential when assessing a child's behaviour' pointing out that '[p]icking up the early warning signs can be difficult in children and more so within a cross-cultural context'.[224]

Evidence to the Commission described the difficulties Aboriginal consumers face in accessing treatment, care and support in the current 'crisis driven' mental health system.[225] The Victorian Aboriginal Children and Young People's Alliance noted the impact of the system on access to mental health services for Aboriginal children:

> The crisis response of the public mental health system means gaining early intervention access to their services is difficult, access to a psychiatrist for an urgent review and diagnostic clarification is impossible – which considerably delays the commencement of appropriate treatment.[226]

It is the Commission's position that Aboriginal children and young people need access to both well-resourced Aboriginal community-controlled health services and culturally safe mainstream mental health and wellbeing services, which work in partnership.

Case study:

Workin' with the Mob

Workin' with the Mob is an Aboriginal family therapy program delivered by the Bouverie Centre and funded by La Trobe University and the Victorian Department of Health.

Because many Aboriginal families are unable to travel to the Bouverie Centre, which is located in Brunswick, Melbourne, it offers an outreach model providing families with the option of single-session family therapy in their home. Families who access the Workin' with the Mob program may be seeking help to resolve worries that are affecting the whole family or individuals within the family. These challenges might include family violence, complex post-traumatic stress disorder, sexual abuse, children living in out-of-home care and alcohol and other drug use.

As well as collaborating with families in relation to presenting issues, the Centre also works with families on preventing ongoing transgenerational trauma.

Clarisse Slater, a Yorta Yorta and Kamilaroi woman and Cultural Consultant and Workforce Development Trainer at the Bouverie Centre, said the Workin' with the Mob program is congruent with Aboriginal culture:

> It assumes the whole family and the community are significant for the person with the problem and takes a whole system approach which respects the role of Elders and family members. It also recognises that a person's context—their country, history and culture—are meaningful for the identity and experiences of the individual.

Ms Slater explained the Bouverie Centre recognises that cultural safety is central to the Workin' with the Mob program:

> The culturally respectful and holistic approach used in the Workin' with the Mob program is endorsed by Community, other Aboriginal agencies and the families that we work with.

Most families only attend the program for one session. However, the Bouverie Centre tells all families they are welcome to return.

The Bouverie Centre and La Trobe University also run a university-level postgraduate qualification in family therapy. It is specifically designed for Aboriginal workers who are currently working in the community. Non-Aboriginal family workers from Aboriginal organisations who have been endorsed by their organisation are also eligible to take part. A review of the program undertaken by the Lowitja Institute described the training program as tailored to meet the needs of Aboriginal families: 'a hand-in-glove fit with Aboriginal people in terms of being holistic, contextual and trauma-informed'.

Source: Elliott, A, McIlwaine, F, Stone, N & Proctor, K 2015, *The Bouverie Centre's Aboriginal Family Therapy Training Program: Impact Analysis Report*, The Lowitja Institute, Melbourne;

The Bouverie Centre, Correspondence to the RCVMHS, 2020.

Aboriginal community-controlled health organisations will be supported to provide care in partnership with the new Infant, Child and Youth Area Mental Health and Wellbeing Services, as described in Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing*. These partnerships will allow Aboriginal community-controlled health organisations to connect with paediatric mental health specialist expertise in the infant, child and family mental health and wellbeing service stream to support young consumers. This could include primary consultations, such as specialists working alongside primary care providers seeing consumers in communities, and secondary consultations to allow health professionals to seek advice from specialists. Specialist services will also be available to provide secondary consultation through universal services, such as maternal and child health services to support parents and families. Aboriginal community-controlled health organisations may also partner with mainstream mental health and wellbeing services to provide continuous shared care for young clients to support transitions to and from mainstream acute services (such as hospitals), where necessary.

More information about shared care partnerships can also be found in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services*.

20.7.3 Family therapeutic services

Evidence before the Commission identified the importance of approaching child mental health within the context of children's families and relationships. Professor Louise Newman AM, Professor of Psychiatry at the University of Melbourne and Practising Perinatal and Infant Clinician, told the Commission:

> Ideally, a clear model for the provision of mental health care for infants and young children needs to include an understanding of the importance of the early developmental period and the role of families/carers in shaping development during this period. The focus of support and intervention includes both the parents/carers and the infant/child and is based on a model that recognises the significance of attachment relationships and context.[227]

She explained that this requires 'comprehensive assessment of the child in the context of their family and caretaking relationships …', in collaboration with families, and that this approach is likely to mitigate the risks of misdiagnosis and over-diagnosis of children.[228]

Similarly, Professor Harriet Hiscock, Paediatrician at the Centre for Community Child Health, Director of the Health Services Research Unit at The Royal Children's Hospital and speaking in a personal capacity, recommended that professionals should not just work with the child, but rather should work in partnership with the whole family. She said:

> This approach has been evaluated and found to improve the developmental progress of children, parent-child interactions and the psychological functioning of parents, families and children.[229]

Witnesses and Aboriginal organisations also stressed to the Commission that the social and emotional wellbeing of children and young people must be understood in the context of family and community experiences. The Victorian Aboriginal Child Care Agency described the vital role of family in daily life and in social and emotional wellbeing:

> The family network dominates community and family life, governing social interactions. Aboriginal people are connected through kinship, possessing a shared sense of identity, care, responsibility and control. This inter-connectedness is applied to healing by adopting a whole family and community response to addressing [social and emotional wellbeing].[230]

The agency's submission stated that involving family in mental health services helps to ensure connection to family is strong, which can help reduce risk factors, and that '[a] family orientated approach is vital to promoting resilience and sustainable recovery'.[231]

The Commission recognises that collective and family-oriented approaches are vital in addressing the negative effect of intergenerational trauma and associated disadvantage on the social and emotional wellbeing of children and families. As described earlier in this chapter, those impacts are often experienced at the level of the extended family. Mr Jackomos described this shared experience as follows:

> As an Aboriginal person, you feel and suffer the consequences of the many, as you also celebrate our collective successes. Mental health and related illnesses, along with suicide and self-harm, imprisonment and child protection intervention has impacted significantly on my family, my children and extended family, and myself.[232]

Family-inclusive practice

Evidence before the Commission identified the benefits of family-inclusive practice for supporting people experiencing mental illness, families, carers and supporters. The state-wide service, Bouverie Centre, describes family-inclusive practice as 'activities which directly involve members of the client's family and social network in their care and treatment.'[233] This is discussed in more detail in Chapter 19: *Valuing and supporting families, carers and supporters*. As detailed in that chapter, family-inclusive practices include a range of methods, theories and styles, including single-session support, behavioural family therapy and multiple group family therapy. The range of family-inclusive practices (or family therapies) allows services to better identify and target treatment approaches for consumers in consideration of their condition and its impacts within the relational context.

Research indicates a range of benefits of family-inclusive practices or family therapies. In its 2008 report, *Family Relationships and Mental Illness: Impacts and Service Responses*, the Australian Institute of Family Studies noted the potential for family services to:

> [s]creen for, identify and deal with mental health problems as they become evident in the therapeutic process … [and] not only address the impact of mental health problems on couple and family relationships, including parenting, but also the impact of these family relationships on mental health and wellbeing.[234]

Ms Sandra Keppich-Arnold, Director of Operations and Nursing at Alfred Health's Mental and Addiction Health, emphasised to the Commission that '[b]est practice service responses for young people *must* be family inclusive and ensure the family system is considered'.[235]

Dr Robyn Miller, CEO of McKillop Family Services, emphasised the importance of family-inclusive practice for children and families in contact with child protection, particularly those in residential care:

> Children have a hunger for family connection. There is a great gap in the mental health system where clinicians do not have training to think systemically or to think family. If you can engage family members to be believing and bear witness to the suffering of the child, the child will get better faster. It is so simple, but it is complicated to do and frequently in mental health and in residential care, clinicians are much more focused on the placement and the child as an individual, rather than recognising that physical separation from family does not equate with emotional separation for the child or young person.[236]

Family-inclusive practice in Aboriginal social and emotional wellbeing services

Family-oriented therapeutic care recognises the effect of intergenerational trauma on individuals, families and communities. The Bouverie Centre, which delivers family therapeutic services, identifies transgenerational trauma and grief and loss experienced by Aboriginal people, particularly for Stolen Generations survivors, as one of the major issues for Aboriginal families presenting to the service. The Workin' with the Mob case study provides an overview of the Bouverie Centre's approach to Aboriginal family therapy.

Single-session Aboriginal family therapy

The Bouverie Centre developed Single-Session Family Consultation which combines family consultation with single-session therapy.[237] The benefits of Single-Session Family Consultation are discussed in more detail in Chapter 19: V*aluing and supporting families, carers and supporters,* and in Chapter 13: *Supporting the mental health and wellbeing of young people.*

Evidence to the Commission indicates that Single-Session Family Consultation can be valuable for young people and families,[238] by providing initial support to families who can then use their own resources as well as brief support from therapists.[239]

There is also emerging evidence supporting the delivery of Single-Session Family Consultation for Aboriginal families. One study described the perspectives of two Aboriginal family counsellors from the Bouverie Centre who use single-session approaches with Aboriginal families:

> Brief therapy fits in with building hope that change can happen. It feels really good to be shifting my initial [scepticism]. Just listening and actually making it about what the family want to talk about, is a decolonising approach. It's reconciling all that past imposition of a worker/therapist wanting to direct the session: 'We're going to talk about this because this is the priority,' instead of actually just meeting the person and saying: 'What would you like to get out of today?'—'What's the biggest thing for you today?' I think it's really respecting the person and family.[240]

> 'What are your best hopes from us meeting today?' I just ask that one question and it's that question that starts it all—the way that I view any individual, couple, or family who go to therapy is like they are asking for help—and in that, hope is implicit. Any person that walked in the door has come because they have hope.[241]

As described in the Workin' With the Mob case study earlier in this chapter, the Bouverie Centre and La Trobe University partnered to develop and deliver a postgraduate qualification in family therapy. Students come from Aboriginal community-controlled organisations and mainstream services, including family violence, children, justice and drug and alcohol services. To reduce barriers to accessing further education, workers without undergraduate degrees but who have worked in and contributed to the field are eligible for the course.[242] To address other barriers to study:

> - training is provided within the community, so that the university 'comes to them'
> - the program enables a safe and empowering climate in which the considerable skills and knowledge of the students are built upon
> - student places within the course are sponsored
> - supervision is provided for two years post-training to support the implementation of family therapy skills.[243]

The Commission heard that increasing and upskilling the Aboriginal workforce is vital to improving the availability of culturally responsive care.[244] In its survey of Aboriginal health workers for the *Balit Durn Durn* report, the Victorian Aboriginal Community Controlled Health Organisation identified that the vast majority of participants were interested in pursuing education to upskill but that factors such as cost, organisational capacity and lack of access for workers in regional areas were barriers to further study.[245]

The Commission acknowledges both the importance of family and kinship ties in Aboriginal social and emotional wellbeing, and the need to respond to the role of intergenerational trauma in the social and emotional wellbeing of children, young people and families. Aboriginal organisations have stressed the need to ensure 'there is a focus on children, and children within family and community to support generational change'[246] and for 'Aboriginal children and young people have access to culturally safe, therapeutic family strengthening services and early intervention'.[247]

In Victoria's future mental health system, the Victorian Aboriginal Community Controlled Health Organisation will be supported to commission the delivery of family-oriented, therapeutic care to children and young people. This approach will allow Aboriginal community-controlled health organisations to provide both clinical support (through partnerships with mental health services as outlined above) and therapeutic treatment, care and support to children and young people within communities.

The Victorian Government will provide ongoing funding to the Victorian Aboriginal Community Controlled Health Organisation to commission the delivery of culturally congruent, family-oriented, social and emotional wellbeing services. Recognising the critical link between parent-child social and emotional wellbeing, families with Aboriginal children should be able to access family therapy. The Commission has identified the following parameters as relevant based on a range of evidence and in consultation with the Bouverie Centre's Indigenous Family Therapy team:

- family therapy should come at no cost to the family
- families should be provided with the choice, where possible, for an Aboriginal family therapist to see them
- families should be provided with the choice, where appropriate, for the first session to be held offsite at their home, or in a neutral setting of the family's choice
- families should be offered a single-session approach with the possibility of the family returning for more sessions if requested or required, with the set number of sessions determined by the family in partnership with the family therapist. Clinical reviews should take place at regular intervals
- families should be provided with the option to have the case manager included in the sessions if they wish
- families with children in out-of-home care should be prioritised.[248]

The Victorian Aboriginal Community Controlled Health Organisation should also be funded to ensure that funded family therapy providers can provide secondary consultation to Aboriginal workers in their own agencies. The Commission understands that demand for Aboriginal family therapy far outweighs the availability of services, with the Bouverie Centre, a major provider of family therapy services, only being able to meet 50 per cent of demand.[249] It is expected that with appropriate resourcing and enhanced communication about the program, demand will further increase. The Commission is aware that the Bouverie Centre is undertaking a process to staff and structure a family therapy walk-in service for Aboriginal families based on feedback from families.[250] The Victorian Government should consider development of a proof of concept of this model for future investment.

Critical to sustainable delivery of these services will be the Victorian Government's ongoing investment in developing the Aboriginal family therapy workforce and in supporting and nurturing the professional development of graduate cohorts, including through mentoring.[251] Furthermore, the Victorian Government should provide funding to the Victorian Aboriginal Community Controlled Health Organisation to ensure that a comprehensive evaluation is undertaken of Aboriginal family therapy services to support continuous improvement and to inform future investment.

Personal story:

Jessie

Jessie* is an Aboriginal Heath Liaison Officer (AHLO), helping Aboriginal patients and families navigate services and offering cultural support across multiple hospitals. Jessie provides cultural advice to colleagues through education sessions, meetings and at times one on one. Jessie said their motivation for working in the role is that they have always wanted to bring about better outcomes for their mob and others.

Jessie said they feel well supported culturally by their employer, and can access other external supports.

> I have supervision with a social worker monthly, and my manager. There is a local Aboriginal group which I use to debrief, and [the Victorian Aboriginal Community Controlled Health Organisation] has an Improving Care of Aboriginal Patients (ICAP) Zoom group monthly for peer support.

However, the AHLO role has limited pathways for career progression. Jessie said that while this role suits them, the lack of pathways makes it hard to attract young people.

Jessie's employer is very supportive and has offered a number of training opportunities and the flexibility to undertake additional work outside their normal working hours.

Prior to this role, Jessie worked as a counsellor and would like to use these skills more in their current role.

> [The health service] tend[s] to use the people employed in specific roles—for example, counsellors to counsel … regardless of cultural safety and comfortability.

Jessie would also like to see the AHLO role cover other parts of the hospitals too.

> I would like to see people at different points in their care. With ED, a lot of people come in over the weekend when no one is around. An ED support worker could support people coming through with mental health issues and may improve situation and response if done by an Aboriginal worker with the mob. Currently the AHLO doesn't get to see this mob as they are in and out—I only see them if they come back and haven't self-discharged, which makes it hard to follow up.

Source: RCVMHS, *Interview with 'Jessie'*, (pseudonym), August 2020.

Note: *Name has been changed to protect privacy.

20.7.4 Intensive multidisciplinary treatment, care and support for children and families

Throughout its deliberations, the Commission heard extensive evidence regarding the need for intensive therapeutic services for some children and families. As outlined in Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing*, too often, children and families are in crisis before they can access vital comprehensive treatment, care and support. Witnesses and Aboriginal organisations have impressed on the Commission the need for intensive, multidisciplinary wrap-around services to support Aboriginal children and families.

The Victorian Aboriginal Community Controlled Health Organisation identified the need to invest in 'multi-disciplinary social and emotional wellbeing teams' consisting of 'psychologists, general practitioners, psychiatrists, social workers, counsellors, Aboriginal social and emotional wellbeing and mental health workers, Aboriginal health practitioners, and mental health nurses' to support families and communities. The organisations also stressed that to 'ensure self-determination and cultural safety Aboriginal staff must be in leadership roles within these multi-disciplinary teams'.[252]

The Victorian Aboriginal Children and Young People's Alliance discussed several models of intensive, therapeutic family services across Aboriginal communities. This includes the Keela Borron wrap-around child and family service operated by the Ballarat and District Aboriginal Co-operative[253] (refer to Box 20.4).

The Victorian Aboriginal Children and Young People's Alliance identified multiple benefits of delivering models of child and family therapeutic wrap-around services designed for Aboriginal children and families, particularly families in or at risk of contact with child protection.[254] For example, such models recognise the time required to engage with and gain the trust of families, who may have experienced negative interactions with government services. They also recognise that the unique stresses and complexities of issues facing Aboriginal families may require ongoing and flexible approaches, including linking in with multiple services to support families. One member of the Alliance described to the Commission their organisation's approach:

> We engage and continue to engage, whether that be dozens and dozens of phone calls or door knocks, whatever it takes. It takes time to build trust and a relationship. And the talking doesn't stop—we talk to other service providers and systems including education, housing, police and legal centres to advocate on behalf of our clients to ensure they are getting fair treatment and proper access. If we are making progress with our families—we don't close the case.[255]

The member went on to describe their success with one family, telling the Commission, '[I]t took two years of intensive work to get that family where they are today—but it kept seven children out of the system, and it is our hope that it broke the cycle'.[256]

Box 20.4: Ballarat and District Aboriginal Co-operative—Keela Borron wrap-around child and family services[257]

Keela Borron in Wathaurong language means 'speak children' and is an innovative demonstration project that is designed to work with parents of Aboriginal children, where moderate to severe parental mental illness puts the child at risk of entering the child protection system.

With a core value of listening to the voices of the children, this project aims to support the healing of families and to strengthen cultural connections. The project also supports family reunification, where the parent's mental illness has already resulted in child protective services involvement. A trauma-informed view of the complexities faced by Aboriginal communities is at the forefront, with the aim to build resilience and self-determination.

Keela Borron recognises the need to be flexible, innovative, culturally focused and safe. The service delivery model is based on an intensive case management and a wrap-around model of care. While the safety and protection of children is at the forefront of this program, the core functions of this project model include mental health assessment and commencement of treatment, care coordination, linking in to health and social support needs, advocacy and parental skills development.

Some of the group programs established under Keela Borron include psychoeducation, Circle of Security, mental health self-management, parenting skills, mindfulness and stress reduction, communication skills and life skills programs. It has a cultural support worker who ensures the work the organisation does is culturally appropriate, and links to community, family and culture are maintained and strengthened.

The ongoing mental health support has proved to be invaluable to the overall success of client participation. The flexibility of Keela Borron to deliver programs such as Circle of Security to meet the needs of individuals has been appreciated by clients. Outcome measures have also highlighted improvements in mental health over a 12-month period, a reflection of how specialist mental health care and intense support can lower levels of depression, stress and anxiety.

Witnesses and Aboriginal organisations also emphasised the importance of self-determination in relation to the design and delivery of treatment, care and support. Ms Kennedy described the need to empower communities through 'co-design [which means] generating ideas, testing them and making decisions about how these ideas could shape responses to [social and emotional wellbeing]'.[258] Ms Kennedy further explained that this involves a 'shift in power, responsibility and control … so that Aboriginal consumers and communities become active partners in designing, shaping and resourcing services, programs, and activities rather than being passive recipients of those things'.[259] However, the Commission heard that this is not always the way that services for Aboriginal communities are designed and delivered:

> **despite commitments to Aboriginal self-determination in words we are yet to see the transfer of power, control and resources that true self-determination requires. We are still coming up against a system that isn't designed for us, where investments and policies trickle down to Aboriginal communities as an afterthought.**[260]

Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing*, recommends the establishment of two residential short-stay family centres to support infants, children and families. Both centres will be developed in consultation with Aboriginal communities and with an explicit focus on ensuring they are culturally appropriate and safe for Aboriginal children and families to access.

Furthermore, the Commission recognises that the unique challenges faced by many Aboriginal children and families necessitates an additional reform, specific for Aboriginal communities,[261] and developed by Aboriginal communities. As has been made clear to the Commission, the mental health system has too often failed to respond effectively or swiftly to the trauma within Aboriginal communities or to understand the impact of disadvantage and oppression on social and emotional wellbeing.[262] Aboriginal organisations have emphasised that 'Aboriginal led approaches to healing and recovery from trauma responses'[263] are integral to fulfilling the Victorian Government's commitment to self-determination.

The Commission supports Aboriginal communities being empowered to design, deliver, evaluate and continuously improve services that meet the needs of Aboriginal children and families.

Consequently, the Victorian Government must resource the Victorian Aboriginal Community Controlled Health Organisation to design and establish a culturally appropriate, family-oriented service for infants and children who require intensive social and emotional wellbeing supports. This should be done in partnership with an Infant, Child and Youth Area Mental Health and Wellbeing Service. The Victorian Government, through its self-determination reform framework, acknowledges that 'Aboriginal Victorians hold the knowledge and expertise about what is best for themselves, their families and their communities'.[264] It recognises that to enable self-determination, power and resources must be transferred to communities so that they are 'empowered to own and drive safe, relevant and accessible responses to meet their needs'.[265] In delivering on this reform, the Victorian Government must be led by the Victorian Aboriginal Community Controlled Health Organisation, in partnership with Aboriginal community-controlled organisations, on all aspects of the design and delivery of the model, including in determining the most appropriate agencies to lead delivery of the service.

20.8 The Aboriginal health workforce

The Commission has heard compelling evidence about the need for and benefits of Aboriginal roles within mental health services. Access to lived experience workers, including peer support workers, can contribute to recovery and healing from trauma.[266] Evidence indicates that there is a need to increase access to Aboriginal peer support roles, with 72 per cent of respondents from one Aboriginal workforce survey noting 'more cultural mentoring and peer supports would make their job easier'.[267] In the context of Aboriginal mental health and wellbeing, peer support roles undertake a similar support role to liaison officer roles. These roles, typically staffed by Aboriginal people, are demonstrated to improve mental health outcomes for Aboriginal people.[268] They support consumers to navigate and access services[269] and can support services to work more effectively with Aboriginal families through 'cultural expertise, liaison and co-case management'.[270]

Ms Kennedy described to the Commission how Aboriginal liaison officer roles support the work of local mental health and wellbeing services:

> An example of a mainstream Aboriginal mental health initiative is the Koori Mental Health Liaison Officer (KMHLO) program run in Victoria. Whilst these roles are only based in approximately 8 services, their work includes supporting Aboriginal patients, building links between Aboriginal mental health service (AMHSs) and ACCOs [Aboriginal community-controlled organisations], providing culturally sensitive practice advice to clinicians and other mental health workers, participating in health promotion activities, and providing cross-cultural training in collaboration with ACCOs.[271]

The Commission has heard of the importance of a workforce that understands the unique perspectives that Aboriginal people have of social and emotional wellbeing. At the Victorian Aboriginal Children and Young People's Alliance roundtable, one member told the Commission:

> The work our staff do with families goes to the heart of trauma experienced in Aboriginal communities. A western and clinical concept of mental health, does not adequately understand or adequately address this trauma—and this is why so many Aboriginal families fall through the gaps.
>
> But our workforce does understand. They see the whole person and see the cultural, social and historic impact of this trauma on their lives. They often understand it because they are part of the Community and they are best placed to work with our families.
>
> The cultural knowledge and understandings are invaluable.[272]

The Commission recognises the considerable 'cultural load' borne by Aboriginal health workers, many of whom are exposed to high levels of distress and trauma experienced by Aboriginal consumers, without sufficient opportunities to debrief or receive support.[273] Given the small number of Aboriginal health workers in mainstream mental health services,[274] these workers may be the sole Aboriginal voice in an organisation. The Commission suggests that services should be supported to increase the number of Koori mental health liaison officers across each service setting. The Commission has also heard that the lack of Aboriginal representation in management and across all levels of health services is a barrier to delivering safe and responsive health care.[275]

Significant workforce reform will be critical to create culturally safe services that meet the needs of Aboriginal people using Victoria's mental health and wellbeing services, as well as to create culturally safe workplaces that support the retention, and social and emotional wellbeing, of an Aboriginal workforce. In Chapter 33: *A sustainable workforce for the future*, the Commission details priority measures to improve the wellbeing of the workforce, including coordinating the development and delivery of tailored resources, professional supports and communities of practice for Aboriginal practitioners. This will go some way towards the necessary changes to create culturally safe workplaces. The Commission supports the government's commitment to grow the recruitment and retention of the Aboriginal workforce in the health sector, through the funding of training grants to increase the workforce participation of Aboriginal people 'in both clinical and non-clinical roles at all levels of the health and human services system'.[276]

20.9 Culturally safe and responsive mainstream services

A large proportion of Aboriginal people rely on mainstream services for their health care, either due to lack of access to Aboriginal community-controlled health organisations or a preference for mainstream services.[277] The 2014 *Contributing Lives* review found that, nationally in 2012–13, slightly less than half (47 per cent) of Aboriginal people used Aboriginal community-controlled health organisations for their primary health services.[278]

According to Census data, Aboriginal people make up 0.8 per cent of Victoria's population,[279] yet they comprise 2.8 per cent of people using clinical public mental health care, indicating they are overrepresented in these services.[280] Consequently, mainstream services need to be culturally responsive to the needs of Aboriginal people:

> **There is a role for culturally specific organisations, but all organisations need to be culturally competent. For example, I think VAHS [Victorian Aboriginal Health Service] is pretty unique in providing a safe clinical space for Aboriginal people, but we do need to recognise that not all Aboriginal people want to go to a culturally specific health service. All organisations have to be culturally competent, regardless of whether they are targeting a particular cultural population.**[281]

The Commission has heard that some mainstream services—such as Mildura Base Hospital and Goulburn Valley Health[282]—have built cultural competency through partnerships with Aboriginal community-controlled health organisations. However, a 2014 Victorian Auditor-General report indicated that such collaboration is not the norm.[283]

In the future, the Commission expects that the entities supporting the design and delivery of the new mental health and wellbeing system will work closely with Aboriginal people to support their social and emotional wellbeing. The new Mental Health and Wellbeing Promotion Adviser, recommended in Chapter 4: *Working together to support good mental health and wellbeing*, will work in close partnership with Aboriginal organisations to identify how to best support the social and emotional wellbeing of Aboriginal communities through the Statewide Plan for the Promotion of Mental Health and Wellbeing and the Prevention of Mental Illness.

It is the Commission's position that the new mental health and wellbeing system must respond to the diverse needs of Aboriginal people and be able to adapt its approach to ensure that all people get the right service, at the right time, in their local area. The Commission has identified that the way services are planned, funded and monitored is critical to creating a system that is innovative, respects the needs and preferences of individuals and is adaptive to changing needs. The new commissioning approach, detailed in Chapter 28: *Commissioning for responsive services,* will continue to progress the self-determination of Aboriginal services to Aboriginal people. The interim regional bodies—and, when established, the Regional Mental Health and Wellbeing Boards recommended in Chapter 5: *A responsive and integrated system*—will work towards advancing Aboriginal self-determination by progressively supporting Aboriginal organisations and communities to lead decisions on Aboriginal social and emotional wellbeing services. The Commission recognises that the genuine involvement of Aboriginal organisations and Aboriginal communities more broadly in the design and delivery of mental health care is integral to supporting self-determination.

Requirements under the new community model

The new mental health and wellbeing system will design and deliver services in relation to the needs of their communities. This is discussed in more detail in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services*. Partnering with a range of community organisations will be integral to meeting the needs of Victoria's diverse populations. This includes working with community-led organisations supporting diverse populations, including LGBTIQ+ communities, culturally diverse communities and people with disabilities. It is expected that mental health services will partner with Aboriginal community-controlled health organisations and Aboriginal community-controlled organisations to improve access to, and the cultural safety and responsiveness of, mainstream mental health services.

The Commission acknowledges that a person's identity is the construct of a range of intersecting factors, such as age, race, gender, sexuality, cultural background and disability, and that the new mental health and wellbeing system needs to be able to respond to the different needs that people have. An intersectional approach supports greater inclusion and equality, and will underpin the diverse communities mental health and wellbeing framework detailed in Chapter 21: *Responding to the mental health and wellbeing needs of a diverse population*.

The new mental health and wellbeing system will better engage the knowledge and expertise of Aboriginal consumers, families, carers and supporters. Aboriginal people will lead decision making in the design and delivery of Aboriginal social and emotional wellbeing services, and mainstream mental health services will engage with Aboriginal people to ensure their services are responsive to Aboriginal social and emotional wellbeing. Together with a greater emphasis on trauma-informed practice, these reforms are expected to deliver a more culturally safe system. The reforms will significantly increase the capability of the workforce to adopt trauma-informed approaches and ensure cultural safety, as well as providing training and support for consumers, families and carers to take on leadership roles in the new system. A more detailed description of these reforms can be found in Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress* and Chapter 19: *Valuing and supporting families, carers and supporters*.

Aboriginal people experiencing homelessness or insecure housing, substance use or addiction and engagement in the criminal or youth justice system will receive more coordinated and integrated supports in the new system. A more 'joined-up' approach will prevent people from falling through the cracks between systems, and ensure that supports are more holistic and responsive to the range of factors that can affect social and emotional wellbeing. Further detail regarding the joined-up approach between specialist mental health and other service systems is described in Chapter 16: *Supported housing for adults and young people,* Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction* and Chapter 23: *Improving mental health outcomes across the criminal justice, forensic mental health and youth justice systems*.

Suicide prevention and response

The Commission's reforms as described in Chapter 17: *Collaboration for suicide prevention and response* aim for a more compassionate and comprehensive approach to suicide prevention and response. The reforms recognise the disproportionate incidence of suicide in Aboriginal communities and include a commitment to implement culturally safe community 'gatekeeper' training that is developed and delivered by Aboriginal people. In addition, the social and emotional wellbeing teams in Aboriginal community-controlled health organisations, which the Commission's interim report recommended, will provide postvention bereavement support services for Aboriginal people.

Collaboration will be critical for suicide prevention and response, and, indeed, is the guiding theme informing all initiatives outlined in this chapter. As stated in Chapter 1: *The reform landscape*, it is only with collaboration—between communities, organisations and all tiers of government—that meaningful change can occur.

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6 Victorian Aboriginal Community Controlled Health Organisation, p. 11.

7 Victorian Aboriginal Community Controlled Health Organisation, p. 11.

8 Victorian Aboriginal Community Controlled Health Organisation, p. 10.

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13 *Witness Statement of Professor Dan Lubman*, 28 May 2020, para. 99; *Witness Statement of Georgie Harman*, 2 July 2020, para. 159.

14 Royal Commission into Victoria's Mental Health System, *Interim Report*, p. 469.

15 *Witness Statement of Helen Kennedy*, para. 34.

16 Victorian Government, Royal Commission into Victoria's Mental Health System—Letters Patent, 2019, para. I(4.1).

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Chapter 21

Responding to the mental health and wellbeing needs of a diverse population

Recommendation 34:

Working in partnership with and improving accessibility for diverse communities

The Royal Commission recommends that the Victorian Government:

1. ensure the active engagement of Victoria's diverse communities throughout the process of planning, implementing and managing the reformed mental health and wellbeing system.
2. legislatively provide that the Secretary of the Department of Health is responsible for the delivery of a mental health and wellbeing system that responds to the needs of Victoria's diverse communities and promotes access and equity of outcomes, with this function able to be delegated to the Chief Officer for Mental Health and Wellbeing (refer to recommendation 45(1)).
3. ensure that the Mental Health and Wellbeing Division:

    a. collects, analyses and reports on data on the mental health and wellbeing of Victoria's diverse communities for planning and funding purposes and to improve transparency in mental health and wellbeing outcomes for diverse communities;
    b. ensures that Victorians, regardless of first or preferred language, hearing, literacy or neurocognitive ability, have access to appropriate mental health and wellbeing information and means of communication throughout the mental health and wellbeing system;
    c. enables Victoria's diverse communities and community-led organisations to:

        - design and deliver mental health and wellbeing information and awareness campaigns; and
        - assist their communities to navigate the mental health and wellbeing system.

4. by the end of 2021, provide recurrent funding to Switchboard Victoria to deliver its Rainbow Door program, at scale, to support people who identify as lesbian, gay, bisexual, trans and gender diverse, intersex, queer and questioning to navigate and access the mental health and wellbeing system.
5. enable the development of digital technologies to support the delivery of language services that assist access to and engagement with mental health and wellbeing services.

21.1 A safe, inclusive and responsive mental health and wellbeing system for people from diverse communities

Victoria's population is diverse, growing and changing.[1] Victorians speak more than 200 different languages,[2] follow or practise a broad range of religions,[3] and identify with many characteristics based on age, gender, ability, sexuality, ethnicity and culture.[4] To effectively meet the needs of Victoria's diverse population, it is critical that the mental health and wellbeing system is safe, responsive and inclusive. Furthermore, it must have the foresight and capability to anticipate and respond to the needs of Victoria's evolving population into the future.

Victoria's mental health system has not delivered safe, responsive or inclusive treatment, care and support for many people from diverse communities and social groups.[5] The Commission heard compelling evidence of the many ways, large and small, that the system excludes people from diverse communities, and the consequences of this exclusion for mental health and social and economic participation. Witnesses also described to the Commission the detrimental impacts of discrimination—including discrimination experienced within, and through exclusion from, the mental health system—on their mental health and wellbeing.[6]

The Commission recognises steps the Victorian Government has taken to invest in and support the inclusion and participation of Victoria's diverse communities. The Victorian Government's stated position is that 'Equality is not negotiable in Victoria'.[7] The Victorian Government has clearly articulated the need to 'foster inclusion, participation and equality of opportunity [and to] redesign services to respond to the needs of diverse communities and remove barriers to participation'.[8]

In 2015 the Victorian Government established Australia's first (LGBTIQ+) Equality portfolio, overseen by a Minister for Equality, and a Victorian Commissioner for Gender and Sexuality (recently retitled the Commissioner for LGBTIQ+ Communities). The portfolio 'champions diversity and inclusion through developing whole-of-government policy and programs to support LGBTIQ+ communities' and is supported by an LGBTIQ+ Communities Taskforce that includes a Health and Human Services Working Group. The Victorian Multicultural Commission, constituted under the *Multicultural Victoria Act 2011* (Vic), aims to promote the full participation of Victoria's culturally diverse communities in the social, cultural, economic and political life of Victoria, including through equitable access to government services.

Recognising the distinct yet comparable strengths and challenges faced by diverse communities and social groups in Victoria, the current Victorian Government has also recently brought together the youth, LGBTIQ+, multicultural affairs, women's, disability and other portfolios within the Department of Families, Fairness and Housing.

Box 21.1 notes the other chapters of this report in which the mental health and wellbeing of specific communities and social groups are considered.

Box 21.1: Consideration of communities and social groups across this report

Throughout this report, the Commission has considered the mental health and wellbeing needs and experiences of many different communities and social groups. Other chapters within this report focus on:

- young people, as explored in Chapter 13: *Supporting the mental health and wellbeing of young people*
- older people, as described in Chapter 14: *Supporting the mental health and wellbeing of older people*
- Aboriginal communities, as explored in Chapter 20: *Supporting Aboriginal social and emotional wellbeing*
- people living in rural and regional Victoria, as described in Chapter 24: *Supporting the mental health and wellbeing of people in rural and regional Victoria*.

This chapter examines the experiences and mental health and wellbeing needs of people from Victoria's culturally and linguistically diverse communities, LGBTIQ+ people and people living with disabilities.

The Victorian Government must now bring the knowledge and intelligence of diverse communities—and supporting government portfolios—together with the Mental Health and Wellbeing Division of the Department of Health and the Mental Health and Wellbeing Commission. Together, a plan must be established to ensure the mental health and wellbeing system meets the needs of diverse communities now and into the future, putting the rhetoric around inclusive and responsive services into action.

Achieving this will require coordinated and systematic reform across every domain of the mental health and wellbeing system, including the funding, commissioning, design and delivery of services and the governance, leadership and workforces that underpin the system.

The Victorian Government must also enhance system-wide data collection and analysis and ensure there is transparency in relation to the mental health access and experiences of Victoria's diverse communities compared with the general population. The Victorian Government must establish system-wide accountability for the mental health and wellbeing of Victoria's diverse cohorts. It must also publicly report against targets—developed in consultation with diverse communities—that measure mental health and wellbeing outcomes for diverse communities and that demonstrate change over time.

At a minimum, improving mental health and wellbeing outcomes for Victoria's diverse communities will require:

- a reduction in all forms of stigma, discrimination, hate speech and vilification, as explored in Chapter 25: *Addressing stigma and discrimination*
- strategies to promote mental health and wellbeing and prevent mental illness that recognise and respond to the needs of diverse communities; this is described further in Chapter 4: *Working together to support good mental health and wellbeing*
- acknowledgment of the capacity of existing and emerging community leaders and community-led organisations to engage and support the mental health of their communities and to facilitate access to mental health services
- a mental health and wellbeing system that is safe, inclusive and responsive to all communities; this is explored further in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services*
- the availability of ethno- or cohort-specific specialist services to provide tailored mental health and wellbeing responses where required, as outlined in Chapter 5: *A responsive and integrated system* and Chapter 15: *Responding to trauma*.

The Victorian Government must invest in building partnerships with Victoria's diverse communities to identify community priorities and community-led solutions. The government should consider its investment in working alongside diverse communities as a necessary and effective mechanism to improve mental health and wellbeing outcomes for diverse populations.

The reforms proposed in this chapter are intended to build a future where all Victorians have an equal opportunity to experience good mental health and wellbeing. Victoria's future mental health and wellbeing system will ensure people from diverse communities receive safe, inclusive and responsive treatment, care and support, free from stigma and discrimination. The future system will also empower Victoria's many diverse communities and community-led organisations to support the mental health and wellbeing of their members.

21.2 Mental health of diverse communities

As outlined in the interim report, some diverse communities are both at an increased risk of experiencing mental illness in comparison with the general population and less likely to access mental health services. There are many factors that contribute to the increased risk of mental illness in diverse communities. The World Health Organization notes the increased risk of mental illness in 'population subgroups … because of greater exposure and vulnerability to unfavourable social, economic, and environmental circumstances, interrelated with gender'.[9] In evidence to the Commission, people from diverse communities and community-led organisations stated that experiences of discrimination and stigma negatively affect mental health and wellbeing and access to services; this is discussed further in sections 21.2.2 and 21.2.3.

The Commission recognises that people have and identify with many attributes. Everyone has many layers to their identity that affect their daily interactions, their access to power and privilege and their experience of mental health. This is sometimes referred to as 'intersectionality' (refer to Box 21.2).

Box 21.2: Intersectionality

The interim report identified intersectionality as a way to understand and respond to the diversity of Victoria's population. Drawing on the Victorian Government's 2019 *Everybody Matters: Inclusion and Equity Statement*, the interim report described intersectionality as:

> A theoretical approach that understands the interconnected nature of social categorisations—such as gender, sexual orientation, ethnicity, language, religion, class, socioeconomic status, gender identity, ability or age—which create overlapping and interdependent systems of discrimination or disadvantage for either an individual or group.[10]

Ms Adriana Mendoza, Manager of Victorian Transcultural Mental Health, emphasised the value of intersectionality as a framework for responding to diversity, telling the Commission:

> This will assist service providers to identify how overlapping identities can impact on a person's overall sense of self and how they are perceived within different social contexts. People have overlapping identities (such as 'female', 'migrant', 'person of colour') and these identity points do not exist independently of each other. Some identity points can result in privilege, while others can result in disadvantage. This may depend on the particular social context and how a particular identity point is perceived by society.[11]

21.2.1 Diverse communities in Victoria

LGBTIQ+ people

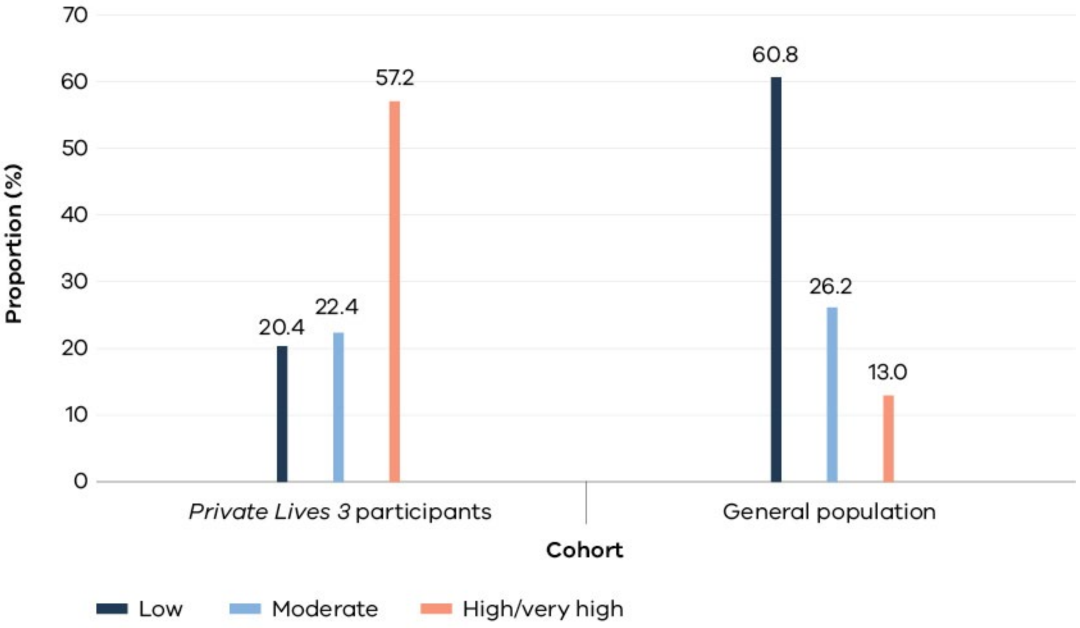
People from LGBTIQ+ communities are at greater risk of mental illness, self-harm and suicide than heterosexual and cisgender populations.[12] The 2017 Victorian Population Health Survey found that the proportion of the adult LGBTIQ+ population who had ever been diagnosed with anxiety or depression is 44.8 per cent, compared with 27.4 per cent of the total Victorian population.[13] Furthermore, the 2020 *Private Lives 3: The Health and Wellbeing of LGBTIQ People in Australia* report identified that 57 per cent of LGBTIQ+ survey respondents reported high or very high levels of psychological distress in comparison with the general population[14] (refer to Figure 21.1). The *Private Lives 3* report also identified higher rates of suicidal ideation (suicidal thoughts) in LGBTIQ+ respondents than in the general population[15] (refer to Figure 21.2). Younger LGBTIQ+ people are at particularly greater risk of suicide, with young LGBTIQ+ people aged 16–27 being five times more likely to attempt suicide than their peers.[16] Transgender people aged 18 or older are nearly 11 times more likely to attempt suicide in their lifetime, and people with an intersex variation aged 16 or older are nearly six times more likely to attempt suicide in their lifetime compared with the general population.[17]

Despite being at an increased risk of experiencing mental illness, the Commission heard that many LGBTIQ+ people are reluctant to use mainstream mental health services, often because of previous negative experiences with the system.[18] Research undertaken by the Lifeline Research Foundation shows that more than 71 per cent of LGBTIQ+ participants chose not to use a crisis support service during their most recent personal or mental health crisis. Many participants said this was because they expected to experience discrimination based on their sexuality, gender identity or another stigmatised or minority identity.[19] Past negative experiences of mental health services when young can deter transgender, gender diverse and intersex people from seeking treatment, care and support, despite having a higher risk of mental illness or psychological distress compared with the general population.[20]

In their witness statement, Ro Allen, Victorian Commissioner for LGBTIQ+ Communities, explained to the Commission that:

> Trans and gender diverse people face persistent challenges in navigating the health and mental health system. In part, this may be because people providing care and services were taught that gender incongruence is a mental illness.[21]

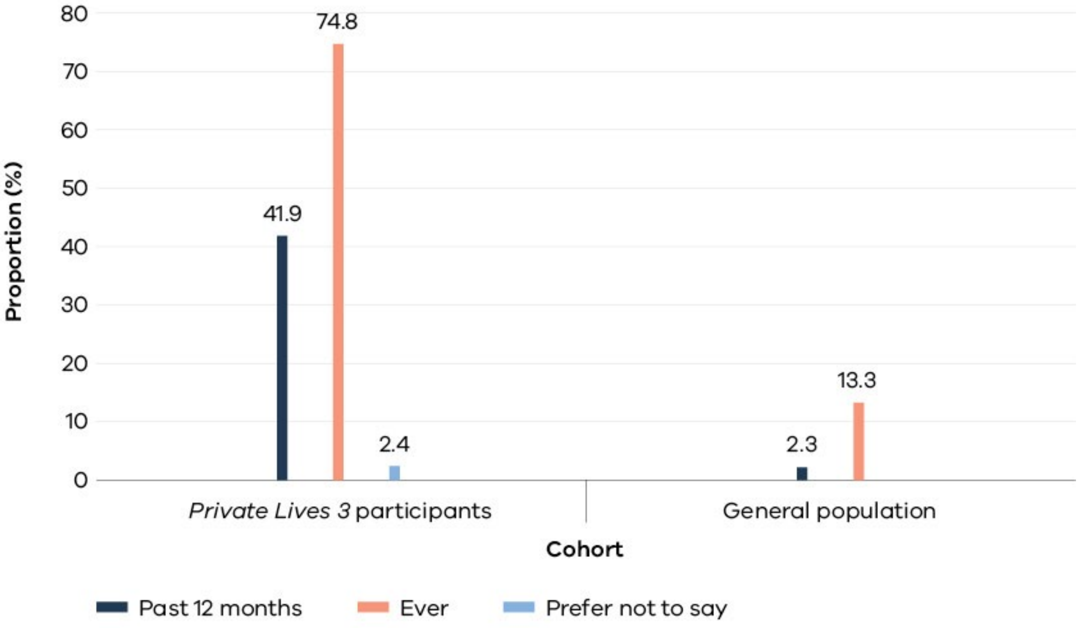
Figure 21.1: Proportion of *Private Lives 3* participants experiencing low, moderate or high/very high psychological distress, Australia



Source: Hill and others, *Private Lives 3: The Health and Wellbeing of LGBTIQ People in Australia* p. 46.

Note: Sample size n = 6,676. The Kessler Psychological Distress Scale was used to classify respondents as having either low, moderate or high/very high psychological distress according to criteria used by the Australian Bureau of Statistics.

Figure 21.2: Proportion of *Private Lives 3* participants experiencing suicidal ideation in the past 12 months, Australia



Source: Hill and others, *Private Lives 3: The Health and Wellbeing of LGBTIQ People in Australia* p. 50.

Note: Sample size n = 6,799.

Culturally and linguistically diverse communities

Some culturally and linguistically diverse communities are at an increased risk of mental illness. Research indicates that refugees and asylum seekers experience mental illness and suicidal behaviour at significantly higher rates than the general population.[22] They are also at greater risk of developing a range of psychological disorders including post-traumatic stress disorder, anxiety and depression arising from their pre-migration experiences or during settlement in Australia.[23] Mr Paris Aristotle AO, CEO of Foundation House, the Victorian Foundation for Survivors of Torture, described the extreme pre-arrival trauma experienced by some Foundation House clients:

> one of the key features of refugee trauma derives from the objectives of the persecutory regime from which people have fled. Such regimes use torture to deliberately remove control from people's lives in order to subjugate and make an example of them, thereby suppressing challenges to their authority by others.[24]
>
> The loss of control and constant threat of violence, characteristic of the refugee experience, creates a chronic sense of fear, intense anxiety and loss of hope for the future, often leading to severe depression.[25]

Due to a lack of available or quality data, it is difficult to estimate the prevalence of mental illness in culturally diverse communities.[26] The 2017–18 National Health Survey found that the prevalence of mental illness among people who spoke a language other than English at home was less than the general population (10.1 per cent compared with 21.6 per cent),[27] but this is likely to misrepresent the true level of mental illness in these communities. This is because, in addition to a lack of adequate data collected within mental health services, people from some culturally diverse communities may be reluctant to seek treatment, care and support due to stigma and discrimination.[28]

The Commission is aware that there are lower than expected numbers of young people from refugee and newly arrived migrant backgrounds presenting to mental health services.[29] Young people born in several regions outside Australia are at high risk of not obtaining the mental health services they need.[30] Overall, people from culturally diverse communities typically present to services when they have higher intensity needs, suggesting there are barriers to early intervention and care.[31] While being less likely to access mental health services, people from refugee and migrant backgrounds are more likely than the general population to be admitted to inpatient units[32] and are over-represented on compulsory treatment orders, making up 23 per cent of active compulsory treatment consumers in Victoria in 2019–20.[33]

There is also evidence suggesting that while international tertiary students living in Australia are at higher risk of experiencing mental illness,[34] they also underutilise healthcare and other support services.[35] An investigation by the Victorian Coroner's Prevention Unit noted that international students who died by suicide were less likely to have accessed mental health services than domestic students.[36] The investigation concluded there was 'an underlying systemic issue with engaging international students in mental health treatment in Australia'.[37]

People with disabilities

People with a disability or restrictive long-term health condition (conditions that restrict everyday activities) also have higher than average rates of mental illness. It is estimated that the prevalence of mental illness is as high as 57.9 per cent for people with profound or severe 'core activity' limitations (for example, limitations related to mobility, self-care or communication) and 42.2 per cent for people with other disabilities or restrictive long-term health conditions.[38] In comparison, around 13.7 per cent of people without these conditions live with mental illness.[39] It is estimated that between 20 and 57 per cent of people living with acquired or neurodevelopmental disabilities also have a mental illness, although it is likely that mental illness is underdiagnosed for people whose communication skills are limited.[40]

People with disabilities also face barriers to accessing appropriate treatment, care and support.[41] For example, research indicates a discrepancy between the prevalence of mental illness and the uptake of mental health services for people with disabilities.[42] Other research indicates that children with intellectual disabilities are less likely to receive mental health care in comparison with children in the general population.[43]

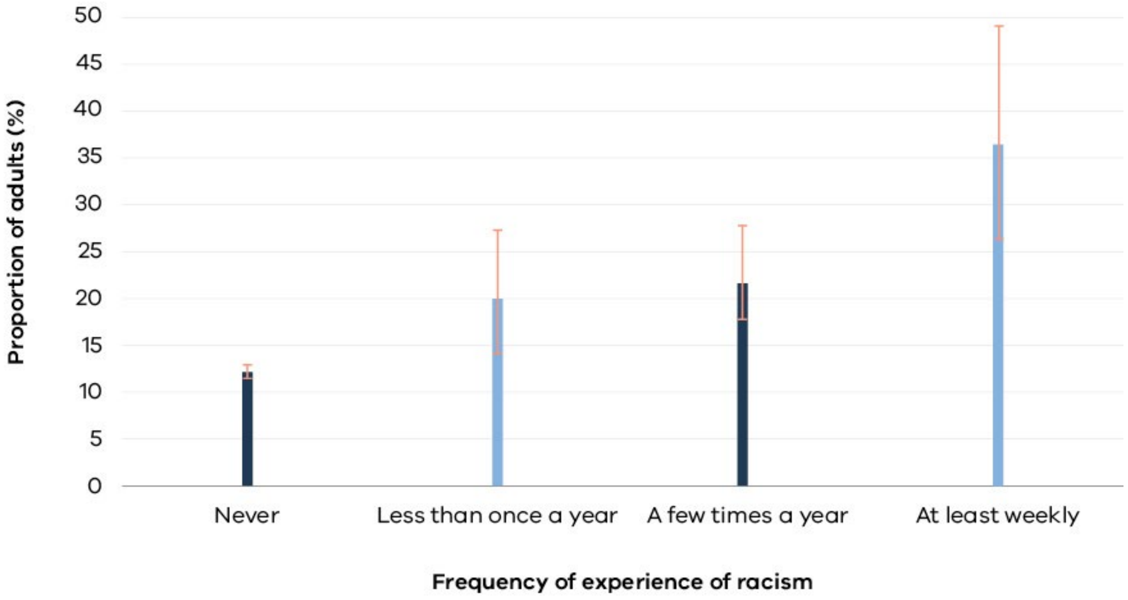
21.2.2 The impact of discrimination

The Commission has identified the need for substantial reform to reduce experiences of stigma and discrimination for people from diverse communities. Reducing mental health stigma within diverse populations is a key reform area for the Commission, discussed further in Chapter 25*: Addressing stigma and discrimination*.

The World Health Organization has identified discrimination as a factor increasing the risk of mental illness.[44] Research indicates a clear relationship between experiences of discrimination and increased risk of mental illness. For example, a meta-analysis that included 293 studies indicated a strong association between experiencing racism and reporting poorer mental health.[45] Findings from the 2014 Victorian Population Health Survey indicate Victorian adults who frequently experience racism are almost five times more likely than those who do not experience racism to have poor mental health (refer to Figure 21.3).[46] The findings also suggested that experiences of racism increase as socioeconomic status declines.[47]

The Commission has heard compelling evidence regarding the negative impact of discrimination on mental health and wellbeing and on a person's ability to access mental health services. Across many diverse communities, experiences of discrimination contribute to mental illness. For example, high levels of harassment and discrimination from strangers towards LGBTIQ+ people[48] and experiences of racism or faith-based discrimination among people from diverse faith or cultural backgrounds[49] are linked to psychological stress and other mental illnesses.[50] Experiences of discrimination for deaf and hard-of-hearing people are also linked to higher prevalence of mental illness.[51] Discrimination can also extend to the marginalisation of 'non-traditional' families, which in turn can make it more difficult for families, carers and supporters to support someone living with mental illness and maintain their own wellbeing.[52]

Figure 21.3: Proportion of adults with high or very high psychological distress by frequency of experiences of racism, Victoria, 2017



Source: Department of Health and Human Services, *Racism in Victoria and what it means for the health of Victorians*, 2017, p. 16.

Note: Data were age-standardised to the 2011 population of Victoria. 95% CI = 95 per cent confidence interval.

The minority stress model suggests that people from socially stigmatised population groups are exposed to unique chronic stressors that negatively affect their mental health and wellbeing.[53] As Ro Allen explained:

> LGBTIQ people do not suffer from poorer mental health by virtue of who we are, but rather because of experiences of discrimination and violence based on sexuality, gender identity or intersex status. This can include actual experiences of discrimination or violence, and vigilance against the possibility of discrimination or violence. This is sometimes referred to as 'minority stress'.[54]

For people with disabilities, experiences of discrimination, marginalisation, violence and abuse are associated with poor mental health.[55] Victoria's *Absolutely Everyone: State Disability Plan 2017–2020* identifies the impact of such minority stress on people with disabilities:

> Discrimination and a lack of inclusion have a negative effect on a person's health, both directly and indirectly. Constantly dealing with barriers, discrimination and negative attitudes brings about anxiety, stress and ill-health.[56]

Newly arrived or emerging migrant populations and asylum seekers may be at increased risk of being subject to racism, an experience that can be fuelled by negative media portrayals.

Professor Rob Moodie, Deputy Head of School and Professor of Public Health at the University of Melbourne, told the Commission:

> Mainstream Australia, particularly through the agency of tabloid media and shock jocks and shock janets, is incredibly effective in stigmatising and discriminating against certain groups. In relation to the recently arrived groups, South Sudanese people have been particularly targeted in Victoria.[57]

Mr George Yengi, a witness before the Commission, described how racism and discrimination negatively impacts on mental health in African migrant communities:

> Racism and discrimination also play a big part in contributing to mental health issues in my community. For example, these experiences are common in day to day life: someone sees a black African walking down the street and crosses the road; people act fearful in they see a group of young Africans walking together; and someone call the police because Africans are at the local park. These types of things take away that person's sense of belonging in Australia.[58]

More recently, the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) reported that enquiries about racism have increased since the COVID-19 pandemic began, with anonymous reports of racism during the early period of the pandemic in Victoria in 2020 more than doubling.[59] VEOHRC also identified a change in the nature of these reports, with increased reporting of discrimination and vilification, 'suggesting a shift away from racial discrimination at work or in employment towards racial abuse and other unfair treatment on the street, on public transport or online'.[60]

Discrimination is also a barrier to accessing treatment, care and support. Anticipated or actual discriminatory behaviour by health professionals may deter people from seeking help, particularly if they have had negative experiences of the system in the past. The Commission heard from the African Australian Communities Leadership Forum that:

> Black people see using mental health services as a degrading and alienating experience: the last resort. They perceive that the way services respond to them mirror some of the controlling and oppressive dimensions of other institutions in their lives, e.g. exclusion from schools, contact with police and the criminal justice system. There is a perception that mental health services replicate the experiences of racism and discrimination of African Australian and black people in wider society, particularly instances where individuals have experienced the more controlling and restricting aspects of treatment.[61]

LGBTIQ+ consumers may be reluctant to disclose matters relating to their sexual identity and relationships to mental health and related services if services are not considered 'safe spaces' for LGBTIQ+ people.[62] In the *Private Lives 2* survey, nearly 34 per cent of LGBTIQ+ Australians said they 'usually or occasionally' hide their sexual orientation or gender identity when approaching services to avoid possible discrimination and abuse.[63] Mind Australia told the Commission that LGBTIQ+ people report 'negative experiences of the health and mental health service system and medical professionals, ranging from ignorance to outright prejudice and discrimination'.[64] Furthermore, some LGBTIQ+ people in Victoria have been exposed to harmful conversion practices conducted covertly as counselling, psychology or religious activities; this is explored further in Box 21.3.

Box 21.3: Prohibiting conversion practices

In November 2020 the Suppression (Conversion) Practices Prohibition Bill 2020 was introduced into the Victorian Parliament to 'denounce and prohibit change or suppression practices (sometimes referred to as 'conversion practices') which describe harmful practices that seek to change or suppress an individual's sexual orientation or gender identity'.[65]

Commissioner for LGBTIQ+ Communities, Ro Allen, described conversion practices as 'typify[ing] out-dated and harmful beliefs about sexuality, gender identity and intersex status'.[66] This was echoed by a report by the Human Rights Law Centre, La Trobe University and Gay Lesbian Health Victoria, called *Preventing Harm, Promoting Justice: Responding to LGBT Conversion Therapy in Australia*, which found that 'conversion therapy practices … have had a major and lasting impact on the mental health and wellbeing … [including] depression, thoughts of self-harm and suicide, and more acute forms or mental ill-health triggered by particular interventions'.[67] Furthermore, the report found that conversion practices breach the right to health for LGBT people and represent a violation of the right to health enshrined in the *International Covenant on Economic Social and Cultural Rights*.

If enacted, the new laws will:

- establish of a civil response scheme established within VEOHRC
- promote understanding of the prohibition on change or suppression practices
- provide VEOHRC with the powers to consider and respond to reports of change or suppression practices from any person, as well as launch investigations where there is evidence of serious or systemic change or suppression practices
- introduce new criminal offences, including for people who subject others to change or suppression practices, and for any person who takes or arranges to take another person from Victoria for the purpose of subjecting them to change or suppression practices.

In the second reading of the Bill, Victorian Attorney-General, The Hon. Jill Hennessy, noted that:

> These are practices which have no basis in medicine; there is no evidence that sexual orientation or gender identity can be changed or suppressed. Not only are change or suppression practices ineffective, they are deeply harmful and can cause long-term mental health issues and, in the most tragic of cases, suicide. A disproportionate number of LGBTIQ+ people experience poor mental health outcomes and suicidality …

> Change or suppression practices often involve the subtle and recurrent messaging that with faith and effort a person can change or suppress their sexual orientation or gender identity. However, change or suppression practices are not only religious or faith based and can take other forms, including counselling, psychotherapy and support groups. In all cases however, these practices are based on a flawed ideology or pseudoscience that a person can be 'broken' due to their sexuality or gender identity. This could not be further from the truth.[68]

Witnesses also described to the Commission how discrimination can be provoked or influenced by public events or circumstances. Ro Allen described to the Commission the impact that public negative commentary regarding the Australian marriage law postal survey had for many people from LGBTIQ+ communities:

> The public debate was highly stressful for many LGBTIQ people, and, in my opinion, the negative public commentary further emboldened people to be hateful and violent towards LGBTIQ people.[69]

A study undertaken by the Australia Institute and the National LGBTI Health Alliance indicated that 'experiences of verbal and physical assaults (perpetrated against people who identify as LGBTIQ+) more than doubled in the three months following the announcement of the postal survey compared with the prior six months'.[70] The study also found an increase in reported anxiety, depression and stress among LGBTIQ+ people in the months following the announcement of the survey.[71]

Efforts to address discrimination are crucial to supporting good mental health and wellbeing for Victoria's diverse communities. Chapter 25: *Addressing stigma and discrimination* explores this in further detail, recommending a suite of reforms to address mental health discrimination. The Commission is aware that the Victorian Government has committed to a range of efforts to address discrimination more broadly including through initiatives delivered through its anti-racism action plan, the development of its LGBTIQ+ strategy, and efforts to reduce faith-based discrimination, gender inequality, conversion practices and hate speech. The Commission considers these efforts to be foundational to supporting the mental health of Victoria's diverse communities and encourages the Victorian Government to continue to resource and support these efforts.

21.2.3 Stigma in diverse communities

While stigma associated with mental illness or psychological distress persists throughout Victoria, in some communities the stigma is so great that mental illness is 'very much a hidden phenomenon'.[72] Talking about his experiences as an African migrant, Mr Yengi described perceptions of mental illness in the South Sudanese community as:

> almost like a taboo thing, it's not a thing. And it's like, you know, it's called a Westerner's illness. So, it's like a white person's thing, you know, because we don't know what it is; it's never explained to us when we're growing up and never explained that you may feel this.[73]

Similarly, the Centre for Multicultural Youth described a multicultural youth worker noting that 'we try to refer someone to headspace, and they won't go. There is stigma associated. Or the perception that "headspace is a place that white people go"'.[74]

Foundation House described the view of many of its clients from Syrian and Iraqi communities:

> Mental health is rarely spoken about within community. 'This is how I am' is a common view within community about mental health issues—a normalising reaction—it is a norm to be suffering.[75]

Attitudes towards mental illness may also stem from differences between how mental illness is treated within the health systems of some migrants' countries of origin. For example, in some countries, mental health services only extend to custodial or hospital treatment for very ill patients and psychotic consumers.[76]

Beliefs about other people's attitudes—particularly a fear that people with mental illness are viewed negatively—are part of the reason people do not seek help.[77] In its submission, Jewish Care suggested that the 'specific religious and cultural traditions of the Jewish community have at times created hurdles to the effective prevention, identification and support of individuals and families affected by mental ill health'.[78] These hurdles, which the Commission notes are not exclusive to the Jewish community, include an emphasis on keeping mental illness 'within the family' to avoid shame and concerns about the impact of disclosure in the small and close-knit nature of the community.[79]

Similarly, a witness, Mr Adwin Town told the Commission:

> Many Asian cultures, including Chinese culture, can be very conservative and inward looking when it comes to mental health … Chinese people often do not want to talk about mental health problems, as they do not want to be seen as abnormal. I believe that people in the Chinese community are much less open about mental health than people in Western communities. This conservative culture often means that when Chinese people have issues with their mental health they do not disclose them to their friends and family or reach out to help-lines or other available services.[80]

Experiences of stigma in relation to mental illness can be amplified by experiences of discrimination relating to other attributes such as gender, sexuality or disability.[81] For example, discrimination based on sexuality or gender may affect the mental health of those identifying as LGBTIQ+, especially young people.[82] In many parts of the Western world, homosexuality was itself considered a mental illness until the 1970s, and being trans or gender diverse was listed in the *Diagnostic and Statistical Manual of Mental Disorders* until 2018.[83] Stigma may also discourage trans people from accessing care. Associate Professor Michelle Telfer, a General Paediatrician, and Adolescent Medicine Physician and Head of the Department of Adolescent Medicine at The Royal Children's Hospital, explained:

> One of the main barriers preventing TGD [trans or gender diverse] young people from accessing mental health services is the feeling of shame towards their own identity and the shame of not conforming to society's expectations in relation to gender and gender expression. This is referred to as internalised transphobia and often manifests as a result of the negative experiences TGD people have when expressing themselves to their family, peers or broader society.[84]

In summary, the Commission agrees with the Multicultural Centre for Women, which noted that:

> The specific ways that mental illness is described, understood and experienced can be different across linguistic, ethnic and cultural communities, and can be shaped by shared beliefs about health, wellness and spirituality. However, the negative consequences of stigma and misinformation about mental health are universal.[85]

Personal story:

Aynur and Hafize Coskun

Aynur and Hafize Coskun are mother and daughter. Andy, their husband and father, respectively, migrated to Australia as a child and went on to build a life here. He died as a result of suicide after experiencing depression and psychological distress. Aynur and Hafize described Andy as being intelligent, smart, raw and loud. They said that he could get along with anyone.

But according to Aynur, everything changed in 2017:

> Andy came up to me and said 'Honey, I feel funny. There's something funny inside me; something is wrong inside'. He kept saying, 'There's something black. You don't understand'. He couldn't explain it to me.

Aynur and Hafize reflected that they come from a tight-knit community, but that they felt so much judgment after Andy's suicide. All of a sudden, people were looking for a reason and something to blame it on. Aynur recalled that time:

> We were not completely isolated, but we felt isolated from the community, because we felt so much judgement. The kids stopped going to Friday prayers. Going into crowded places like the mosque was hard, because we felt judged. People don't whisper quietly ... I needed someone to talk to, but no-one understood.
>
> In our religion, if a person takes his life, he's not accepted. You can't even do a prayer for your loved one and bury him.

After Andy's death, the family had many visitors—family, friends, neighbours, people from the community, people from the footy club and Andy's work. Aynur reflected that many of them cannot understand mental health, so they would speculate about other reasons for his suicide. 'It just showed that there is not enough awareness about mental health,' she said.

Aynur and Hafize said Andy had repeatedly sought help through the public mental health system, and had seen various health professionals in the lead up to his death, but he found the process very frustrating, as did the family. They did not get any information as carers about how to support or care for Andy at home.

> The hospital should have given us information. Even a pamphlet or a key contact number would have been helpful. There were enough of us in the room that if one of the doctors had said something to one of us, then one person would have picked up on what the other person didn't. They could have told us what to Google.

Despite all of the frustrations, grief and loss, the family has used their experience to raise awareness in their community. Aynur told the Commission:

> Having been through this, our family wants to raise awareness about mental health. [M]y son has hosted some fundraising boxing matches, and online challenges.
>
> But I think that there is a flaw in the system that is not simply a funds issue … All the money in the world is not going to fix the issues. We need to fix the problem … [T]he systems are already in place—they're just not working properly.

Source: *Joint Witness Statement of Aynur Coskun and Hafize Coskun*, 29 May 2020.

21.3 Experiences of diverse communities in the mental health system

The Commission recognises that individuals and specific social groups have unique experiences and challenges that negatively affect mental health and wellbeing, and that preclude access to mental health treatment, care and support. In examining these experiences, the Commission found that diverse communities share many common themes in their experiences of treatment, care and support. Key themes include lack of safety, responsiveness and inclusiveness and challenges navigating the mental health system.

The Commission also identified the important role of community-led organisations in providing treatment, care and support and helping community members to access safe, inclusive and responsive mental health care.

21.3.1 Lack of safety, responsiveness and inclusiveness

The Commission has heard compelling evidence that mainstream mental health services can be unsafe for people from diverse communities.[86] A submission from an LGBTIQ+ community organisation described how people from LGBTIQ+ communities, for example, are often 'hyper-vigilant and fearful of mainstream or universal mental health services'.[87] Katie Larsen, General Manager of Diversity, Inclusion and Participation at Mind Australia, told the Commission that for many people from LGBTIQ+ communities, 'the experience of accessing mental health services can be harmful and re-traumatising due to experience of stigma and discrimination, even when unintentional'.[88] Within inpatient settings, LGBTIQ+ people may experience discrimination from staff as well as abuse, harassment and violence from patients.[89] Transgender people can face particular challenges in accessing safe and secure services:[90]

> There are few places to obtain care in Victoria where trans and gender diverse people feel safe and secure, with such services largely being provided by a small number of specialist general practice, community health and hospital services that are concentrated in Melbourne.[91]

For asylum seekers and refugees, pre-arrival exposure to highly traumatic events, including torture,[92] increases the risk of mental illness,[93] which may then be exacerbated by the assessment and referral process within Victoria's mental health system. The Victorian Refugee Health Network explained:

> For people from refugee backgrounds this is problematic, as it relies on people telling their story, often of torture or other traumatic events, as part of the intake process, and then being referred to see someone else, where this story may need to be told again. This is re-traumatising, and functions as a barrier to engaging with mental health services.[94]

The Australian Federation of Disabilities emphasised the relationship between mental illness and experiences of trauma—such as violence, abuse and neglect—for many people with disabilities, and the harm then caused through 'coercion in the mental health system' by the use of seclusion and restrictive practices.[95] People living with autism have described hospital interactions in relation to mental health as 'ineffective, traumatic or destructive', commenting that they have felt 'profoundly misunderstood and unsupported when they had attempted to obtain care'.[96]

The Commission has been told that some health professionals displayed a lack of understanding of basic cultural safety. That is, care was provided without 'respect for culture, knowledge, experience, [or where there was] assault on a person's identity of dignity'.[97] For example, in some instances, LGBTIQ+ people take on the dual role of being treated by, as well as educating, the mental health workforce on LGBTIQ+ matters, particularly around (incorrect) assumptions that their mental illness is directly related to their identity, sexuality or intersex status.[98] The Y-Change submission cited a young transgender consumer who described feeling culturally unsafe within the mental health system:

> **When I started accessing services for help, no-one was educated enough to support me as a trans person. Barely anyone could even call me by my correct pronouns or the correct name. It made me feel so unsafe. I can't unpack trauma when I don't even feel safe in the room. I don't think it's too big of an ask that the mental health professional I'm seeing calls me by my correct name—I don't feel like I've ever been asking for a lot.**[99]

Deaf Victoria noted the difficulty of finding mental health professionals who understand deaf identity and the experiences of deaf and hard-of-hearing people.[100] The organisation noted that 'assessments and treatments used by mental health professionals are often not "deaf-friendly" and do not recognise the cultural and linguistic differences needs of these individuals'.[101]

The Commission also heard a range of evidence regarding the lack of access to appropriate language services and communications resources.[102] This poses a clear risk to the safety of people from linguistically diverse communities and consumers who face challenges communicating.[103] Access to and quality of language services is discussed further in section 21.4.

Access to inclusive services is also a challenge for people living with disability. Women with Disabilities Victoria discussed the inaccessibility of services for women with disabilities, including 'lack of physical access and a recurrent focus being on their disability, rather than their health concerns'.[104] Amaze described the lack of 'autism friendly environments' due to factors like the built environment, lighting, acoustics, design and the lack of provision of non-verbal communication as a barrier to accessing mental health services for people with autism.[105]

Mental health services were also described in submissions to the Commission as being almost exclusively 'Western'[106] in their approach to mental health and wellbeing, resulting in services that fail to adequately acknowledge or respond to the beliefs, experiences and needs of people from different cultures. Ms Mendoza discussed the differences in the way mental health is considered by some culturally diverse communities, and the impact of this on care:

> CALD [culturally and linguistically diverse] people are often conscious that their understanding of or views on mental health issues may be different to those of the mental health clinicians. This arises due to the existence of different explanatory models—that is, different ways of understanding what is happening in our body, our minds and what responses are needed.[107]
>
> CALD people may associate their mental health outcomes with their own beliefs, which are often connected to the individual's culture or religion. For example, a CALD person may believe that a challenge in their life reflects their relationship with God, whereas the relevant mental health clinician may not understand this association and approach the situation from another perspective. The result is that there are two different narratives with the potential to cause misunderstandings and barriers to effective service provision.[108]

The African Australian Leadership Forum recommended that:

> Western health practices and beliefs should be balanced against the health practices and beliefs of other cultures, absorbing and using different techniques where appropriate. We should also consider alternative strategies in casework: for example, group work and other therapeutic methods, and natural medicine.[109]

Similarly, Mr Aristotle described the benefits of 'using language that resonated on a more spiritual level, and incorporating rituals such opening and closing the group with prayer' for a support group for mothers, developed in collaboration with South Sudanese community members.[110]

As outlined in more detail in Chapter 19: *Valuing and supporting families, carers and supporters*, carers from diverse communities may also experience lack of safe, responsive and inclusive care within mental health services. Research indicates immigrant and refugee carers may face a lack of 'high quality, culturally appropriate and accessible support services'.[111] Tandem described the difficulties LGBTIQ+ family members can face being provided with information by health professionals.[112] Similarly, Carers Victoria told the Commission it had:

> been advised of examples where an [LGBTIQA+] carer with medical power of attorney has been ignored and dismissed by a doctor; and of other carers having to deliberately deceive hospital staff about their relationship with the patient in order to maintain contact during the hospital stay.[113]

At a roundtable hosted by the Commission with culturally diverse community-led organisations, one participant commented on the failure of mental health services to recognise and be responsive to the ways in which families are conceptualised in culturally diverse communities, explaining that:

> Fracturing of relationships is what the current mental health system does well. It does this not because staff don't care and because they need a cook book on culture to refer to as a how-to guide, but because the system supports a homogenous, monocultural, individualistic, biomedical approach to recovery with one of the world's most diverse populations.[114]

Overall, evidence submitted to the Commission describes a mental health system that frequently fails to listen to, understand or respond to the needs of Victoria's diverse communities. As summed up by a participant during community consultations:

> People from marginalised or priority groups, including migrant and refugee communities, report that when accessing mental health services, they do not feel heard, do not feel safe and do not feel understood.[115]

21.3.2 Navigating the mental health system

Many people told the Commission about the difficulties of finding and accessing timely and appropriate mental health services.[116] As outlined in Chapter 8: *Finding and accessing treatment, care and support*, the mental health system is complex, consisting of Victorian Government, Commonwealth Government, private and non-government services that are not well integrated.[117] In addition, the mental health system is not well connected to other support services that people living with mental illness and psychological distress often require, such as disability services, housing and social services.[118] This complex and fragmented system can leave people without access to appropriate and timely treatment, care and support.

These difficulties can be compounded by cultural and language barriers for migrant communities, and communications challenges for people who are deaf or hard of hearing, and people with limited communication skills.[119]

Dr Elizabeth Deveny, CEO of the South Eastern Melbourne Primary Health Network, noted that the current process for accessing services is convoluted and relies on people having the appropriate resources and language skills or being able to call on people who do, such as family:

> you may have a family member that lives in Warrnambool and in order to find services, you may have to contact multiple organisations and hope that someone answers the phone, knows what services exist and whether they are available. This also assumes that the consumer has the money and time to make calls, can speak English and, if it is a family member, is in a position to advocate for their relative in need of a service.[120]

In addition, consumers are sometimes responsible for 'building their own bridge between primary and tertiary [specialist] services in Victoria's mental health system', including transferring patient information between services.[121] This adds to the complexity of navigating services for diverse communities.

Personal story:

Rafi

Rafi* was 17 and living in Melbourne when he told his family overseas that he was gay.

> I was battling with my depression, and then I came out with my sexuality. I was born into a Muslim family, I left the religion, and I came out with my sexuality. So these two things turned everything upside down for me. My family disowned me, threatening to kill me.

Rafi's family stopped supporting him financially and he became homeless. The threats intensified and he said he felt helpless.

> In my home country the punishment for anyone who comes out as an LGBT person or in an LGBT relationship, they get killed in public on the street. And people have to see that so that they don't do it again or someone doesn't dare to do it. So when I say that I think I had it in my heart that I wanted to escape, I wanted to escape.

Rafi experienced trauma and mental health challenges from an early age.

> I'm brown, dark Indian brown, not Middle Eastern brown. So I put up with a lot of extended family abuse, trauma and torture for that. According to them, I am a weak child compared to a Middle Eastern strong manly child.

When Rafi was admitted to an emergency department after attempting suicide in Melbourne, he said that the staff did not believe what he was saying about his family, the threats and punishment he would experience in his home country. He also reflected on the cultural difficulties he faced while he was receiving treatment, care and support.

> Doctors used to talk in front of me as if I don't know any English. I'm not good at English, but still, they used to talk in front of me as if I don't know any English.
>
> I did not eat hospital food because I didn't grow up eating pork and things like that. I had a different food.

Rafi said that the doctors contacted his family overseas against his wishes and told them about his mental health challenges. He also said that staff planned to return him to his family, until the Department of Home Affairs and a psychiatrist intervened. Rafi described the importance of that intervention: 'If that senior psychiatrist had not trusted me, I would be dead today.'

Rafi has built a family of choice in Australia and spends his time volunteering and supporting others to access mental health supports.

Source: RCVMHS, *Interview with 'Rafi' (pseudonym),* November 2020.

Note: * Name has been changed to protect privacy.

The siloed nature of the mental health sector also makes it hard to access joined-up services that allow people to move between culturally safe mainstream and community-led services, such as those offered by LGBTIQ+ service providers.[122] The fragmentation of services can mean there is no clear entry point into the system or easily available information showing what culturally safe services are available for diverse communities, where these are located, and what the eligibility criteria are. One submission noted:

> Consumers who have been in the service system for some time commented on what a difference for the better it would have made if the knowledge they had now had been available to them when they first entered the system. As one consumer who now works as peer worker put it: There are a lot of things you learn after seven years [in the system] that would have been helpful to know in the first six months.[123]

For people with disabilities, who frequently rely on the help of carers or advocates to access services,[124] navigating between disability and mental health services is particularly problematic. Poor referral processes between services, and a lack of pathways in, out of and between mental health and disabilities services, can leave people without access to mental health care.[125] The Commission has heard that health professionals may also struggle to find appropriate mental health services for consumers with disabilities. Amaze told the Commission that not only do people with autism and their carers ‘find it hugely difficult to navigate the mental health system, but health professionals also find this challenging’.[126]

Navigating the mental health system can be particularly challenging for people with complex needs and those who have contact with multiple service systems, such as health, housing and employment. Dr Ruth McNair AM, a GP at the LGBTIQ+ friendly Northside Clinic, told the Commission she believes this is especially true for ‘emerging or marginal groups [who] have less ability to understand the system and to navigate the system … as well as being more marginal in terms of their mental health’.[127] Dr McNair further noted the difficulties faced by LGBTIQ+ communities in regional and rural Victoria:

> We also don’t have readily identifiable LGBTI expert counsellors in rural and outer urban settings, so I think this is a major limitation. And I see this in my client group: a lot of patients come to our clinic from rural or outer urban areas of Melbourne and Victoria.[128]

Lack of affordability is also an impediment to accessing services. From the perspective of transgender people, the Commission heard that:

> The cost to rural and regional people of accessing services, especially medical gender affirmation services, play a major part in limiting service access. In some cases, these services can be regarded as life-saving healthcare because of the associated risks of depression, self-harm, and suicide that trans and gender diverse people can face.[129]

Telephone and online support services are an important entry point to the mental health system for many consumers. However, technology-based services may not always be suited to members of culturally diverse communities, who can face language and cultural barriers and may lack access to the necessary technology.[130] Mainstream helpline and online services also appear less likely to be used by LGBTIQ+ communities.[131] Lifeline identified that '[t]here are a number of marginalised communities that Lifeline is aware are not accessing our crisis support services to the extent required.'[132] The Centre for Multicultural Youth also identified a lack of responsiveness among youth mental health websites, which demonstrate 'little if any acknowledgement of cultural diversity or of the additional barriers, or alternative understandings of mental illness offered'.[133]

21.3.3 The role of community-led organisations

As outlined in Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect*, communities play an important role in supporting the mental health and wellbeing of community members. The Commission recognises community-led organisations play a vital role in supporting diverse communities and delivering treatment, care and support, often outside formal government systems. The non-government, peer-led nature of many community-led organisations can be empowering for community members,[134] particularly for people who, for a range of reasons, have been unable to access care or who have not experienced safe, responsive and inclusive care in government services.

For migrant, refugee and asylum seeker populations, community groups and community-led organisations are a significant source of settlement support, including through the provision of housing, foodbanks, employment and language services.[135] For LGBTIQ+ people, who are twice as likely as non-LGBTIQ+ Australians to have no or minimal contact with their biological families,[136] community-led organisations across Victoria can be essential sources of social connection and peer support and advice. Ro Allen described the rise of LGBTIQ+ organisations in 'the face of discrimination and rejection from families and communities' and the community response to HIV/AIDS as 'testament to the resilience and focus of LGBTIQ communities'.[137]

Community-led organisations are an important source of stigma education and mental health literacy, as well as a range of community mental health supports. Submissions stressed the need for mental health services to work with a range of community mental health 'gatekeepers'—such as church and mosque leaders, youth groups and other community services—to provide tailored mental health literacy programs and offer opportunities for people to seek advice.[138]

Experts and community-led organisations have also impressed upon the Commission the essential role that such organisations play as conduits between community members and mental health services. As trusted sources of information and support, community-led organisations are often the 'front door' to mental health care for diverse community members. In its submission, Jewish Care discussed the important role of ethno-specific services as 'soft' entry points to mainstream mental health services.[139] These organisations can help consumers from culturally diverse or faith-based communities to overcome obstacles to accessing treatment, care and support, such as fear and mistrust of mainstream services, and cultural and religious barriers.[140]

Similarly, Ro Allen told the Commission:

> A vital element for success is LGBTIQ community ownership of design as well as the delivery of supports or programs. This is the notion of 'by community, for community' and is important to ensure sensitive and effective design and delivery. It also supports LGBTIQ community engagement and fosters LGBTIQ community willingness to connect with the support or program.[141]

The Commission also heard that Switchboard is an important source of LGBTIQ+ peer-led support.[142] Switchboard's programs, including its Rainbow Door program, are further discussed in a case study overleaf.

Despite the breadth of support offered by community-led organisations, the funding currently available to such organisations is insufficient to meet the demand.[143] The Commission understands that reliance on insecure government and philanthropic grants significantly limits the capacity of organisations to deliver services.[144] Short-term funding programs do not take into account the time needed to develop the necessary community trust and partnerships in diverse communities that is required for programs to be successful. Many community programs may only be beginning to gain momentum when their funding ceases.[145]

The African Australian Leadership Forum pointed out that predominantly grants-based funding of community-led organisations can disadvantage new and emerging communities:

> African Australian communities have limited experience in sourcing and managing funding or grants. There is a severe a lack of support for and guidance on applying for funding from mainstream budgets. Those that receive any … [are] time-limited [grants] and are too small or make any impact to do not run for long enough to allow evaluation of the possible impact of the project.[146]

Ms Mendoza also told that Commission that while smaller community-led organisations set up to support new and emerging communities are in a good position to work with people of culturally diverse backgrounds, 'they require external support, recognition and capacity building when it comes to responding to mental health, trauma and suicidal behaviour'.[147]

Case study:

Switchboard's Rainbow Door

Switchboard Victoria is a not-for-profit public benevolent institution (charity) and community-controlled service established in 1991. Switchboard supports the health and welfare of LGBTIQA+ people, their families, allies and communities. Examples of services provided by Switchboard include:

- 'QLIFE Teleweb Services', providing telephone/webchat peer support services for the LGBTIQA+ community
- 'Out and About', a statewide community visitors' scheme for older LGBTIQA+ people that seeks to reduce social isolation and build services' capacity to meet thee needs of older LGBTIQA+ people
- a suicide prevention program, which supports integrated research, training, community and partnership activities to address the complexities of suicide in LGBTIQA+ communities
- the QTIPoC Project, supporting capacity building within Switchboard and beyond to address the needs of QTIPoC (queer, transgender and intersex people of colour) communities.

In 2020, as part of the state's response to COVID-19, the Victorian Government provided 12-month funding for Switchboard's Rainbow Door program. Rainbow Door is a free helpline providing mental health information, support and referrals to LGBTIQA+ Victorians, their friends and families.

Sarah Marlowe, Chair of Switchboard Victoria's Board, said Rainbow Door was established to support people from LGBTIQA+ communities to access safe and inclusive care. Rainbow Door links LGBTIQA+ people and their supporters to culturally safe services for support with a range of areas including mental health, family violence, alcohol and other drugs, housing, sexual assault, elder abuse and general health. The service can be accessed via email, phone and text message.

Sarah explained that in the absence of safe and inclusive services, many in LGBTIQA+ communities, have formed networks of support for each other. However, Sarah noted that LGBTIQA+ communities also need access to mental health services.

> I love my community, as I love and am deeply committed to the value of peer support. But on their own, these things are simply not enough. LGBTIQA+ people need, and deserve, the additional support of specialist mental health and other services, and the safe intake and advocacy support required to access them.

Rainbow Door builds on the existing peer-driven support services to the community including QLIFE, a counselling helpline. Sarah said such services are critical to members of the community seeking support.

> Through my training and the work, I came to understand that 'peer' means safe. Callers often asked for reassurance that I was a member of the community. They felt safe to talk knowing I too had faced experiences like internalised stigma, and the challenges of coming out, of finding community and relationships, and of building a life as part of a minority community.

All Rainbow Door staff are experienced specialist workers with case management, suicide intervention and risk assessment skills. They can provide family violence risk assessment and safety planning and assist with access to LGBTIQA+ friendly services and connections to advocacy or advice.

Sarah said advocacy and support to navigate the service system is crucial, especially for people in urgent need of care, and that Rainbow Door helps to fill a critical service gap. Sarah also recognises that alongside LGBTIQA+ community-controlled organisations like Switchboard, mainstream mental health services play an important role in delivering care for LGBTIQA+ people.

> Mainstream services should always be an option, offering the empowerment of choice. However, in order for that choice to be realised, we need the state wide intake and referral service, Rainbow Door, which helps LGBTIQA+ navigate the mental health system with a peer and opens the way for LGBTIQA+ people to be referred into the services they need.

Source: Switchboard, *Correspondence to the RCVMHS*, 2020; Rainbow Door, About Us, <rainbowdoor.org.au/about-us>, [accessed 17 November 2020]; *Launch of the Rainbow Door*, speech by Sarah Marlowe, 28 September 2020.

Personal story:

Titan Debirioun

Titan is a 21-year-old recording artist who moved to Australia from Sudan in 2004.

He is part of a group that designs and co-designs music programs in his neighbourhood of Tarneit, in the west of Melbourne. Young people can 'drop in' to the program, which runs for four hours per week, be with their friends and learn how to make music. Titan said the music can help the young people talk about their emotions.

> A lot of the kids start making musical tracks where it's like 'I'm this, I'm that', focussing on surface level things, which is cool. But then after a while they start breaking that down and talking about everything else that's happening in their life. It becomes like a form of meditation—they get all their emotion out that they don't usually get out or they don't want to talk about.

Titan also works with Foundation House, a service that supports people from refugee backgrounds who have experienced torture or other traumatic events. He helps the South Sudanese community connect with mental health services.

> Foundation House wanted me to talk about how they could access the community better, how the program could serve the community better and how they could improve their services. I was able to see all the services that I never knew were available. I felt like there were services I might have used, or people in my neighbourhood, but we didn't know about it.

Titan's work with Foundation House involves acting as a bridge between organisations and his community. He talks to people about issues and services, runs workshops and talks to Foundation House about how it can better reach the community. Titan reflected that while his community is using services more, there is a way to go.

> The people they're really trying to reach have a distrust of services that's hard to break down—that takes time and we've been working on it for a while now. Building trust in communities has a lot to do with educating people about services, and not just about service[s], about mental health in general.
>
> So when young people go through things, the older generation is the one who is supposed to assist them and that's not happening because they don't know about mental health or they feel embarrassed about it or that it's something taboo.
>
> Services need to be reaching the kids that are at home saying 'I'm never going to talk to another person about my emotions', 'I'm never going to talk to this organisation' or 'white people don't understand me' because a lot of people feel like that.

Titan also works with the Centre for Multicultural Youth with young people and students from other migrant backgrounds. He is part of the Shout Out program, where he talks to organisations about how cultural and diversity training can help their workplace be more inclusive and culturally responsive. Titian spoke of the importance of supporting the mental health of the migrant community:

> I'm glad the Royal Commission is taking migrant mental health seriously and is starting to realise that there are holes and gaps. I think it is essential to start dealing with those holes and gaps because at the end of the day their future is Australia's future as well, so it's important to invest as much as you can to make sure they have equal ground mentally, physically, socially, economically—and the right to prepare themselves for what they want in the future and who they want to become.

Source: *Witness Statement of Titan Debirioun*, 19 June 2020.

21.4 Language and communications services

Communication between mental health staff and consumers is of paramount importance in the delivery of safe, and high-quality mental health treatment, care and support.[148] In mental health settings, consumers are often required to 'comprehend and express difficult and often subtle meanings concerned with emotional experience and interpersonal relationships'.[149] This is of course made significantly more challenging when mental health staff and consumers do not speak a common language or have a similar level of proficiency in a common language. In these circumstances, the work of a professional interpreter or translator to bridge the communication gap is of utmost importance.[150]

Many witnesses and stakeholders described the importance of interpreter services for effective communication between consumers and health professionals in mental health settings, noting that too often these services are not made available. As explained by Deaf Victoria:

> The mental health system as a whole is inaccessible for deaf and hard of hearing people, particularly those who use Auslan as their preferred language. Deaf and hard of hearing people who use Auslan have frequently complained about Auslan/English interpreters not being provided upon request, which is a common issue across the entire Victorian hospital and health sector.
>
> Hospitals are notorious for failing to provide Auslan interpreters upon request. Staff are not trained properly in regards to booking Auslan/English interpreters and often have the assumption that Auslan/English interpreters are not available after hours.[151]

Online and printed mental health resources are also frequently inaccessible for people who are deaf or hard-of-hearing. For example, online videos may not be captioned or produced in an Auslan version.[152]

Similarly, Ms Kylie Scoullar, General Manager of Direct Services at Foundation House, told the Commission:

> There needs to be effective communication between mental health professionals and persons with refugee backgrounds—this means that health services must engage qualified interpreters when required and translate health information/documentation.[153]

There are many issues that can result from a lack of access to, or use of, professional interpreters where one is required. In 2006 the Victorian Transcultural Psychiatry Unit published guidelines for working effectively with interpreters in mental health settings. The guidelines asserted that:

> Inadequate communication will limit the capacity of a mental health staff member to:
>
> - develop a therapeutic relationship
> - understand the experience and point of view of the client
> - understand the cultural context of behaviour
> - conduct an assessment
> - formulate a diagnosis
> - decide, together with the client, an appropriate program of treatment
> - monitor the illness
> - evaluate the effectiveness, and any adverse effects, of treatment
>
> Where communication between a mental health staff member and client is inadequate, diagnostic and treatment errors are to be expected. Such errors may include:
>
> - under-estimation or over-estimation of severity of psychopathology
> - failure to correctly identify the type of psychopathology present
> - diagnosis of psychopathology that is not present
>
> Inadequate communication will result in a limited or distorted understanding by the client of:
>
> - the role of the mental health professional
> - the role of the service
> - the nature of the illness
> - the purpose of treatment or medication
> - side-effects of medication.[154]

Throughout its deliberations, the Commission heard concerning examples of the use of family members—including children—to translate between mental health professionals and consumers,[155] which contravenes the (former) Department of Health and Human Services' *Languages Services Policy*.[156] The Ethnic Communities' Council of Victoria identified several ways in which the use of family members as interpreters can lead to poor outcomes:

> This practice has clear risks of miscommunication, and some patients may be unwilling to fully open up about their mental health issues in the presence of family members. Reliance on family can also be problematic because family relationships may be a cause of poor mental health in the first place (such as in cases of intergenerational conflict, separation and domestic violence). It is a practice that greatly increases the likelihood of adverse health outcomes.[157]

The Commission also heard of consumers being unable to request or access language services professionals of a certain gender; consumers being allocated interpreters who are not from the same cultural background; and interpreters lacking experience in the area of mental illness. Mr Aristotle described to the Commission the importance of interpreter choice in cases of sexual violence:

> Ensuring the client can choose the gender of their counsellor and interpreter is fundamental to enabling the client to feel safe and more comfortable. The ethnic and faith background of service providers may also be pertinent.[158]

Consumers in rural and regional communities face significant additional barriers to accessing language services. At the North Eastern Victoria Roundtable, participants told the Commission about the difficulties migrant communities faced in accessing proper health care due to the lack of interpreter services available in their primary language, and ignorance on the part of medical practitioners about the obligation to provide language services when required. One participant recounted a mental health care provider informing them that 'we don't know how to work with international people'.[159]

The same participant highlighted further problems faced by people living in rural and regional areas without proper access to interpreters:

> Services are refusing to use interpreters, or [claim that] the cost of interpreters is to be paid for by the patients themselves or the patient need[s] to come back later with someone from their family to interpret for them. Children are being used to interpret for patients in mental health appointments.[160]

Undersupply of services is also an issue in relation to some languages spoken by recently arrived migrants, where interpreters are not yet available in numbers sufficient to service their communities.[161] Another participant at North Eastern Victoria Roundtable noted that many of the humanitarian migrants in their region spoke languages that were relatively uncommon. The participant identified the lack of availability of interpreters in the appropriate languages for the communities that had settled in the region as a barrier to delivering care, noting:

> it's just about not being organised to have booked in the interpreters in time, they're not those common languages that you can just pick up the phone and get somebody on the end of the line.[162]

Foundation House cited a leader and elder of the Karen community (an ethnic group from Myanmar) who noted:

> I was rung one night by the hospital to interpret for a community member who had been admitted for mental health treatment because the hospital had been unable to get an interpreter.[163]

Participants at the North Eastern Victoria Roundtable also spoke of the need for more holistic settlement support for newly arrived refugee communities.[164] It was suggested that this support should include access to English language programs to develop more confidence in learning and studying and engaging in local community life, social and economic participation and support to understand and navigate the health system, including mental health services.[165]

One mental health professional explained:

> if CALD [culturally and linguistically diverse] community members could find jobs or a sense of purpose, a way to contribute positively to their community, my caseload would be significantly reduced.[166]

Another participant described a lack of resources to support settlement:

> [There is an] under resourced settlement model in this region, [a] lack of meaningful orientation to understand our health systems … leading to lack of prevention and treatment of mental health amongst this community … [W]e don't have the niche services that specialise in working with CALD [culturally and linguistically diverse] communities that are available in the other cities. Local mainstream mental health services are not equipped to work with CALD communities, [lack] competency and understanding of working with a cultural lens, cultural sensitivities and … trauma informed based best practice.[167]

Furthermore, evidence to the Commission emphasised the importance of providing communications that meet the cultural and literacy needs of different communities, which may require more than translating written material from English.[168] For example, the Victorian Refugee Health Network submission identified a lack of suitable mental health resources for people from refugee backgrounds, including resources to improve mental health literacy:

> Information in community languages is a current gap within the mental health and broader health system. This requires working with communities to determine the most appropriate messaging relating to mental health and mental health services and also the most appropriate means of communication. For some communities, this means the provision of written materials in community languages, for others this may be audio or pictorial resources. However, this must be tailored based on consultation with communities about which resources work or make sense to them, how the messages can be shaped to better meet their needs, and the most effective means of communicating information. It is important that information is not only provided through interpreters but through a range of other mediums.[169]

A lack of appropriate material can leave consumers and families without important information about diagnosis and care.[170] Foundation House told the Commission that clients had reported mental health services had removed them from their patient lists because the clients had failed to respond to appointment notifications in English, which they did not understand.[171] The organisation also noted examples of clients leaving hospital with discharge summaries (reports prepared by health professionals describing treatments received and future care needs) in English.[172] Foundation House cited a Karen community member who explained:

> I know of someone in the community who was discharged from hospital after treatment for mental illness. The discharge plan was only in English and the family was only given 10–15 minutes explanation at the hospital of what the patient needed at home. There were no home visits once the person returned home and the family really struggled to manage and there was enormous pressure and stress for all the family.[173]

21.4.1 The language services workforce in Victoria

In Victoria interpreters are typically engaged as independent contractors paid through a language services provider, although some hospitals employ in-house interpreters.[174]

Victorian Government policy states that interpreters and translators should have credentials from the National Accreditation Authority for Translators and Interpreters (NAATI) at the Certified Interpreter or Certified Translator level.[175] NAATI-approved tertiary training institutions, including RMIT University and Monash University, provide coursework ranging from diploma to postgraduate studies in interpreting and translating, together with professional development activities.[176]

Evidence to the Commission indicates that there are not currently enough professionally credentialled interpreters providing language services in mental health services.[177] For example, less than half of interpreter services within health settings in 2015–16 were delivered by interpreters with professional NAATI accreditation.[178]

The Federation of Ethnic Communities Councils Australia report, *Australia's Growing Linguistically Diversity: An Opportunity for a Strategic Approach to Language Services Policy and Practice*, identified significant variations in the number of NAATI-credentialled interpreters across new and emerging languages,[179] noting that with NAATI testing unavailable in some languages, 'language service providers recruit individuals to work as "interpreters" without credentials'.[180] The report identified the 'invisible cohort' of non-credentialled interpreters as concerning, noting:

> These workers expose agencies (including hospitals and courts) and their non-English speaking clients to significant risk. Quality of the language service, and understanding of the ethics and role of interpreters, will vary depending on the interpreter's previous experience and training. Agencies and organisations engaging non-credentialed 'interpreters' through language service providers are reliant on the providers for assurance of quality and expertise. While many organisational policies require a certain level of NAATI credential for interpreters who are sourced to provide language services (for example, professional level accreditation), in many cases where an interpreter with that level of accreditation is not available, a lesser accreditation will be accepted.[181]

The report also found that interpreting and translating sector is largely underpinned by casual employment and contracting,[182] with interpreters working across multiple language services providers to maximise workload.[183] The report identified that this industry structure provided little incentive for upskilling interpreters.[184] For example, language providers have a disincentive to fund upskilling of the workforce given that 'the benefit of any such investment will also be enjoyed by the company's competitors'.[185] The cost of NAATI testing can also be 'prohibitive' for many interpreters, particularly if they are not eligible for funding through the Commonwealth Government's FEE-HELP scheme.[186] As the report notes, '[f]or many, the cost of gaining a higher accreditation is not justified given the low income that they draw from working as an interpreter.'[187]

In 2020 a NAATI-certified specialist health interpreter accreditation program was introduced.[188] However, the Commission understands that accreditation does not specifically require knowledge of the mental health system or a command of mental health terminology.[189]

In its submission, the Ethnic Communities' Council of Victoria explained:

> interpreters are largely a subcontracted workforce, and … the ECCV is aware that interpreters are sometimes unwilling to provide their services for mental health consultations. Anecdotal evidence suggests that interpreters sometimes find the medical language complex to translate and the content distressing, particularly when there are personal traumas involved. It is important therefore to provide specialised training on mental health for interpreters, and brief them about how to manage their own self-care, and to provide opportunities for debriefing when it is desired.[190]

21.4.2 Victorian Government reviews of language services and health communications

In July 2016 the Victorian Government announced an independent review of Victorian Government procurement of language services.[191] The aim of the review was to:

> consider how the Government can best ensure access to the necessary volume and quality of language services (interpreters) to meet the current and future needs of Victorians from diverse linguistic backgrounds and also those who are Deaf or hard of hearing.[192]

The government has not made the findings of the review public. However, in July 2018 the government announced whole-of-government language services reforms to improve remuneration for interpreters and translators delivering services to government and funded agencies and who are employed on a casual/contract basis.[193] This included $21.8 million in funding for new minimum pay rates that equated to an approximately 30 per cent increase on the previous remuneration rates and a regional service charge to compensate for travel time to delivering services in regional Victoria.[194]

The government has also funded a general interpreter scholarship program since 2003. Each year, the scholarship program supports development of the language services workforce in languages where there is an identified or emerging need.[195]

Further insight into language and translation services for diverse communities in Victoria was provided by the Victorian Ombudsman in December 2020, with the publication of a report into the detention and treatment of nine public housing towers during the COVID-19 'hard lockdown' in July 2020.[196] This hard lockdown meant residents could not leave their homes for a period of up to two weeks.

The hard lockdown saw individuals, groups and organisations stepping forward to support community members, including to provide information and peer support, as well ensuring people were able to access culturally appropriate food.[197] However, the response exposed gaps in both the government's engagement with the affected communities, and in the delivery of culturally responsive health messaging and access to translation services.

In the first instance, the Ombudsman's report noted that the records of the Department of Health and Human Services appeared to underestimate the proportion of people living in the towers from non–English speaking backgrounds.[198] The report also identified that the decision to lock down the towers was made without consultation or engagement with multicultural community leaders,[199] which the Deputy Chief Health Officer acknowledged was not optimal. Consultation after this point was also 'reactive in nature, driven in part by community concern about the way the lockdown was announced and implemented',[200] although the Ombudsman noted that consultation and engagement subsequently improved.

Concerningly, the Ombudsman found significant delays in the distribution of translated written materials, which meant that 'materials explaining the purpose and terms of the lockdown in community languages were not distributed until the fifth and sixth days of the intervention'.[201] While qualified interpreters were embedded at the housing tower estates, they were not engaged until the second day of the lockdown. During that time, community members acted as informal interpreters.[202]

The Ombudsman explored the experiences of residents, some of whom did not speak English and did not understand the reason for the lockdown and for whom the experiences of law enforcement are associated with past negative experiences. The Deputy Chief Health Officer told the Ombudsman:

> Knowing the demographics of the populations in these towers, I was acutely aware … that these were populations which came from countries [where], when the police came knocking at your door, people disappeared and didn't come back. And, you know, not universally obviously, but there was a significant number of people who had been detained against their will before, who had been victims of torture under dictatorships, and that this was likely to cause significant trauma and distress for them.[203]

21.5 Transforming mental health and wellbeing treatment, care and support for diverse populations

The Commission recognises the Victorian Government's commitment to improving access to and the quality of treatment, care and support for diverse communities. This is evident in a range of legislation, policies and guidelines focused on diverse communities, spanning several decades, a selection of which are provided in Box 21.4.

These include legislation enshrining a range of rights for people from diverse communities; whole-of-government policies that support inclusion and equity and mental health service policies to provide health services with clear guidelines about their responsibilities in relation to delivering safe, responsive and inclusive treatment, care and support.

Box 21.4: A selection of Victorian legislation, policies and initiatives to support outcomes for Victoria's diverse communities

The Multicultural Victoria Act 2011 (Vic): The Act provides a whole-of-government framework that recognises the contribution of cultural, racial, religious and linguistic diversity in Victoria.[204]

Equal Opportunity Act 2010 (Vic): All Victorian Government departments and service providers have a positive duty under the Equal Opportunity Act to take reasonable and proportionate measures to identify and eliminate discrimination.[205]

Charter of Human Rights and Responsibilities Act 2006 (Vic): The Victorian Charter of Human Rights and Responsibilities Act sets out the basic rights of Victorians to live with freedom, respect, equality and dignity and requires public authorities to act compatibly with the Charter.[206]

The Racial and Religious Tolerance Act 2001 (Vic): The Act prohibits behaviour that incites or encourages hatred, serious contempt, revulsion or severe ridicule against another person or group of people because of their race and/or religion.[207]

The Mental Health Act (Vic): The Act sets out that 'persons receiving mental health services should have their individual needs (whether as to culture, language, communication, age, disability, religion, gender, sexuality or other matters) recognised and responded to'.[208]

Multicultural Policy Statement: This whole-of-government statement outlines a vision to enable every Victorian to participate fully in society, remain connected to their culture and ensure we all have equal rights, protections and opportunities.[209]

LGBTIQ+ Strategy: Development of a whole-of-government LGBTIQ strategy is currently underway. The *LGBTIQ+ Strategy* will guide the work of the Victorian Government to support equitable outcomes for LGBTIQ+ people in Victoria.[210]

State Disability Plan: This plan guides the Victorian Government's vision for an inclusive Victoria, which supports people with a disability to live satisfying everyday lives.[211]

Victoria's 10-Year Mental Health Plan: The plan states that the Victorian Government will design and deliver services and support in a way that promotes equitable access and safe and inclusive services for people with diverse cultural, religious, racial, linguistic, sexuality and gender identities.[212]

Language Services Policy and Accompanying Guidelines: *How to Work with Interpreters and Translators*: Supports the department and its funded services in responding to the needs of linguistically diverse people, including migrants, refugees and asylum seekers and those using a form of sign language. The policy identifies when language services should be offered to clients based on legislative requirements and best practice service delivery.[213]

Delivering a mental health system that responds to the needs of Victoria's diverse communities also requires an explicit focus on—and genuine, ongoing, engagement with—core concepts such as cultural responsiveness,[214] cultural safety[215] and cultural humility.[216]

The Victorian Government defines cultural responsiveness as:

> health care services that are respectful of, and relevant to, the health beliefs, health practices, culture and linguistic needs of diverse consumer/patient populations and communities. [Cultural responsiveness] describes the capacity to respond to the healthcare needs of diverse communities. It thus requires knowledge and capacity at different levels of intervention: systemic, organisational, professional and individual.[217]

Cultural safety, a concept often used when considering the needs of First Nations peoples, including Aboriginal people,[218] requires creating an environment:

> where there is no assault, challenge or denial of their identity, of who they are and what they need.[219]

Ms Mendoza also discussed the concept of cultural humility, which is 'the awareness that we do not have all the answers and need to learn from each other'.[220] Ms Mendoza added that 'culturally responsive practice recognises a dynamic and ongoing process of responding to diversity' and emphasised the importance of an intersectional approach to understand the needs of communities.[221]

Achieving system-wide delivery of safe, responsive and inclusive treatment, care and support means that responsibility simply cannot rest solely with individual mental health services.[222] The Victorian Government will need to address systemic challenges to improving access to and quality of care, and support health services to embed responsiveness in the planning, design and delivery of services. It must also ensure the mental health and wellbeing system has access to appropriate specialist services to support diverse communities. This includes high-quality communications and language services, secondary consultation services and specialist services for consumers where required. Figure 21.4 shows some of the key challenges to improving the responsiveness of the mental health and wellbeing system.

21.5.1 Building responsiveness across the system

While there are examples of individual mental health services and health professionals providing safe, responsive and compassionate treatment, care and support, the Commission considers that these efforts are largely undermined by inadequate system level support and accountability. This is despite the well-intentioned objectives of legislation, policies and guidelines to improve outcomes for Victoria's diverse communities and social groups, such as those outlined in Box 21.4. Ms Mendoza told the Commission:

> **While it is promising to see positive steps being taken by the mental health sector, this has not been standardised across the mental health system. This means that culturally appropriate services are currently driven by individual champions of change rather than by entire organisations or state-wide policies. Sometimes the authorising environment does not oblige or encourage organisations to adopt such services.**[223]

Evidence indicates that the current government requirements and reporting processes for access to and quality of treatment, care and support for diverse communities are insufficient to facilitate progress towards delivering responsive care.[224]

For example, the Victorian Auditor-General reported that while departments are required under the Multicultural Victoria Act to report annually to the Minister for Multicultural Affairs and to the Victorian Parliament on their achievements in multicultural affairs for the previous financial year, they 'cannot give assurance that their services are meeting client needs'.[225] It is not clear if or how departments and health services are using this reporting to improve service delivery. The Auditor-General concluded that 'current reporting requirements do not hold service delivery departments sufficiently accountable for their performance with culturally and linguistically diverse (CALD) communities'.[226] The Commission proposes that the Multicultural Affairs portfolio revises its annual reporting to more transparently demonstrate where service delivery efforts could be improved or lag in their responsiveness to culturally diverse communities. It should also include targets for reporting that are developed and agreed with service delivery departments.

Mr Aristotle identified a lack of strong measures associated with diversity and intersectionality within health services' Statements of Priorities, noting that without explicit expectations and accountability requirements, 'the risk is always present of resources being directed to areas (of a health service) that attract greater departmental, ministerial and public scrutiny'.[227]

Figure 21.4: Key challenges faced by mental health services in delivering culturally responsive treatment, care and support

Systemic

- Challenges to capturing cultural diversity in patient-centred care information systems
- Problems with data, measurement of performance, indicators and benchmarks
- The need for tools and instruments for assessing cultural competence in health settings
- Use of biomedical models of service delivery, which prevent holistic approaches to treatment (e.g. using traditional methods of healing)
- Absence of appropriate resources to embed and follow cultural responsiveness guidelines
- Invisibility of cultural diversity in major systems and procedures (e.g. policies and accreditation)
- Treatment of cultural diversity as an 'add-on' and token to the overall work of health services
- Integration and mainstreaming of diversity initiatives has resulted in the loss of focus on cultural diversity

Organisational

- Need for planning and reporting on cultural diversity
- Managing cultural diversity among competing priorities
- Lack of understanding about of cultural competence and failure to incorporate cultural diversity into all areas of core business
- Lack of support from the organisational leaders or management about cultural diversity responsiveness
- Absence of benchmarks and guidelines for successful outcomes in cultural diversity
- Lack of critical mass of some ethnic communities in regional areas to justify cultural diversity needs
- Lack of appropriate data and information on diverse clients

Professional

- Need to deliver culturally responsive services in busy environments
- Lack of training of professionals for cultural diversity (e.g. doctors, nurses, other staff)
- Limited effectiveness of interpreters or appropriateness of translations
- Absence of specialists and expertise to support cultural diversity work
- Difficulties with cross-cultural training (e.g. high costs, lack of impact across agencies)
- Lack of interpreters in some languages or regions

Individual

- Lack of understanding of cultural competence in health service settings
- Prejudicial attitudes to particular diverse groups
- Cultural diversity initiatives seen as 'special' treatment of diverse groups
- Inability to understand and work with cultural needs (e.g. male consent for female consumers)

Source: Adapted from Gurjeet Gill and Hurriyet Babacan, Developing a Cultural Responsiveness Framework in Healthcare Systems: An Australian Example, *Diversity and Equality in Health Care*, 9 (2012), 45–55.

Participants in the Commission's community consultations raised funding and procurement models as a mechanism to encourage engagement with diverse communities. One person said:

> At the moment, we don't have funding models that say: [we] will reward the system for being more responsive to culture [or] that … have anything in [their] accountability or service agreements … [that] says we're actually going to reward you for establishing and consolidating [a] relationship with this community. We don't have a funding system that establishes the core outcomes that we think will improve the situation for people more generally and encourages and rewards the system to find the answers and to be innovative.[228]

The Victorian Multicultural Commission also identified a need to strengthen departmental funding agreements 'to ensure that funded agencies monitor and report on the diversity of their clients/patients and compare them with the demographics of the area they service'.[229]

Evidence to the Commission identified a lack of data collection in relation to diverse communities and their access to and experiences of mental health services. For example, there is a lack of data related to sexual orientation, gender identity and intersex status collected in mental health services,[230] and a lack of detailed data about the experiences of LGBTIQ+ consumers within the mental health system.[231] Rainbow Health Victoria, Thorne Harbour Health and Switchboard Victoria explained:

> Historically, mainstream services and coronial processes have not gathered data that represents the experience of LGBTIQ people within the mental health and suicide prevention system, and staff have voiced a lack of confidence and competence in sensitively and appropriately asking these questions.[232]

There is also a lack of disaggregated data in relation to culturally diverse communities,[233] including whether interpreters were provided when required.[234] The Centre for Multicultural Youth stated that lack of 'up to date, accurate, publicly available settlement data'[235] is a barrier to planning, designing and delivering services for new and emerging communities. One participant in the Commission's community consultation described culturally diverse communities as 'invisible', noting the lack of health department reports containing specific data on the way people from migrant communities use the system. The participant concluded that 'what we know about outcomes for the general population we systematically don't know about immigrant and refugee populations'.[236]

Disabilities organisations also identified a need for improved data collection and reporting in relation to 'mental health needs, access to services and outcomes' of people with intellectual disabilities and for this information to be made 'publicly available and monitored'.[237]

Lack of coronial data in relation to diverse communities is also a barrier to understanding and responding to suicide. Deaf Victoria pointed to a lack of available data relating to suicide deaths among deaf people, which 'significantly hinders attempts to design, implement and evaluate suicide prevention initiatives for the Deaf community'.[238] Lack of coronial reporting in relation to LGBTIQ+ status also undermines efforts to address the disproportionate prevalence of suicide in among LGBTIQ+ people.[239] The Coroners Court of Victoria discussed the challenges of identifying suicide rates among culturally diverse communities due to variations in the way information relating to place of birth, languages spoken and cultural belonging is recorded in the Victorian Suicide Register.[240] The Coroners Court noted that they suspected they were not capturing all people who identify as members of LGBTIQ+ communities, and in the absence of 'any independent means to confirm gender identity and sexual identity [they] are unable to confirm whether [they] are under-reporting the frequency and, if so, how and why the under-reporting has occurred'.[241]

Strengthening system-wide accountability relies on sufficiently detailed and disaggregated data to understand levels of access, services used, experiences and outcomes of care relating to culturally diverse communities, LGBTIQ+ people and people with disabilities. In this context, disaggregated data means data that is broken down by different demographics and attributes relevant to diverse communities, which is important because aggregation can hide or mask information about specific populations. Detailed data is also an essential tool for planning and designing services that meet the needs of communities.[242]

21.5.2 Safe, responsive and inclusive mental health services

The majority of people from diverse communities access treatment, care and support within mainstream services, either out of preference,[243] or due to an inability to obtain alternative services.[244] The Commission heard that developing separate services for all cohorts is neither feasible nor desirable, and that mainstream services need to improve the way care is delivered for all Victorians:

> You can't build capacity within the system to address every minority. So, it's not about doing that. It's about recognising that the important element here is the attitude of the mainstream system towards minority [cohorts] and about how it is that the mainstream system in adopting a different attitudinal approach to minorities is able then to access the resources that are potentially available.[245]
>
> LGBTIQ+ consumers have the same spectrum of mental health issues as the general population and are entitled to be able to access safe, appropriate, mainstream services on the same basis as their heterosexual counterparts, without being discriminated against or traumatised/re-traumatised. In addition, the reality is that we cannot put the onus to cater to an entire population group on already tightly stretched specialist services, no matter how good they may be. And for many LGBTIQ+ people, for example those in rural areas currently, there will be little choice but to rely on mainstream mental health services at some point in their illness.[246]

Case study:

Victorian Transcultural Mental Health

Victorian Transcultural Mental Health advocates for cultural safety and responsiveness in mental health services for all members of the Victorian community. Dr Anita Tan, Manager of Victorian Transcultural Mental Health, explained that the unit helps services consider how mental health, cultural differences and structural inequities interact and implement practices and structures that promote equitable access to mental health services.

> Cultural safety is a key practice principle for providing person-centred, holistic and equitable mental health care and negotiating power in service encounters.

Victorian Transcultural Mental Health partners with clinical and community-managed mental health services to improve its cultural responsiveness to diverse populations. Collaborations between Victorian Transcultural Mental Health and a partner typically last around three years. The partnerships include a focus on engagement to understand the organisation's culture and environment, and sustainability to ensure there is significant and enduring change.

Victorian Transcultural Mental Health also delivers face-to-face and online learning that applies intersectionality and cultural safety to service design and delivery. Group learning includes reflective practice conversations, which help teams to respond to ethical challenges, and clinical discussions, which concentrate on the cultural identity of the consumer and how this may affect their mental health assessment or treatment options. The unit also engages directly with communities and their allies to build their capacity to talk about mental health issues and get the right support.

A companion website, LGBTQIntersect, promotes the development of culturally safe mental health services for LGBTIQ+ people from multicultural communities.

Dr Tan said that while people from culturally diverse backgrounds are well placed to identify their own needs and treatment preferences, they face significant barriers.

> It is important to acknowledge the cultural and social forces that silence people and curtail life opportunities. Service providers must learn from individuals, families and groups, about how they understand wellbeing, distress, and recovery and use formal support services and support networks. The onus is on professionals, organisations and service systems to provide safe spaces, understand the powerful determinants of social and emotional wellbeing, and build human solidarity.

Source: Dr Anita Tan, *Correspondence to the RCVMHS*, 2020.

As outlined in *Victoria's 10-Year Mental Health Plan*, mental health services are required to provide 'equitable access and safe and inclusive services for people with diverse cultural, religious, racial, linguistic, sexuality and gender identities'.[247] The Commission heard examples of organisations focused on delivering services that meet the needs of diverse communities. Witnesses and experts identified several core components of these services. These include:

- designing and delivering services that reflect the needs of different communities.[248] This requires organisations to understand the populations they are serving. For example, Mr Tass Mousaferiadis, Chair of the Board of Star Health, and Kent Burgess, Acting CEO of Star Health, told the Commission:

> Our view is that all sub-population groups (such as LGBTIQ+ people, culturally and linguistically diverse (CALD) people, women and young people) require a nuanced service. For a service to be truly inclusive for all those sub-population groups, and able to deal with a diverse range of needs, it needs to be able to reflect the communities that it is actually working with.[249]
>
> To acquire the knowledge of what your community needs, you have to understand who your community is. There are many ways you can do that, such as looking at simple demographic data, holding focus groups, doing consultations or holding community advisory forums. There is a whole range of tools and mechanisms that you can use to tap into and understand what your community thinks.[250]

- respecting the knowledge and expertise within communities and taking a co-design and co-delivery approach to mental health services. The Commission heard numerous examples of health services partnering with community organisations to provide culturally responsive care.[251] Ms Mendoza told the Commission:

> The mental health system can provide culturally appropriate services through pursuing meaningful partnerships between community mental health organisations. Nowadays where there is a tender for services, we see organisations identifying limitations in [their] services and choosing to collaborate with other organisations with the appropriate expertise. This in itself shows cultural humility, which is the awareness that we do not have all the answers and need to learn from each other.[252]

- recognising and respecting a diversity of conceptions of mental health. Mr Aristotle stressed the need for providers to 'be aware of their own (and their organisation's) world-views, values, philosophies and explanatory models, as well as those of service recipients and their communities'.[253] A health professional in a roundtable of culturally diverse organisations also identified the need for a cultural shift across the mental health system:

> There is no doubt that we need to invest in increasing the size of the mental health workforce but we also need to invest in qualitative aspects of care, especially in relation to cultural safety for our diverse population. However, equally we need to invest in initiatives that will result in a cultural shift in the mental health system, where lived experience, diverse explanatory models and cultural perceptions of mental health are valued equally alongside the clinical knowledge and expertise of our workforce.[254]

- embedding cultural responsiveness in health professional education and training. This would ensure services are respectful to, and understand the basic needs of, diverse communities, including the capability to refer clients to appropriate services. This includes understanding the importance of inclusive language, such as avoiding assumptions of heterosexuality and cisgender identity.[255] In discussing the needs of LGBTIQ+ people, the Mind Australia submission refers to this as 'LGBTIQ+ 101 … to ensure there is a no harm approach and a basic level of cultural safety is provided'.[256]
- creating safe and welcoming spaces for diverse communities. Dr Mariam Tokhi, a GP at DPV Health, explained in a personal capacity the positive impact of recognising diverse communities in the physical environment of health services:

> Healthcare spaces can be really important meeting spaces and support spaces for people on the margins. We need to make sure that there is overt welcome and cultural safety for people who are in minorities and who are struggling. For example, it can be really valuable to have an Aboriginal flag, a rainbow sticker or a 'Refugees Welcome Here' sign in the waiting room. And for those things to be more than tokenism, there needs to be a reflection that people are invited to share their struggles and hopes for their health and wellbeing here. These tokens signal that there are trained medical professionals—and administrative and allied health staff here—who can demonstrate realness, respect and care for people from different cultures.[257]

- employing representative workforces. The Centre for Multicultural Youth identified the benefits of bicultural workers for young people and families:

> Bicultural mental health workers are important resources in the mental health service system. These roles are critical in 'brokering'—that is, building trust and helping young people and families navigate mental health services, and helping services more adequately respond to these communities.[258]

Ms Nicole Bartholomeusz, the CEO of cohealth, told the Commission:

> At cohealth, we attempt, as much as possible, to ensure that our workforce reflects the communities that we serve to bring a level of cultural safety into the workplace. For example, if a client of Sudanese or Burmese background attends one of our clinics, they see one of their own people. Or, if someone who has been unemployed long term, has alcohol and drug issues, walks into a clinic, they should work with a peer worker who has the same kind of social experience or background. This is about breaking down barriers between client and care provider. We have seen that when people walk in the front door and see their own people, or people they can feel comfortable with, it breaks down the barriers between client and care provider, and the client achieves much better outcomes.[259]

- promoting accountability for cultural responsiveness at the leadership level within organisations. Ms Mendoza stressed the importance of leadership to ensure that good practice is not reliant on individual clinicians:

> Those in leadership roles play a crucial part in developing sustainable policies and practices within the mental health system. By having leaders learn about how their organisation can be more culturally sensitive and responsible, these practices are more likely to continue beyond the tenures of individual clinicians and workers. Clinicians and interpreters who work directly with [culturally and linguistically diverse] people need good practices embedded in the system.[260]

In her witness statement, Dr Mariam Tokhi described to the Commission the core components of a responsive health service (refer to Box 21.5).

Box 21.5: Hallmarks of a health service that is responsive to diversity—Dr Mariam Tokhi

> A service that is responsive to diversity has an underpinning mission to serve all people in its community. In order to do that, the service actively gathers information about the needs of community members and patients, so that it can recognise the challenges and understand better the barriers that vulnerable populations and outpatients face in accessing quality health care.
>
> A service that is responsive to diversity has an ethos of treating all people with respect and warmth. It works in partnership with those people, rather than working hierarchically. It has flexible engagement with clients and referrers, recognising that people who are out of the mainstream face extra challenges with understanding and engagement, and so need that flexible engagement.
>
> A service that is responsive to diversity has skilled staff across administration, program management and in clinic areas who are sensitive to the challenges that vulnerable patients face. Having sensitive staff is easier said than done because you really need to upskill staff across all kinds of perspectives in the service.
>
> We need ready access to interpreting services and community liaison support. We need the ability to actively follow up clients who are difficult to engage. Follow-up might happen through community support workers, case support workers or liaison officers.
>
> A team approach to healthcare provision is really important in order to understand diversity and to work through the challenges of meeting different people's needs. As part of that team approach, there needs to be support and linkages between clinicians, non-clinical support workers and patients, so that we can request and give help to people who need it.[261]

21.5.3 Access to specialist care

The Commission considers that statewide services for diverse communities are critical to supporting people with higher levels of need, and it has identified several roles for statewide services within the reformed mental health and wellbeing system, as outlined in Chapter 5: *A responsive and integrated system*. These roles include sharing expertise with Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services so that people can receive treatment, care and support close to home; working with these services to deliver treatment, care and support through, for example, shared care arrangements; and to deliver services directly.

Statewide services are an important source of treatment, care and support for many people within diverse communities. Examples of these include services supporting:

- refugees and asylum seekers, such as Foundation House, Cabrini Asylum Seeker and Refugee Health Hub Specialist Mental Health Service and Monash Health Refugee Health and Wellbeing
- people with dual disabilities, such as the Victorian Dual Disability Service at St Vincent's Hospital, Melbourne,[262] the Centre for Developmental Disability Health at Monash and two Mental Health and Intellectual Disability Initiative programs
- transgender people, such as the gender clinics at Monash Health and The Royal Children's Hospital.[263]

In addition to services offering treatment, care and support, statewide services can support other mental health services to improve the safety and responsiveness of their treatment, care and support. An example of this is Victorian Transcultural Mental Health Services, which is discussed in a case study in this chapter. The Commission also heard evidence in relation to the benefits of programs such as the Rainbow Tick accreditation system,[264] 'which organisations can use to assess how [LGBTIQ+] inclusive they are and identify areas for improvement'.[265]

As discussed in detail in Chapter 5: *A responsive and integrated system*, there is limited data available to understand demand for specialist services,[266] and underinvestment has constrained the growth of services. Evidence indicates that specialist services are unable to meet growing demand for some diverse populations.[267] Foundation House identified 'considerable capacity constraints' in relation to specialist clinical services, which affects their capacity to provide specialist supports to mental health services and to deliver care directly to clients.[268] As discussed in Chapter 28: *Commissioning for responsive care*, the department will develop a plan for each statewide service, which will include planning for statewide trauma and dual disability services.

Personal story:

Alex Smith

Alex* moved to Melbourne in 2004 and has worked in Melbourne and in regional Victoria. Alex identifies as a trans masculine person.

Alex's first interaction with the mental health system was around 2009, at 25 years of age. Alex described being admitted to the emergency department of a large public hospital after self-harming.

> I remember that I was told by staff in the emergency department that I was very silly and that I shouldn't do this again because the hospital needed the beds for people who were actually sick. I was discharged from the emergency department and there was no follow-up in relation to my mental health.

At about this time, Alex signed up for counselling provided by a specific LGBTIQ+ health service. Alex self-referred based on online research. While Alex found that the counsellors were helpful, they were students who moved on quickly. Alex experienced this high turnover of counsellors at a number of community services over the years and said it was tiring to have to retell their story.

In 2010 Alex contacted an employee assistance program and told them about feelings of discomfort associated with gender identity.

> The counsellor I spoke to told me that they didn't have the expertise in matters of gender …. They did not offer a referral to another service. After this experience, I didn't call my work's employee assistance program again. I felt ashamed and rejected following this experience, and I did not disclose my gender-related issues to a mental health professional for another [six] years.

After some time interstate, Alex returned to regional Victoria.

> At this time, I really needed mental health support … I didn't try to access any counselling or mental health services in my region because … I believed that it would be more likely that I would encounter ignorant and discriminatory attitudes about my gender identity, which made me feel really isolated and distressed.

Later, when trying to access specific LGBTIQ+ services in Melbourne, Alex experienced long waiting lists.

> I was only able to access counselling services over the telephone after approximately two months of being on the wait list. This was too little and too late … I believe things might have turned out very differently if I had received appropriate counselling during this time.

Alex found support when transitioning by accessing an online peer support group run by a Victorian trans and gender diverse advocacy organisation.

> This group was absolutely vital to me … as I was able to access health information and practical and emotional support from a community of peers having the same experiences that I was having.

Alex would like to see a publicly accessible database of mental health practitioners who are trans and gender diverse–aware, as well as peer support for trans and gender diverse people interacting with emergency departments and acute mental health services. Alex would also like to see LGBTIQ+ awareness training that covers the unique needs and experiences of trans and gender diverse people, and a better conversation about managing privacy in LGBTIQ+ specialist mental health services.

Source: *Witness Statement of 'Alex Smith' (pseudonym),* 17 July 2019.

Note: * Name has been changed in accordance with an order made by the Commission.

Specialist services for transgender and gender-diverse people have reported significant increases in demand, leading to long wait times for care.[269] The Victorian Government's Lesbian, Gay, Bisexual, Trans, Gender Diverse, and Intersex Taskforce found:

> Waiting times for both paediatric and adult services are unacceptable ... Some people with very complex mental health conditions require much more specialist multidisciplinary support than they receive while waiting for service access. The significant risk of suicide by [trans and gender diverse] people on waiting lists was discussed. The [trans and gender diverse] community is concerned about an increasing number of people accessing mental health services in severe distress.[270]

The report also noted that:

> Access for [trans and gender diverse] people from culturally and linguistically diverse backgrounds was ... especially problematic. Monash Health representatives reported there are 201 languages spoken within its general referral population.

In Chapter 5: *A responsive and integrated system*, the Commission suggests that, in the immediate term, the Victorian Government will need to address the underinvestment in services, and that the expansion of services will need to be informed by planning that ensures additional resourcing goes to the areas of greatest need. The Commission asserts that the need and demand for diverse cohort-specific specialist services must be a key consideration in future planning and investment in specialist services.

21.6 A new approach to supporting the mental health and wellbeing of Victoria's diverse communities

A key tenet of the Commission's recommended reforms is the right for all Victorians to access safe, responsive and inclusive treatment, care and support. The reforms recognise the need for a fundamental shift in the way mental health and wellbeing is understood and the way mental health services are designed and delivered. More broadly, the Commission recognises that access to safe, responsive and inclusive treatment, care and support is only one factor that influences a person's mental health and wellbeing, and that it will take the collective effort of the Victorian community and a range of government departments and agencies to effect change.

Mental health and wellbeing services must offer treatment, care and support that responds to the diverse needs of the many communities and people they serve. To meet these needs, the Victorian Government must ensure the needs of diverse cohorts are at the centre of planning, strategy, monitoring and leadership. Put simply, improving mental health and wellbeing system access and equity of outcomes for Victoria's diverse cohorts will require far more than good intentions.

Inequity of mental health outcomes between social groups is neither inevitable nor intractable. During its deliberations, the Commission heard of several examples of innovative programs and initiatives designed to support the mental health needs of Victoria's diverse communities.[271] Many of these initiatives have been led by community leaders, community-led organisations or individual mental health services. While these initiatives are commendable, the significant and persistent inequities in access and equity of outcomes between diverse populations and the broader population point to the need for a systemic approach to supporting the mental health and wellbeing of diverse communities. As described throughout this report, the 'one-size-fits-all' approach that characterises much of the current mental health system must be replaced with a system that responds respectfully and compassionately to all Victorians. This includes planning, designing and delivering care in partnership with local communities, and providing timely specialist services for those who need them.

As described in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services*, community mental health and wellbeing services will be expected to deliver programs that provide tailored treatment, care and support to specific local communities. These programs will have an in-depth understanding of the community-specific services that operate in their area. Through appropriate planning processes, Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will identify, develop and deliver programs or supports for specific groups in their communities. Such programs or supports will typically be for people whose needs are not being met in mainstream services, and who are at risk of high levels of poor mental health.

The Commission expects that responding to the needs of Victoria's diverse populations will be the core business of mental health and wellbeing services. Furthermore, because no two communities in Victoria are alike, services are expected to offer specific programs in addition to offering treatment, care and support that responds to diverse needs within their local communities.

The Commission considers that providers, including provider partnerships, will deliver safe, responsive and inclusive care in the reformed mental health and wellbeing system, as outlined in Chapter 28: *Commissioning for responsive services*. Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will be expected to partner with providers to deliver services that meet the needs of the communities they serve. They will be encouraged to form partnerships, including with organisations that deliver cohort or population-specific services.

The recommendations made in this chapter provide direction on the additional, deliberate actions the Victorian Government must take to improve mental health and wellbeing treatment, care and support for Victoria's diverse communities. They have been designed to ensure the unique needs of Victoria's diverse populations and social groups are front and centre of broader reform efforts. The reforms also aim to ensure the performance of government in reforming the mental health and wellbeing system is measured not only by improvements to mental health and wellbeing outcomes overall but also its reduction of inequity of outcomes across Victoria's social groups.

21.6.1 Increasing accountability for the delivery of safe, responsive and accessible treatment, care and support for diverse communities

There is a clear need for increased accountability in relation to improving access to, and the quality of, mental health treatment, care and support for Victoria's diverse communities. Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance* outlines the Commission's recommendations for establishing effective governance and strengthening the accountability of Victoria's mental health and wellbeing system. It establishes that a Chief Officer for Mental Health and Wellbeing, appointed in legislation and reporting to the Secretary of the Department of Health, will be the system manager of the mental health and wellbeing system. Additionally, the government will be held to account through establishing a new statutory Mental Health and Wellbeing Commission.

The recommended arrangements will ensure mental health and wellbeing services are responsive, high quality, safe, integrated and coordinated, and that appropriate priority is given to mental health and wellbeing in government decision making. Critically, the reforms also recognise that people who use the system can provide great insight into challenges and opportunities, and they should lead and inform decision making.

It is the Commission's position that delivering a mental health and wellbeing system that is accessible, equitable, transparent, accountable and responsive to the needs of Victoria's diverse communities is the responsibility of the most senior levels of system leadership. Accordingly, the Commission has determined that the Chief Officer for Mental Health and Wellbeing will be responsible for delivering a mental health and wellbeing system that promotes equities of outcomes, among other functions referred to in Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*.

Under these arrangements, the Chief Mental Health and Wellbeing Officer will be required to:

- plan, develop, commission and promote at the state level a range of services in relation to mental health and wellbeing and suicide prevention and response that are person-centred, human rights–based, comprehensive, integrated, safe, inclusive, equitable, free from stigma, and responsive to Victoria's diverse communities
- collect, compile and analyse data about mental health and wellbeing services for the purposes of:
    - planning, funding, managing, monitoring, evaluating and improving mental health and wellbeing services provided by mental health service providers
    - improving understanding of the mental health and wellbeing needs and the service use of diverse communities to improve access and equity of outcomes
    - conducting research into mental illness, mental health and wellbeing, and related fields.

The Commission expects that these changes will significantly elevate the mental health and wellbeing system leaders' focus on Victoria's diverse communities and social groups for several reasons. First, as described in Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*, the Chief Officer for Mental Health and Wellbeing will perform the functions of the Secretary, as specified in the new Mental Health and Wellbeing Act. The Chief Officer will ensure the mental health and wellbeing system responds to diverse communities and supports equity of access and outcomes. Given that the Chief Officer is a statutory appointment at Deputy Secretary level that reports to the Secretary of the Department of Health, this position will ensure there is clear accountability for delivery of a mental health and wellbeing system that serves Victoria's diverse communities. This requires effective and senior leadership from the Chief Officer.

Second, as also described in Chapter 27, the Mental Health and Wellbeing Commission will play a fundamental role in holding government to account for the overall performance, quality and safety of the mental health system, including public health and prevention efforts. The Mental Health and Wellbeing Commission will need to give due consideration to the system's performance in delivering services that meet the needs of Victoria's diverse communities, and in reducing inequity of access and outcomes compared with the broader population. Furthermore, given the powers conferred to it, it will be uniquely placed to identify and inquire into matters relating to the performance, quality and safety of the mental health and wellbeing system for diverse communities, if and as it sees fit.

Third, as described in Chapter 26: *Rebalancing mental health laws—a new Mental Health and Wellbeing Act*, the recommended primary objective of the new Mental Health and Wellbeing Act will support efforts to focus on the good mental health and wellbeing of Victoria's diverse communities and social groups. For example, the Act will include a primary objective to achieve the highest standard of mental health and wellbeing by:

- promoting conditions in which people can experience good mental health and wellbeing
- reducing inequities in access to, and the delivery of, mental health and wellbeing services
- providing a diverse range of comprehensive, safe and high-quality mental health services.

This will encompass the need for mental health and wellbeing services to be respectful of, and to take into account, the needs, preferences and values of culturally diverse communities.

Fourth, the Chief Officer will also undertake a strong stewardship role in supporting the new Regional Mental Health and Wellbeing Boards to successfully perform their functions. With responsibility for planning, funding and monitoring mental health and wellbeing services that are inclusive of diverse communities, the Chief Officer will ensure Regional Boards understand the current and anticipated diversity of their regions, assess the needs of their regions with that in mind, and fulfil their objectives. This includes the commissioning of ethno- or cohort-specific services and with due consideration of the needs of diverse communities.

Finally, the Secretary will be required to submit to the minister an annual report containing, among other things, details about how the Department of Health is meeting its functions. The Chief Officer will report on how the department is ensuring services respond to the needs of diverse groups and that data is being collected, compiled and analysed to improve understanding of the mental health needs and service use of diverse communities. This will complement broader reporting efforts regarding diverse communities that will form part of the recommended Mental Health and Wellbeing Outcomes Framework, in Chapter 3: *A system focused on outcomes*.

21.6.2 Partnering with communities

The Commission recognises that communities are best placed to understand the mental health and wellbeing needs of their members and to support the delivery of safe, responsive and inclusive services. Consultation must involve meaningful and ongoing engagement with communities in relation to the design and delivery of services.[272] Community organisations are also a key part of Victoria's mental health system; *Victoria's 10-Year Mental Health Plan* identified the need to support 'specialist community-controlled organisations to deliver services'[273] to diverse communities. Yet, as noted earlier in the chapter, short-term and insecure funding is a barrier for community-led organisations to deliver ongoing programs and expand services to meet demand. The Commission's proposed reforms will ensure the active involvement of diverse communities across the continuum of the mental health and wellbeing system, from the planning and design of services to the monitoring and evaluation of outcomes and in the delivery of community care and support.

Development of a diverse communities' mental health and wellbeing framework

The Chief Officer for Mental Health and Wellbeing will be required to ensure the active engagement of Victoria's diverse communities throughout the process of planning, implementing and managing the reformed mental health and wellbeing system. As an immediate priority, the Chief Officer should convene a diverse communities' working group to provide expert advice and guidance on the development of a diverse communities' mental health and wellbeing framework and a blueprint for action. This should be co-chaired with the relevant Deputy Secretary of the Department of Families, Fairness and Housing.

The framework should acknowledge the broad range of factors that affect the mental health and wellbeing of diverse cohorts, and align with and complement existing government policies. These include the government's forthcoming LGBTIQ+ strategy, anti-racism action plan and the state's disability plan. The framework should set a series of short- and long-term strategic priorities for delivering safe and inclusive mental health treatment, care and support in Victoria. It should include the promotion of good mental health and wellbeing and support capability uplift of ethno- or cohort-specific specialist mental health services to meet the service standards described in Chapter 28: *Commissioning for responsive services*. The framework should inform the government's future activities in relation to the mental health and wellbeing of diverse communities. The framework should be developed in partnership with the Department of Families, Fairness and Housing, and be informed by the Victorian Multicultural Commission and the Commissioner for LGBTIQ+ Communities. Input should also be sought from the Statewide Trauma Service described in Chapter 15: *Responding to trauma* and the Mental Health and Wellbeing Promotion Adviser described in Chapter 4: *Working together to support good mental health and wellbeing*. The Victorian Government should adequately resource and fund priority activities identified in the framework and ensure activities are funded for a period sufficient to evaluate efficacy.

This approach has been recommended by several witnesses and ethno-specific and community-led organisations, which have emphasised the need to consider the experiences of diverse communities through an intersectional framework.[274] As outlined by Rainbow Health Victoria:

> The recognition of age, class, gender, race, sexuality, cultural background and disability offers a framework for inclusive consideration of multiple intersecting disadvantage. People who are LGBTIQ and from an Aboriginal and Torres Strait Islander or culturally and linguistically diverse background, or who have a disability can face multiple, compounding disadvantages, and are more likely to delay, avoid or prematurely cease mental health care. The effectiveness of programs and supports depends on intersectional needs being recognised and addressed in policy and service design, and service delivery.[275]

Disability organisations submitted to the Commission that:

> In order to support Victoria's mental health system in becoming one that is more responsive, and accessible to, people with disabilities … evidence demonstrates a need to apply an intersectional, gender-sensitive and a public health approach, across all aspects of the mental health system.[276]

Evidence to the Commission described the benefits of developing an intersectional framework like the *Family Violence, Everybody Matters: Inclusion and Equity Statement*, which was developed in response to the Royal Commission into Family Violence (refer to Box 21.6).

Box 21.6: Everybody Matters: Inclusion and Equity Statement[277]

Taking an intersectional approach is at the heart of achieving greater inclusion and equity. This is why intersectionality is the overarching framework that sits at the core of this Statement. An intersectionality framework acknowledges the dynamics of power and social inequality in our society. It recognises that:

- people have many layers and are characterised by multiple, complex social characteristics that are interconnected or intertwined
- embedded within the multiple social characteristics are dimensions of perceived power and/or inequality
- the social characteristics are properties of the individual and of the social environment or worlds in which individuals live. The characteristics and their significance are therefore dynamic and may change.

Intersectionality helps us to understand how power differences can impact across multiple social characteristics and environments in which they are experienced. Adopting an intersectional framework approach:

- enables the identification of barriers to safety and access to services that individuals experience due to discrimination on the basis of Aboriginality, gender, sex, sexual orientation, gender identity, ethnicity, colour, nationality, refugee or asylum seeker background, migration or visa status, language, religion, ability, age, mental health, socioeconomic status, housing status, geographic location, medical record or criminal record
- enables the service system to better understand and respond to the complexity and spectrum of family violence experienced and perpetrated by people with a diverse range of social characteristics
- works towards creating and sustaining a service system that is inclusive, safe, responsive and accountable for all.

Community organisations as a gateway to mental health and wellbeing treatment, care and support

The role of community organisations in supporting the mental health and wellbeing of diverse communities must be acknowledged, and additional recurrent funding should be made available to allow organisations to deliver care that meets the needs of their communities.

To facilitate this, the Mental Health and Wellbeing Division should—with the input and advice of the Department of Families, Fairness and Housing—distribute additional recurrent funding to support community organisations and peak bodies to:

- design and deliver tailored mental health information and awareness campaigns that respond to community need
- assist diverse communities to navigate Victoria's mental health and wellbeing system.

To enable community organisations to deliver effective and meaningful support, funding should:

- support a mix of short- and long-term projects to suit the needs of communities
- as far as practicable, reduce the administrative burden on grant applicants and recipients
- be advertised in languages other than English, including Auslan, with all media files captioned
- be prioritised for Deaf community leaders and organisations, young people with a disability, and emerging communities.

Supporting Switchboard Victoria's Rainbow Door

The Commission believes that the significantly increased risks of mental illness faced by LGBTIQ+ people and the barriers they face when seeking to access culturally safe treatment, care and support warrants an immediate and targeted response.

As identified earlier, difficulty navigating the mental health system to ensure access to safe, responsive and inclusive services is a barrier to LGBTIQ+ people obtaining treatment, care and support. Telephone and web-based services, such as those provided by Switchboard, are an important source of support for LGBTIQ+ people.[278] As a specific LBGTIQ+ service, Switchboard can reduce the barriers to accessing care for people who are reluctant to use mainstream services.[279] Respondents in Lifeline-funded research regarding access to, and use of, crisis support services by LGBTIQ+ people described their experiences with mainstream crisis support services:

> Getting assigned a random call centre operator is a gamble I am not able to risk when I'm already in a heightened state of distress. The chance that I could be matched with someone who is well meaning–but ignorant–is high, and even a small misstep, or misunderstanding on their part … could be the straw that breaks my resolve to not harm myself.[280]
>
> [I] don't have a lot of faith in the public system so I use informal supports while I wait for a psych/GP appointment. [I] also have quite a stigmatised illness and have had a bunch of bad experiences with counsellors, psychologists and specialists before so don't have a lot of trust for practitioners I don't already know/aren't explicitly at LEAST queer friendly.[281]
>
> Telephone and web counselling services are known to not be knowledgeable about LGBTI+ terminology, experiences, community, etc. I don't want to access a service, only to spend all the time educating the person who is supposed to be supporting me.[282]

Switchboard receives referrals from mainstream helplines, such as Lifeline and Beyond Blue, for callers who identify as LGBTIQ+ and for callers wanting to talk about sexuality or gender expression. Switchboard also refers callers in crisis to Lifeline, although negative experiences of crisis services such as Lifeline may deter LGBTIQ+ people from accessing the service.[283]

Multiple witnesses and submissions emphasised the important role that Switchboard Victoria has played in delivering services to the LGBTIQ+ community for nearly 20 years, and the need for increased, secure funding to meet demand.[284] Switchboard is largely staffed by volunteers and receives limited ongoing funding—currently the only ongoing state government funding the organisation receives is through bloodborne virus prevention program funding through the Department of Health.[285] Switchboard does not currently receive any ongoing funding for mental health services.[286] In their joint submission, Rainbow Health, Thorne Harbour and Switchboard described the organisation's funding as 'tenuous' and identified a need for 'urgent, ongoing investment'.[287]

In 2020 the Victorian Government provided short-term funding to Switchboard to commence a pared down version of Rainbow Door—the program that the organisation had developed during the COVID-19 pandemic to provide mental health assessment and short-term case management for LGBTIQ+ people, and to link them to culturally safe mental health services. Switchboard developed the Rainbow Door program in recognition of the growing need for a pathway for LGBTIQ+ people from immediate crisis response into appropriate statewide mental health services. Key components of the Rainbow Door include:

> A dedicated single intake point for LGBTIQA+ communities
>
> A spectrum of support provided by the Switchboard service including information, support, intake and assessment, risk assessment, safety planning case and case planning, management, and evaluation
>
> Information and warm referrals to a range of other services including acute and community mental health, family violence, family support, parenting support, and child protection.[288]

Switchboard described the way Rainbow Door will build on and support LGBTIQ+ inclusive mental health and wellbeing treatment, care and support:

> One of the exciting prospects of the Rainbow Door is that it would work as a wraparound service that builds on the work already underway in the sector for LGBTIQA+ inclusion. This would be achieved by Rainbow Door staff inviting callers to stay connected to Switchboard in the earlier stages following a warm referral and let us know if they experience a block to service or have a bad experience. This would allow Switchboard to identify service gaps and work alongside mental health providers to provide real time feedback and build capacity that will support the mental health needs of LGBTIQA+ people.[289]

Ongoing and secure funding will allow Switchboard to continue to build the Rainbow Door services, providing LGBTIQA+ people with a safe entry point into the mental health system through a dedicated mental health linkage service. This funding will be sufficient to allow Switchboard to:

- operate Rainbow Door seven days a week
- undertake extensive marketing and communications activities to support awareness of the service
- employ program management, team leaders, helpline and case management staff, including specialist positions such as dedicated Aboriginal, culturally diverse and disability roles
- support access to mental health counselling for populations that face significant barriers to access services, such asylum seekers, international students and young people
- undertake comprehensive and long-term evaluation of Rainbow Door.

21.6.3 Improving the collection and use of data

The Commission has identified the need for improved data collection and analysis to support improved service delivery and better system administration, research, innovation and evaluation. The Mental Health and Wellbeing Division, in partnership with the Department of Families, Fairness and Housing, and the Commissioner for LGBTIQ+ Communities, must undertake a comprehensive review of mental health and wellbeing data with the primary objective of improving the transparency of mental health access and outcomes for diverse communities, and informing future planning and investment. This should form part of broader reforms related to data collection across the system detailed in Chapter 35: *New approaches to information management*.

The review should:

- map existing Victorian mental health datasets (including administrative and survey data)
- identify inconsistencies across Victorian datasets and surveys in relation to the mental health of diverse cohorts and describe the implications of these inconsistencies
- provide recommendations to improve data collection and analysis in line with the objectives described above
- provide recommendations for mechanisms for oversight of implementation of data reform efforts.

As an immediate priority, to increase transparency in access to language services within mental health services, the Chief Officer for Mental Health and Wellbeing, together with the Multicultural Affairs portfolio, should revise data collection requirements relating to language services use to include:

- the proportion of consumers who were offered an interpreting service
- the proportion of consumers requesting or requiring an interpreter
- consumers' first or preferred languages (including Auslan) where an interpreter was required or requested
- interpreter fulfilment rates.

21.6.4 Improving language and communication services

Good communication between mental health staff and consumers is the foundation of responsive mental health services and is vital to delivering effective and safe care.[290] It is therefore imperative that the Victorian Government implements several key reforms to ensure availability of, access to, and quality of, language and communications services. These include reforms to ensure all Victorians, regardless of first or preferred language, hearing, literacy or neurocognitive ability, have access to appropriate mental health information and means of communication throughout the mental health and wellbeing system. These reforms will enable the development of user-centric digital technologies that support the delivery of accessible, confidential, timely language services for mental health and wellbeing.

Although recommendations relating to whole-of-government arrangements for Victorian Government services is outside of the terms of reference of this Commission, the Commission considers the reliance on independent contractors and the casualisation of the workforce in the language services sector[291] as factors limiting the provision of quality and timely language services in mental health settings. The Commission acknowledges the Victorian Government's significant investment in language services in recent years and various efforts to improve the pay and working conditions of contractor and casually employed interpreters. It also acknowledges programs aimed at improving the quality and availability of language services, including in new and emerging languages. The Commission supports further reform in relation to government procurement and purchasing of language services, and a move to models of interpreter and translator engagement that reduce contracting arrangements, improve interpreter job security and employment conditions, and support increased professionalisation of the workforce. With regard to interpreters and translators within mental health settings and upskilling of knowledge and capability in mental health settings, the Commission has determined a need for the following reforms.

Increasing the supply of interpreters with specialist mental health knowledge

To improve the capacity of the interpreter workforce to deliver professional mental health interpreting services, the Commission recommends that the Mental Health and Wellbeing Division of the Department of Health, working in partnership with NAATI, language services professionals, registered training organisations and consumers, designs a certified specialist mental health interpreter accreditation course. The course will support the credentialling of certified mental health interpreters who will be competent to interpret complex, highly specialised and sensitive communication in mental health settings. To support the upskilling and availability of interpreters for the Deaf community, the Victorian Government should also provide ongoing funding to support delivery of the specialist NAATI-certified Auslan/English interpreters and Deaf interpreters mental health training course. These services received once-off funding in 2018 through the Disability Advocacy Innovation Fund through the Office of Disability at the (former) Department of Health and Human Services.

To support the uptake of these courses, the Victorian Government should develop and provide scholarships for specialist mental health interpreters. Priority should be given to interpreters who speak the languages of emerging communities or who provide language services for the deaf community. The Statewide Trauma Service should provide input into the development of these courses, both of which should include a focus on the mental health impacts of trauma and delivery of trauma-informed care, including management of any vicarious trauma experienced at work.

Furthermore, the Victorian Government should ensure there are financial incentives for mental health and wellbeing services to engage certified mental health interpreters, and that accredited interpreters are provided with continuing professional development at no cost to the interpreter. Interpreters should be required and supported to update their certification at appropriate intervals.

Ensuring interpreter use in mental health settings

The former Department of Health and Human Services' *Language Services Policy* provides comprehensive guidance for 'departmental staff at all levels and funded organisations in the planning and provision of language services'.[292] The Commission agrees with the assertions made in the policy that the provision of language services is a quality and safety issue, and that 'use of language services alone does not mean that the obligation to provide culturally safe and appropriate services has been met'.[293] The policy asserts that a consumer's English proficiency:

> should not be assumed to be at a sufficient level. It is important for clients to be offered an interpreter service. Departmental and funded organisations are responsible for ensuring clients are made aware of:
>
> (a) their right to communicate in their preferred language
> (b) when and how to ask for an interpreter
> (c) provision of an interpreter is at no cost to the client
> (d) interpreters are professionals and confidentiality is part of their code of conduct
> (e) interpreters are also there to assist the clinician.[294]

It also asserts that:

> Departmental services and funded organisations are responsible for providing appropriate language services when:
>
> (a) the client requests an interpreter or expresses a need to communicate in their preferred language, and/or
> (b) staff are unable to effectively communicate with a client.[295]

The Victorian Government must ensure that, as a matter of equity, quality and safety, all Victorian mental health and wellbeing services are aware of, are supported to adhere to, and are measured against their adherence to the *Language Services Policy*. Furthermore, the Victorian Government must provide training and opportunities to support mental health workers and professional interpreters to learn how to work effectively with each other.[296]

The Commission firmly agrees that departmental services and funded organisations have a role in promoting language services, including by 'using a range of communication methods, such as prominent signage displaying the National Interpreter Symbol, posters and brochures in client contact areas, reception areas, in other public areas, and on websites'.[297]

Increasing the availability of in-language and accessible mental health information

It is also vital that communication resources are available in a range of languages and formats to suit different health literacy levels and cognitive capabilities.[298] Aspergers Australia identified the need for 'clear, plain English (and translations where required) ... to ensure people can find services and applications processes must be streamlined and accessible, not filled with jargon and obstacles'.[299] The Ethnic Communities' Council of Victoria identified emerging communities as 'generally most in need of support with their health literacy and understanding of the Victorian mental health system'.[300]

In delivering on its responsibilities to provide a mental health and wellbeing system that is responsive to the needs of diverse communities, the Victorian Government must ensure the following:

- All mental health information provided via Victorian Government websites or digital platforms should be available in key languages and Auslan. Video files should be captioned.
- At least 5 per cent of all mental health campaign advertising budget should be spent on multicultural media. This is in line with existing government policies.[301]
- All public mental health campaigns should include representation of diverse cohorts and should be available in languages other than English. Multicultural media channels should be used where possible.
- Quality, accessibility and relevant translated mental health literature, visual and audio resources should be developed by commissioning the co-design of material with relevant communities. The co-design of resources for new and emerging communities should be an immediate priority.

The Commission recommends the Victorian Government, as part of the responsibilities of the Chief Health Mental Health and Wellbeing Officer, invests in improving the quality, accessibility and relevance of translated mental health literature, visual and audio resources through commissioning the co-design of material with relevant communities. The co-design of resources for new and emerging communities and the deaf community should be an immediate priority.

Strengthening the standards for data collection on interpreting and translating services

The lack of sufficient data collection in relation to language services access makes it difficult to estimate the level of need for interpreting services within mental health services.[302]

An independent review of interpreting services in Victoria found that:

> improved data collection, reporting and analysis has the potential to:
>
> - improve access. Identify emerging trends and system service gaps in order to respond to consumer needs and reduce the risks associated with failure to supply quality and timely services
> - improve efficiency. Enable assessment of the effectiveness and efficiency of workforce utilisation, support and inform workforce development initiatives and innovative service models
> - inform procurement. Performance data across departments drives superior contract management and drives the strategic response of providers through access to market share information and comparative performance information.[303]

The *Standards for Data Collection on Interpreting and Translating Services* assist government departments, program areas and funded agencies that regularly use interpreting and translating services to improve their own understanding of the needs of their client group, and monitor the accessibility of the services they provide.[304] The standards require departments and funded agencies to collect data relating to client demographics, expenditure and in-house staff. However, data collection reporting on language services providers is optional, and the lack of detailed data collected around the provision of language services within health settings suggests that mental health services are not collecting and/or reporting on this data. The Commission recommends that the Victorian Government strengthen the *Standards for Data Collection on Interpreting and Translating Services* to require the collection of data around language services. As identified above, this would include at a minimum:

- the number of consumers who were offered an interpreting service
- the number of consumers requesting or requiring an interpreter
- consumers' first or preferred languages (including Auslan) where an interpreter was required or requested
- interpreter fulfilment rates
- the NAATI certification level of the deployed interpreter
- wait times for interpreters.

Supporting innovation in language services

Evidence suggests that, overall, the delivery of language services in Victoria has changed little over the past decade or more. Services in Victoria are delivered almost entirely on site or via telephone, with little use of digital technologies. The COVID-19 pandemic has seen a substantial shift towards remote service delivery within health care, including increased use of videoconferencing and telephone consultations—that is, 'telehealth'. At The Royal Melbourne Hospital, for example, video interpreting appointments have increased from 10–15 appointments per month before COVID-19 to 100–200 per month during Melbourne's lockdowns.[305]

However, the shift towards remote services has several potential drawbacks, such as poor video or audio quality[306] that can interrupt the flow of information.[307] Such impediments to communication can be a barrier to accessing reliable health information for most people, but especially for people with limited English proficiency.

The shift to remote services also has the potential to exclude those with no access to technology and/or low digital literacy, which may particularly affect older generations and those with limited or no English. In her witness statement, Dr Tokhi discussed the disproportionate impact of the move to telehealth on 'vulnerable' populations, noting:

> we're going to start doing a lot more telehealth consultations in the face of this COVID-19 pandemic, and it's a real challenge to be able to set up a face-to-face consultation via Skype with someone whose English isn't great, or who doesn't have a great internet connection on their phone, or even reliable phone credit. Both those technological issues—booking appointments online and having telehealth consultations—are obviously more apparent in vulnerable populations.[308]

The move to telehealth during the pandemic has occurred with little technological or digital improvements to help transition both health services and communities to this model.

An independent review of language services in Victoria identified booking systems and technology platforms as being two areas ripe for innovation. The review found that each agency 'employs different strategies on managing interpreter bookings to maximise efficiencies and control costs relating to onsite service delivery' and described one opportunity to:

> drive system efficiency is the adoption of sophisticated booking systems and protocols that:
>
> - Support the efficient scheduling of bookings, such that multiple non-English speaking clients at the one location are serviced during the booking period, with extensions if needed;
> - Capture data relating to the number of occasions of service per scheduled booking; and
> - Ensure staff are adequately trained regarding the effective booking procedures.[309]

The Commission considers that there is a strong opportunity to foster innovation in technology solutions that enhance access to—and the experience of—language services use in mental health settings.

In delivering on this recommendation, the Mental Health and Wellbeing Division of the Department of Health, in collaboration with the Multicultural Affairs portfolio, should consider:

- undertaking a series of focus groups with mental health consumers who require an interpreter (including consumers from the Deaf community), mental health practitioners and administrative or support staff, and interpreters and language services providers, to understand the nuances of challenges in accessing or providing languages services in the context of state mental health service settings
- establishing a grants program to support the development of user-centric digital technology solutions that respond to any of the challenges identified in focus groups. For example, funded programs may support the development of technology solutions that:
    - make it easier for mental health consumers to advise they need an interpreter
    - make it easier for mental health practitioners or administrative support staff to book an accredited interpreter
    - quickly match an accredited interpreter with a health service making a request for one
    - improve the consumer and practitioner experience of using interpreters remotely using digital technologies
    - improve the capacity of health services to collect, monitor and report on language services use.

The Victorian Government should support the development of prototypes for the most promising solutions, as determined by a panel including representation from diverse mental health consumers, mental health staff and language services providers.

The Chief Mental Health and Wellbeing Officer should trial and commission the evaluation of these solutions in mental health and wellbeing services across the state. This initiative should be considered as part of broader innovation reforms considered in Chapter 36: *Research, innovation and system learning*.

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Chapter 22

Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction

Recommendation 35:

Improving outcomes for people living with mental illness and substance use or addiction

The Royal Commission recommends that the Victorian Government:

1. by the end of 2022, in addition to ensuring there is at least one highest-level emergency department suitable for mental health and alcohol and other drug treatment in every region (refer to recommendations 3(3) and 8(3)(c)), ensure that all mental health and wellbeing services, across all age-based systems, including crisis services, community-based services and bed-based services:

   a. provide integrated treatment, care and support to people living with mental illness and substance use or addiction; and
   b. do not exclude consumers living with substance use or addiction from accessing treatment, care and support.

Recommendation 36:

A new statewide service for people living with mental illness and substance use or addiction

The Royal Commission recommends that the Victorian Government:

1. establish a new statewide specialist service, built on the foundations established by the Victorian Dual Diagnosis Initiative, to:
    a. undertake dedicated research into mental illness and substance use or addiction;
    b. support education and training initiatives for a broad range of mental health and alcohol and other drug practitioners and clinicians;
    c. provide primary consultation to people living with mental illness and substance use or addiction who have complex support needs; and
    d. provide secondary consultation to mental health and wellbeing and alcohol and other drug practitioners and clinicians across both sectors.
2. as a matter of priority, increase the number of addiction specialists (addiction medicine physicians and addiction psychiatrists) in Victoria.
3. work with the Commonwealth Government to explore opportunities for funded addiction specialist trainee positions in Victoria.

22.1 An integrated approach to improve consumer outcomes

Co-occurring experiences of mental illness and substance use are so common that international experts suggest that services should consider this to be 'an expectation, not an exception'.[1] In Victoria a substantial number of people are living with both mental illness and substance use or addiction, but many are not getting the comprehensive treatment, care and support they need to recover and lead a contributing life.

There is promising evidence that well-delivered integrated care, where both mental illness and substance use or addiction are understood and supported simultaneously by mental health and wellbeing services, delivers better outcomes for consumers.[2] The evidence also suggests that integrated care may be more cost-effective than separate care models.[3] Integrated, comprehensive treatment, care and support is particularly important for people with the most complex support needs, who are often the people living with mental illness and substance use or addiction.[4]

However, most Victorian mental health services are not providing integrated treatment, care and support. Instead, consumers must navigate two distinct systems that often treat their interrelated needs separately. This approach to care is at odds with what many consumers, families, carers and supporters want and reflects a siloed approach to service delivery.[5] Consumers have told the Commission that the lack of integrated care offerings in Victoria is inconsistent with their needs. For example, one consumer explained that:

> you can get set up with a [care] plan, but you have to chase it all down … you have to go from here, to here, to here and not all the workers are working together … there's no cohesion.[6]

Ms Catherine White, a witness before the Commission, with lived experience of alcohol use and mental illness, told the Commission that when she sought help, the connection between her use of alcohol and her mental health was not well understood and did not inform the model of care she was offered:

> not a lot of people got the connection between trauma, mental health and addiction. For example, even the psychologist who diagnosed me with PTSD … ignored the fact that I was still drinking. I obviously didn't have the necessary coping skills. I kept getting triggered and drinking … he minimised the distress of my alcohol abuse, virtually dismissed it which made me feel like it wasn't a big issue. However, it was affecting all areas of my life and I needed a professional to view it as the problem it was for me. I felt embarrassed, ashamed and invalidated.[7]

Families, carers and supporters of people living with mental illness and substance use or addiction have also told the Commission about how a lack of integrated care had adversely affected people they cared for.

For example, Mr Michael Silva, witness before the Commission and carer, stated that:

> I am a carer for my brother Alan. Alan has a dual diagnosis of bipolar disorder (with psychotic episodes) and addiction to alcohol and drugs … We have never had an experience in the public mental health system of Alan being treated in an integrated way with respect to his dual diagnosis … The psychiatrists will only see you for your mental health issues … [they] may [tell you] that you should not take the drugs or smoke marijuana, but that is about the extent of the integration.[8]

Treatment, care and support delivered separately by different services is not delivering good health and wellbeing outcomes for many consumers.[9] A common experience is that consumers are 'bounced' between different services, forced to retell their story over and over.[10] Too many consumers living with mental illness and substance use or addiction are missing out on treatment, care and support, unable to access support from alcohol and other drug services because they are 'too unwell' but are 'not unwell enough' to access a mental health service.[11] Associate Professor Dean Stevenson, Clinical Services Director of Mercy Mental Health, told the Commission that the current approach does not work from the perspective of a mental health service:

> We are certainly seeing a high concurrence of major mental illness and substance use disorders, and the substance use disorders are addressed by services outside of mental health programs … it's not an effective model. We would much prefer to see drug and alcohol services embedded within mental health services.[12]

Decades of separate service systems have resulted in many mental health services seeing substance use or addiction as outside of their core business.[13] This has increased the burden on Victoria's alcohol and other drug services, which currently care for many consumers with complex mental health support needs. A critical shortage of addiction specialists limits the ability of alcohol and other drug services and mental health services to access the expertise needed to support consumers with complex support needs. Associate Professor Simon Stafrace, Program Director of Alfred Mental and Addiction Health at the time of giving evidence, and giving evidence in a personal capacity told the Commission:

> Whilst we aspire to being a mental and addiction health service, I think we have a lot of work to do to ensure that the people [who] come to us with severe mental illnesses and serious substance use disorders are getting as much evidence-based attention for the one as they for do the other.[14]

Consumers who have been able to access integrated treatment, care and support from the relatively small number of services that currently offer this have spoken about the benefits to their mental health and wellbeing. For example, one consumer told the Commission about their experiences of care at First Step, a service in St Kilda that provides integrated care for people with addiction, mental illness and other health or support needs:

> I entered a program at First Step, which is a recovery centre where … everything is covered … I was able to get legal advice, I was able to see a psychologist, a counsellor … and I was … able to get a diagnosis for a mental health condition that I'd had for a very long time. You know, that's what worked well for me, is having gone to one place and getting help in so many areas … it's been amazing actually.[15]

The intent of the Commission's reforms is to reorient the treatment, care and support for people with more complex and related support needs to Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services, which will offer integrated care as well as wellbeing supports. Ensuring consumers can get the right treatment, care and support at the right time will be achieved through a responsive and integrated system. These reforms are described in detail throughout this report and include the following:

- Regional Mental Health and Wellbeing Boards will promote integration through commissioning, including collaborating with alcohol and other drug services within each region, as described in Chapter 28: *Commissioning for responsive services*
- new community-based mental health and wellbeing services will provide integrated treatment and therapies. This includes treatment, care and support to consumers who have co-occurring challenges with substance use or addiction, as set out in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults* and Chapter 13: *Supporting the mental health and wellbeing of young people*
- bed-based services will provide holistic and integrated treatment, care and support to consumers who need it for substance use or addiction and are described in Chapter 10: *Adult bed-based services and alternatives*
- crisis and emergency services will provide integrated care for people with co-occurring mental illness and substance use or addiction. In addition, each region will establish at least one emergency department that provides intensive treatment, care and support through a behavioural assessment unit and are set out in Chapter 9: *Crisis and emergency responses*.

These reforms align with those recommended by the Productivity Commission in its *Mental Health Inquiry Report*. The report recommended that all governments 'should require mental health services, including hospitals and clinical and community health services, to ensure treatment is provided for both substance use' and mental illness for consumers with both.[16] This recommendation was based on the findings that mental illness and substance use or addiction are interrelated and that integrated care has numerous recognised benefits.[17]

The reforms described in this chapter outline a shift to integrated treatment, care and support for consumers living with mental illness and substance use or addiction. A new statewide service with a mandate to increase the capability of services to deliver integrated care, and an increased number of addiction specialists to support those with the most complex support needs, will aid this important shift.

The Commission recognises the importance of Victoria's alcohol and other drug services and their role in providing treatment, care and support to thousands of Victorians who seek help from them each year, and who benefit from their model of care. Victoria's alcohol and other drug services will continue to form an important part in the continuum of care for consumers but will no longer be expected to provide care for those with the most complex mental health support needs. The capability of the alcohol and drug sector to deliver treatment, care and support to consumers with less complex support needs will be enhanced through the work of the new statewide service.

22.2 The Commission's approach to mental illness and substance use or addiction

The Commission's letters patent define the scope of its inquiry. In undertaking its work, the Commission has considered the language preferred by people with lived experience of mental illness and substance use or addiction.

22.2.1 The scope of the Commission's inquiry

The Commission's letters patent include the requirement to 'inquire into and report on … [h]ow to best support those in the Victorian community who are living with both mental illness and problematic alcohol and drug use, including through evidence-based harm minimisation approaches'.[18] The Commission has undertaken that inquiry.

The Commission's letters patent explicitly directed it to focus on reforms that respond to the needs of consumers living with *both* mental illness and 'problematic alcohol or drug use'.[19] Accordingly, the Commission has focused its inquiry into how Victoria's future mental health and wellbeing system and the alcohol and other drug sector can better meet the needs of these consumers.

The Commission did not inquire more broadly into the entirety of Victoria's alcohol and other drug sector as it relates to matters other than the treatment, care and support offered to consumers who experience mental illness and substance use or addiction.

The letters patent also require the Commission to consider the role of evidence-based harm minimisation strategies to support consumers living with mental illness and substance use or addiction.[20] Harm minimisation means a health policy approach that recognises that there are complex and interrelated health, social and economic consequences of substance use or addiction that affect individuals, families, carers, supporters and the community.[21] A harm minimisation approach recognises that a person's drug use is individual and can range from occasional use to dependency or addiction.[22] The approach does not condone drug use, but recognises that a variety of strategies are required to support a progressive reduction in substance-related harm.[23]

A harm minimisation approach is based around three pillars.[24] The first is harm reduction, which aims to reduce risky behaviours associated with substance use or addiction and provide safer environments such as smoke-free areas or free water at music festivals.[25] The second pillar is supply reduction, which is about controlling the supply and availability of substances.[26]

The third pillar is demand reduction, which aims to prevent the uptake of substances. Demand reduction also involves helping people who use substances to recover through a range of evidence-based treatment, care and support options.[27]

Australia's National Drug Strategy highlights that:

> It is critical that Australia's strategy enhances and maintains access to quality evidence-informed treatment. Integrated care is critical to Australia's response and this includes approaches that allow individuals to connect to services which will address barriers to recovery, which might lead to issues such as physical and mental health needs, social, economic, legal or accommodation considerations. It is important that these services are accessible and tailored to the diverse needs of individuals …[28]

The Commission's recommended approach to integrated care in Victoria's future mental health and wellbeing system aligns with a harm minimisation approach. Specifically, it is consistent with the demand reduction element of harm minimisation that gives priority to services that can assist people experiencing substance use or addiction to recover.[29]

22.2.2 The language used in the Commission's letters patent

The Commission has inquired into '[h]ow to best support those in the Victorian community who are living with both mental illness and problematic alcohol and drug use'.[30] This included considering the experiences of people living with 'both mental illness and problematic alcohol and drug use' in Victoria's mental health system, in Victoria's alcohol and other drug sector, and across the community more broadly.[31]

In preparing this report and considering the design of Victoria's mental health and wellbeing system, the Commission considered the preferred prospective language to be used in describing this group of people and their experiences. The Commission's letters patent use the language of 'problematic alcohol and drug use' to describe substance use that is harmful to a person's health and wellbeing or other aspects of their lives. As noted in the Commission's interim report and this report, '[l]anguage is powerful, and words have different meanings for different people.'[32] The language used to describe people's experiences can either 'empower or embolden' or, conversely, can 'be divisive when used to dispossess and divide, and to stigmatise and label'.[33]

'Problematic alcohol and drug use' or 'problematic substance use' were terms commonly used by the former Victorian Department of Health and Human Services.[34] In the course of its inquiry, witnesses have told the Commission that pejorative terms to describe a person's substance use (including adjectives such as 'problematic') place a moral value judgement on substance use, which can contribute to stigmatising attitudes or beliefs. Dr Enrico Cementon, Consultant Psychiatrist at NorthWestern Mental Health, explained that:

> stigma is also driven by the terminology we use in relation to addiction and substance use. For example, we frequently refer to urine samples as being 'clean' or 'dirty'. When a drug-dependent person has been sober or abstinent, we use the term 'clean' or 'good'. We need to remove these pejorative and value-laden terms from our practice … As a result of this language and stigma … patients are often very reticent to talk about their substance [use] … Stigma discourages consumers from openly seeking help and support. Stigma also discourages and prevents clinicians from choosing to engage or specialise in [alcohol and other drug] and addiction health.[35]

Professor Dan Lubman, Executive Clinical Director of Turning Point, Eastern Health and Professor of Addiction Study and Services, Monash University, providing evidence in a personal capacity, also critiqued the term 'problematic alcohol and drug use' as prejudicial.[36] Professor Lubman also explained that the term does not adequately convey that a 'substance use disorder' is a 'mental disorder':

> **The term 'problematic drug and alcohol use' is reflective of how the current health system typically views and addresses substance use disorders—not as legitimate health conditions, or even mental disorders, but something that is self-inflicted and trivialised. It is akin to dismissing depression as a genuine health disorder by saying that people have a 'problematic mood', a term that minimises the suffering experienced and insinuates a level of blame, weakness or poor self-control. The failure to address substance use disorders by their proper name enables them to be dismissed as a health issue by both the health system, including mental health providers, and the community.**[37]

A 'substance use disorder' is recognised as a 'mental disorder' and is contained in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition ('DSM-5'), which is the most widely used diagnostic handbook by psychiatrists and other clinicians around the world. The clinical description of a substance use disorder is substance use that is harmful to one's health or where the person has a substance dependence.[38] Dr Cementon similarly remarked that the failure to recognise a 'substance use disorder' as a mental illness means that some mental health services view it as something that 'must be treated elsewhere' rather than within mental health services themselves.[39]

A recent publication, *Power of Words*, which was produced by peak bodies in Victoria and the then Department of Health and Human Services, suggested that the terms 'substance use' or 'addiction' are the terms preferred by consumers, noting that 'person experiencing addiction' is best practice when describing an individual.[40] Addiction to substances means compulsive substance use that is outside a person's control, even when it has adverse effects on that person or families, carers and supporters. It is sometimes referred to as drug or alcohol dependence. The guide highlights that 'substance use disorder' is a clinically appropriate term to describe a diagnosis.[41]

In light of this evidence, the Commission has chosen to use the language of 'substance use or addiction' and 'substance use disorders' in this report. This reflects the commitment to using language that empowers and does not stigmatise or label. Not all consumers will meet a diagnostic threshold for a 'substance use disorder' but may nonetheless wish to seek assistance to reduce or cease their use of substances.[42] For this reason, the Commission has defined substance use more broadly than a 'substance use disorder' but uses this term when appropriate—for example, to describe the findings of data about people with this diagnosis.

The Commission also notes that the term 'dual diagnosis service' has historically been used to describe services in Victoria that provide treatment, care and support to consumers living with mental illness and substance use or addiction. However, the Commission understands that this terminology is being reconsidered by some services that provide integrated treatment, care and support.[43] For example, Mr Gary Croton, Clinical Nurse Consultant, Hume Border Victorian Dual Diagnosis Initiative, Albury Wodonga Health, said that the language used by the Victorian Dual Diagnosis Initiative has evolved to 'people with dual diagnosis and other complex needs' because 'it's seldom dual diagnosis'.[44]

Mr Patrick Lawrence, CEO, First Step, also stated that:

> It is wrong to think that these two factors are inherently more important than psychosocial indicators such as poverty, social isolation, dysfunctional relationships, emotional under-development or homelessness. It is important to diagnose 'dual' mental illness and addiction, but a good service goes much further. We sometimes refer to this as 'dual diagnosis plus plus' at First Step. The term 'dual diagnosis' is almost never used at First Step because almost all of our clients have multiple treatment needs ...[45]

In light of this, the Commission does not use the language of 'dual diagnosis' except where it describes an existing service of that name, or where evidence before the Commission uses this language.

22.3 Mental illness and substance use or addiction

Integrated treatment, care and support acknowledges the interrelated nature, and the estimated prevalence of, co-occurring mental illness and substance use or addiction.

22.3.1 The relationship between mental illness and substance use or addiction

The relationship between mental illness and substance use or addiction is complex, and each can contribute to the other.[46] Once mental illness and co-occurring substance use or addiction are established, they can be difficult to disentangle.[47] While there appears to be insufficient evidence to conclude that substance use *causes* mental illness in a general sense, substance use appears to be a factor that can increase the risk of a person experiencing poor mental health, or exacerbate the symptoms of mental illness.[48] Some studies indicate that a complex range of factors, including environmental stressors (such as violence in the home environment or encounters with the justice system) or even genetic factors, are likely to play a role in the onset of both substance use or addiction and poor mental health, but more research is needed to understand the links between these factors, particularly for developing brains in young people.[49]

People use substances for many different reasons, including to avoid symptoms of withdrawal or to counter the effects of other substances.[50] Substance use can also be a way for people to manage the distress caused by poor mental health, trauma or other complex life stressors.[51] Particularly when consumers cannot get the treatment, care and support they need, substance use can be a coping strategy or form of self-medication.[52] Addiction experts have informed the Commission that consumers with complex and enduring addiction to substances have frequently experienced trauma early in their lives, such as childhood family violence, sexual abuse, interpersonal violence, neglect, poverty or experiences of out-of-home care or the youth justice system.[53] As Professor Lubman told the Commission at a 2020 hearing panel on how to support people living with mental illness and substance use or addiction:

> Nearly everyone that we see in the alcohol and drugs space are using drugs to solve a problem, to help with … distress or issues in their lives … the alcohol and drugs are emotional analgesics that are helping them deal with underlying mental health, stress, life, a whole range of life complexity.[54]

As discussed in Chapter 20: *Supporting Aboriginal social and emotional wellbeing*, poor mental health and substance use disorders are estimated to account for up to 14 per cent of the health gap between Aboriginal and Torres Strait Islander Australians and non-Aboriginal and Torres Strait Islander Australians.[55] Research indicates that trauma, including adverse childhood events, is also associated with poor mental health outcomes, including increased likelihood of substance use disorders.[56] For Aboriginal children and young people, experiences of trauma can also relate to intergenerational trauma.[57]

Research on patterns of substance use for Australians with 'mental health conditions', based on the 2019 National Drug Strategy Household Survey, indicates that of those surveyed, the most common substances used were tobacco, alcohol and cannabis.[58] Of those surveyed and identified as having a diagnosed 'mental health condition', 2.6 per cent of these people reported recent use of methamphetamines, 6.2 per cent reported recent use of cocaine and 4.9 per cent reported use of pain relievers or opioids.[59] The research also suggests that use of some substances (methamphetamine, opioids and cigarettes) has decreased slightly compared with previous years for those aged over 14 years old.[60]

Mental illness and co-occurring substance use or addiction are likely to vary over time for each person.[61] This can include how and when someone uses substances and also reflects the fact that people who experience a mental illness or use substances often have periods of stable health and wellbeing and periods of ill health or increased substance use.[62] People with a long-term substance use or addiction may experience a longer journey to recovery, including periods of relapse.[63] This can be because:

> **Recovery from a severe substance use disorder is usually a long-term process where there is substantial internal emotional and psychological change that occurs … Although this is also relevant to recovery from other mental health issues, it is essential in recovery from addiction. Consumers with addiction are very aware of this need, however their capacity and motivation to engage in this difficult process varies with time and circumstance, thereby affecting their engagement in treatment and mutual help.**[64]

Australian research suggests that people living with both mental illness and substance use or addiction frequently have more complex health and other support needs than people with mental illness or substance use issues only, including poorer physical and mental health and more severe drug use.[65] Research by the Centre of Research Excellence in Mental Health and Substance Use indicates that people living with both mental illness and substance use or addiction 'present to treatment with a more complex and severe clinical profile'.[66] This includes:

- poorer mental and physical health
- more severe drug use
- poorer social and occupational functioning
- increased risk of self-harm and suicide
- increased likelihood of homelessness and increased risk of violence
- increased risk of stressed relationships, including with family and friends.[67]

People living with both mental illness and substance use or addiction often face additional barriers to improved wellbeing and recovery compared with those without substance use or addiction. This includes increased rates of relapse, admissions to hospital, attendances at emergency departments, interactions with the justice system, unemployment and homelessness.[68]

Treatment for co-occurring mental illness and substance use or addiction can be more challenging because it can be difficult to identify which condition is causing particular symptoms, or can involve a more complex approach to treatment, care and support.[69] This can be because substance use or addiction can interfere with certain medications and can also interfere with other therapeutic treatments such as counselling.[70] Substance use or addiction can complicate mental health assessments, making it difficult to identify the most appropriate approach to treatment, care and support. [71] In some cases, treatment, care and support is also made more complex where a consumer is discharged from a mental health service due to substance use or addiction.[72]

22.3.2 Estimated prevalence of co-occurring mental illness and substance use or addiction

Estimating the population prevalence of co-occurring mental illness and substance use or addiction in Victoria is difficult. The reasons for this include a lack of consistent data across service systems, different definitions of mental illness and substance use or addiction, and differences in the demographics of populations across Australian states and territories.[73]

Large-scale population studies suggest that co-occurring mental illness and substance use or addiction is relatively common, although there are different estimated prevalence rates for different groups. For example, the 2007 National Survey of Mental Health and Wellbeing indicated that 63 per cent of Australians aged between 16–85 who reported misusing drugs nearly every day also experienced symptoms of a 'mental disorder', including 'substance use disorders', in the previous 12 months.[74] The survey also estimated that the rates of a co-occurring 'substance use disorder' were 12 per cent for people with 'anxiety disorders' and 18 per cent for those with an 'affective disorder'.[75]

A systematic review by the Centre of Research Excellence in Mental Health and Substance Use of a range of Australian studies on co-occurring mental illness and substance use suggested that 31 per cent of men and 44 per cent of women living with a 'substance use disorder' live with at least one other diagnosable mental illness.[76]

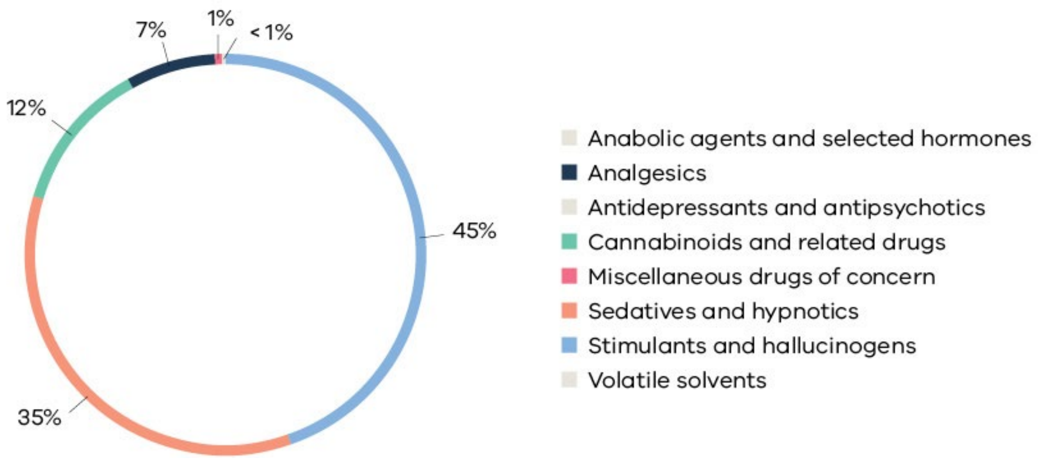
Research suggests that people who seek help from alcohol and other drug services have higher rates of mental illness. For example, research indicates that 50–76 per cent of Australians who use these services meet the diagnostic criteria for at least one co-occurring 'mental disorder'.[77] The research in this area has resulted in some international experts arguing that mental health services should consider co-occurring mental illness and substance use or addiction as 'an expectation, not an exception'.[78]

Alcohol was the largest primary drug type for people accessing emergency departments in Victoria for alcohol- or drug-related reasons in 2019–20, as set out in Figure 22.2. The 'stimulants' category includes methamphetamine and accounts for a relatively small proportion of all drug-related emergency department presentations.

22.3.3 Methamphetamine use and its effects on individuals, communities and health services

The estimated use of methamphetamine in Australia has steadily declined over the past 20 years and makes up a relatively small proportion of drug use overall (an estimated 1.3 per cent of Australians used methamphetamines in 2019 compared with 3.4 per cent of Australians in 2001).[79] However, as the Commission acknowledged in its interim report, methamphetamine use has disproportionately harmful effects for many individuals, families, carers, supporters and communities in Victoria compared with other drugs.[80] Data analysed by the Commission suggests that methamphetamines are in the top three 'main drug of concern' for consumers who seek help from Victoria's alcohol and other drug services. Around 25 per cent of consumers who accessed alcohol and other drug services in 2018–19 nominated methamphetamines as their major drug of concern (the category of stimulants and hallucinogens in Figure 22.1 includes methamphetamines).[81] Although the use of prescription pain killers and opioids has slightly decreased in the last three years (from 3.6 per cent of Australians to 2.7 per cent) it is still a concern due to the risk of overdose.[82]

Figure 22.1: Estimated percentage of consumers of alcohol and other drug services, by broad drug of concern, Victoria, 2018–19



Source: Department of Health and Human Services, Victorian Alcohol and Drug Collection 2018–19.

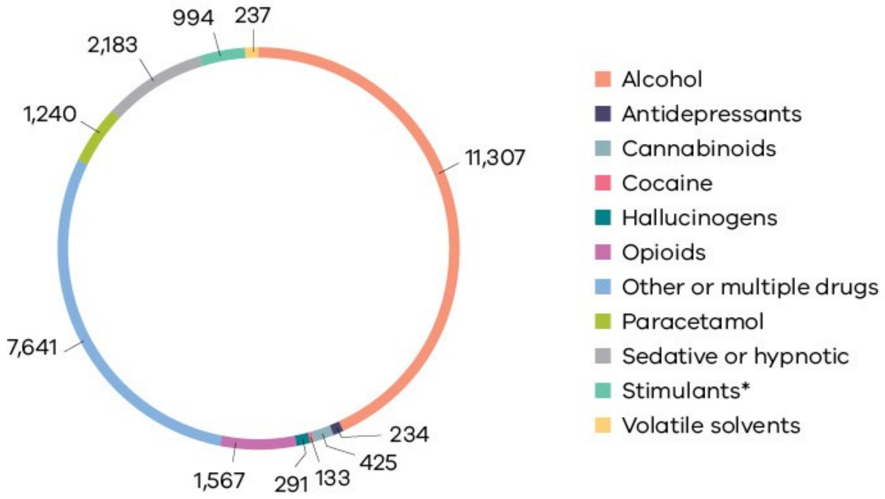
Note: The broad drug of concern is irrespective of whether the drug is the principal drug of concern or not. Percentages may not total 100 due to rounding.

Noting this, data analysed by the Commission and shown in Figure 22.3 from Victoria's emergency departments indicates that methamphetamine- and cocaine-related presentations to emergency departments have both increased substantially since 2008–09.

A recent systematic review and meta-analysis of 59 global studies of the relationship between methamphetamines and mental health suggested that methamphetamine use was associated with increased risk of mental health and 'behavioural issues'.[83] It indicated that any use, compared with no use, was associated with a 4.4 times greater likelihood of experiencing suicidal ideation and a 1.6 times greater likelihood of experiencing depression.[84]

People using methamphetamines can require treatment, care and support in emergency or crisis services, sometimes because of acute intoxication or related health needs such as physical injuries.[85] There is evidence to suggest that some people using methamphetamines are presenting to emergency departments or are being admitted to inpatient units in Victoria. In some cases, these presentations cause health and safety challenges to these services.

Figure 22.2: Number of mental health–related emergency department presentations with an alcohol or other drug-related diagnoses, by primary drug type, Victoria, 2019–20



Source: Department of Health and Human Services, Victorian Emergency Minimum Dataset 2019–20.

Notes: Mental health-related emergency department presentation defined as (a) the presentation resulted in an admission to a mental health bed (inpatient or residential), or (b) the presentation received a mental health related diagnosis ('F' codes, or selected 'R' & 'Z' codes R410, R418, R443, R455, R4581, Z046, Z590, Z609, Z630, Z658, Z765), or (c) the presentation was defined to be 'Intentional self-harm', or (d) the presentation involved interaction with a mental health practitioner.

*Stimulants category includes methamphetamine.

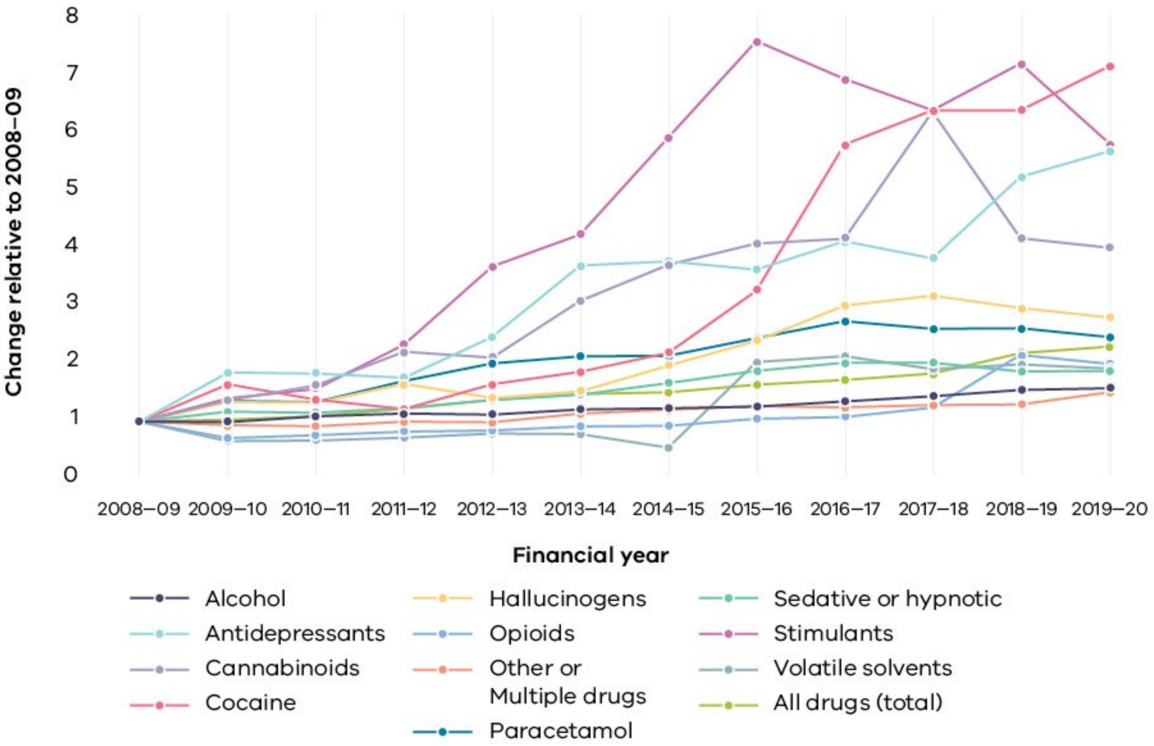
For example, one study comprising a sample of 229 emergency department attendees found that 40.2 per cent (92 people) returned a positive result for any drug, and of that group, 85 people returned a positive test for methamphetamines.[86] Another study, involving 232 'patients' admitted to a mental health inpatient unit over a three-month period, indicated that 30.6 per cent (71 people) of that sample either self-reported or tested positive (or both) to methamphetamine.[87] However, these results should be treated with caution because of the very small samples sizes and the limitations of study methodologies.

Methamphetamine intoxication can create challenges for health and emergency services and those who work in them.[88] This includes increased risk of exposure to occupational violence.[89] This is because methamphetamine use is associated with an increased risk of acute psychosis, agitation, aggression and violence.[90] For example, a recent systematic review indicates that any use of methamphetamines is associated with twice the likelihood of a person experiencing psychosis and 2.2 times the possibility of experiencing violence.[91]

Behaviours of concern resulting from substance intoxication are often referred to as 'acute behavioural disturbance' and can result in health workers or other consumers experiencing violence in the form of verbal abuse, threats, physical harm or bodily fluid assaults.[92]

A challenge for emergency departments is that their physical environments are often busy and brightly lit. This makes them highly stimulating environments, and this can exacerbate the distress that a person who is intoxicated feels.[93] It can also be very challenging for clinicians in an emergency department to know whether a person is intoxicated only, or if they also have an underlying mental illness.[94]

Figure 22.3: Change in the number of mental health–related emergency department presentations with an alcohol or other drug-related diagnoses, by primary drug type, Victoria, 2008–09 to 2019–20



Sources: Department of Health and Human Services, Integrated Data Resource, Victorian Emergency Minimum Dataset 2008–09 to 2018–19; Department of Health and Human Services, Victorian Emergency Minimum Dataset 2019–20.

Notes: Mental health–related emergency department presentation defined as (a) the presentation resulted in an admission to a mental health bed (inpatient or residential), or (b) the presentation received a mental health related diagnosis ('F' codes, or selected 'R' & 'Z' codes R410, R418, R443, R455, R4581, Z046, Z590, Z609, Z630, Z658, Z765), or (c) the presentation was defined to be 'Intentional self-harm', or (d) the presentation involved interaction with a mental health practitioner.

The Commission's definition of mental health-related emergency department presentation may differ slightly from the definition used by the Department of Health and Human Services. Stimulants category includes methamphetamine.

Data excludes the Albury campus of Albury Wodonga Health.

Change expressed relative to the reported number of relevant emergency department presentations in 2008–09. For example, a change of three represents a tripling of presentations.

The Commission notes the findings of the Special Commission of Inquiry into Crystal Methamphetamine and other Amphetamine-type Substances (The Special Commission of Inquiry), conducted in New South Wales. The Special Commission of Inquiry identified that people who seek care in emergency departments, and who are experiencing acute behavioural disturbance, require therapeutic care in a low-stimulus setting away from emergency departments.[95] The Special Commission of Inquiry highlighted the practice of Victoria's behavioural assessment units at the Royal Melbourne Hospital as exemplars of the care that should be provided to people experiencing acute behavioural disturbance.[96]

The Commission's reforms will see these specialised behavioural assessment units refined and established in every region as a component of the highest-level emergency department suitable for mental health and alcohol and other drug treatment outlined in Chapter 9: *Crisis and emergency responses*. These facilities are major responses and changes to the way that care is delivered in Victoria and will provide the necessary intensive care support options to consumers who need this. This reform will also ensure that there is a specialised response, including multidisciplinary teams, providing integrated treatment, care and support.

People who frequently use methamphetamines are likely to have other complex support needs, including for mental illness, and so can often require holistic and intensive treatment, care and support.[97] However, in Victoria's current approach to care, a major barrier to successful treatment, care and support for people who experience methamphetamine addiction is the 'disjointed transition between assessment, withdrawal and treatment … Given that key characteristics of this cohort include mental health comorbidity and other complexities … quality coordination of care' is needed.[98] The future system will provide integrated care to those consumers with complex care and support needs, including from addiction specialists.

The Special Commission of Inquiry examined the challenges of methamphetamine from different angles, including health, and made a number of recommendations. While Victoria conducted a parliamentary inquiry on the issue of methamphetamine in 2013, the Commission has received evidence that methamphetamine use remains a persistent and troubling issue for many Victorians.[99] Methamphetamine use is a complex health, social and justice issue, and reforms to the mental health system alone cannot deal with the entirety of the issue.

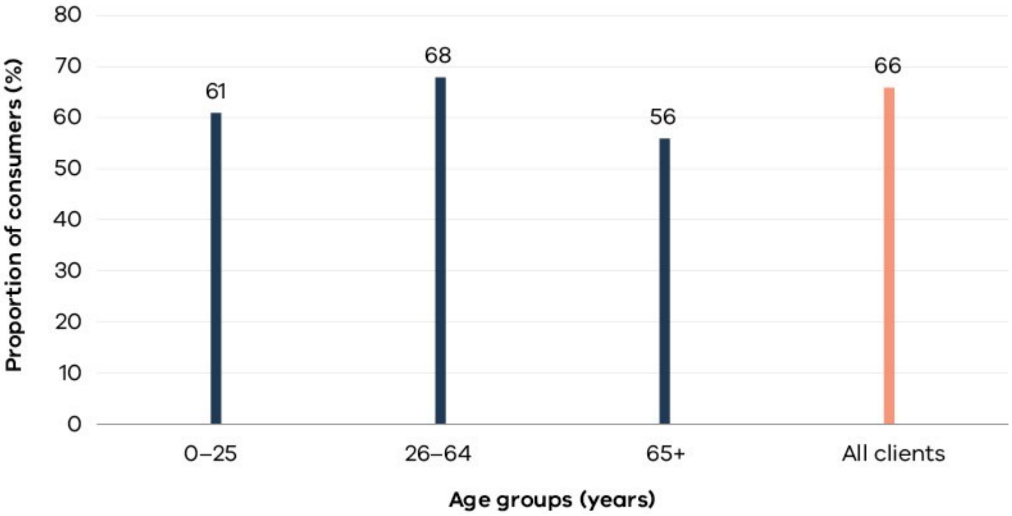
22.3.4 Gaining access to treatment, care and support

Data from Victoria's mental health and alcohol and other drug services helps to estimate the number of people in Victoria who use both services over a specific period of time. It can also identify how many consumers with co-occurring mental illness and substance use or addiction are accessing either a mental health or an alcohol and other drug service (consumers who use one but not the other). As noted in its interim report, the Commission has taken care to distinguish between data about registered consumers of Victoria's mental health system and data that can provide estimations of population prevalence.[100]

A relatively small number of consumers in Victoria are getting treatment, care and support from *both* a public specialist mental health service and an alcohol or drug service. In 2018–19, approximately 7,147 consumers accessed care from both. This represents 19 per cent of the total number of consumers who accessed an alcohol and other drug service (36,735 consumers) and 9 per cent of the total number of consumers who accessed public clinical mental health services (75,379 consumers) in that period.[101] This data is in the context of the difficulties many people have accessing Victoria's mental health system, as outlined in the Commission's interim report.[102]

However, analysis of the data suggests that a far larger cohort of consumers who use Victoria's alcohol and other drug services also have poor mental health or a diagnosed mental illness. Across all age cohorts, approximately 66 per cent of consumers who accessed alcohol and other drug services in 2018–19 indicated that they had received a mental health diagnosis from a mental health practitioner (refer to Figure 22.4).[103]

Figure 22.4: Estimated proportion of Victorian alcohol and other drug service consumers where mental health diagnosis status is known, Victoria, 2018–19



Source: Department of Health and Human Services, Integrated Data Resource, Victorian Alcohol and Drug Collection 2018–19.

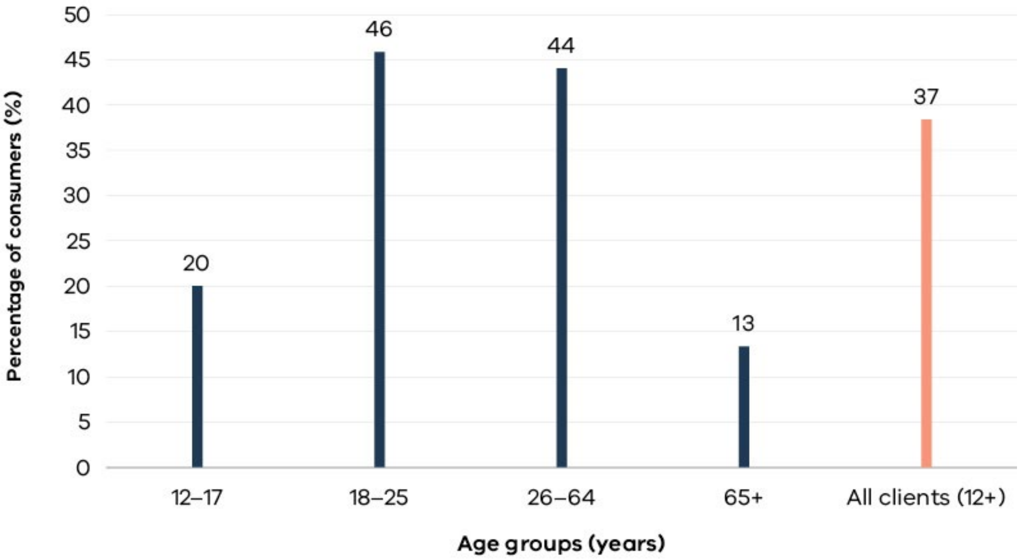
Notes: Data includes diagnosis groups such as conditions of psychological development. 16,091 consumers in 2018–19 did not have a diagnosis recorded or it was inadequately described.

When analysing data recorded by Victoria's mental health services, the Commission observed that approximately 27 per cent of consumers in the five-year period from 2014–15 to 2018–19 were recorded as having a substance use disorder diagnosis.[104]

Other data analysed by the Commission regarding the percentage of consumers who accessed public specialist mental health services who were assessed using an age appropriate Health of the Nation Outcome Scale as having a substance use issue is shown in Figure 22.5 and indicates the following:

- of those consumers aged 12–17 years old, 20 per cent had a substance use issue
- of those consumers aged 18–25 years old, 46 per cent had a substance use issue
- of those consumers aged 26–64 years old, 44 per cent had a substance use issue
- of those consumers 65 years and older, 13 per cent had a substance use issue.

Figure 22.5: Estimated proportion of public clinical mental health service consumers with a substance use issue, Victoria 2019–20



Source: Department of Health and Human Services, Client Management Information/Operational Data Store 2019–20.

Notes: Estimation is based on consumers who have a completed Health of the Nation Outcome Scale (HoNOS), Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) or Health of the Nation Outcome Scale 65+ (HoNOS 65+) assessment and were rated 2, 3 or 4 on those scales in the questions relating to problem drinking or drug-taking, or problems with alcohol, substance or solvent misuse. 68.3 per cent of clients aged 12–17 had a completed questionnaire; 61.7 per cent of clients aged 18–25 had a completed questionnaire; 59.7 per cent of clients aged 26–64 had a completed questionnaire and 64.3 per cent of clients aged 65+ had a completed questionnaire.

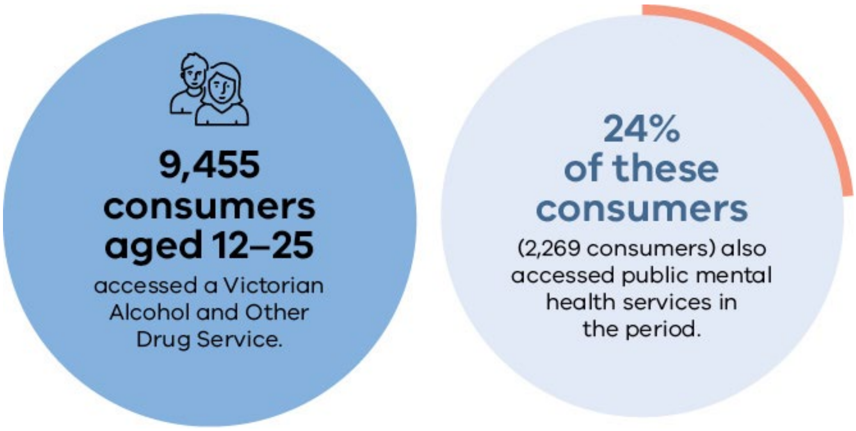
22.3.5 Co-occurring mental illness and substance use or addiction at different ages and in different service settings

Anyone can experience mental illness and substance use or addiction. However, there are different patterns of mental illness and substance use or addiction at particular ages and life stages. This is particularly the case for young people and older adults. Further, the acuity or severity of distress for different consumers (including the other complex support needs they have) differs, meaning that different service settings see consumers with different levels of need.

Young people

Service use data analysed by the Commission suggests that in 2018–19 approximately 9,455 consumers aged 12–25 years old accessed a Victorian alcohol and other drug service.[105] The Commission estimates, based on analysing the linked administrative datasets, that 24 per cent of those consumers (2,269 consumers) also used a public specialist mental health service in that period. However, a larger number of young people—61 per cent (6,001 young people)—who used an alcohol and other drug service indicated that they had received a mental health diagnosis from a mental health practitioner.[106]

Figure 22.6: Estimated proportion of youth alcohol and other drug service consumers who also used public mental health services, 12–25, Victoria, 2018–19



9,455 consumers aged 12–25 accessed a Victorian Alcohol and Other Drug Service.

24% of these consumers (2,269 consumers) also accessed public mental health services in the period.

Source: Department of Health and Human Services, Integrated Data Resource, Client Management Information/ Operational Data Store, Victorian Alcohol and Drug Collection 2018–19

Note: In this instance, mental health consumers includes consumers who accessed mental health services in the public specialist system, private hospitals and emergency departments.

In Chapter 13: *Supporting the mental health and wellbeing of young people*, the time of early adolescence or young adulthood is described as a time of substantial development and often a time where a young person's substance use or addiction and mental health issues emerge.[107] Research suggests that young people's patterns of substance use differ from those of adults; for example, they may be more experimental or more likely to engage in 'binge' drinking.[108]

Responding to co-occurring mental illness and substance use or addiction experienced by young people requires a response that considers factors relevant to young people's stage of life and development, including:

- the young person's family, and any substance use issues or addiction within their family or relational context
- the influence of social relationships, including peers
- factors that may increase a young person's risk of substance use or addiction, including abuse, neglect or trauma.[109]

Several previous reviews have identified a need for integrated care for young people living with mental illness and substance use or addiction.[110] This includes a review in 2000 that recommended that '[t]he model of care for young people with problematic substance use should be integrated with other youth focussed services and systems such as … mental health'.[111]

A 2015 review by Victoria's largest youth alcohol and other drug service, the Youth Support and Advocacy Service, recommended that alcohol and other drug services should '[f]urther integrate with other youth focussed service systems capable of addressing complex psychosocial issues' and that Victoria should '[e]nsure youth [alcohol and other drug] services are fully integrated with other youth and health service systems'.[112] In particular, integrated care is recommended for young people considered to be at greater risk of developing co-occurring mental illness and substance use or addiction, particularly young people in out-of-home care or who interact with the youth justice system.[113]

Two submissions to the Commission raised the issue of young people with severe substance use or addiction who interact with the youth system and who may struggle to complete residential rehabilitation programs.[114] It was suggested that young people in this situation could be assisted through a residential therapeutic treatment program that would be court-ordered, and therefore compulsory.[115] The Commission's reforms aim to reduce compulsory treatment, so that it 'must only be used as a last resort', and are discussed in detail in Chapter 32: *Reducing compulsory treatment*. The Commission's expectation is that the engagement strategies used by reformed mental health and wellbeing services for young people will benefit young consumers with severe substance use or addiction needs and mental illness. Young people with the most complex support needs relating to mental illness and substance use or addiction will be able to access integrated care in the service stream of youth mental health and wellbeing services, including addiction specialist support.

Older adults

In Chapter 14: *Supporting the mental health and wellbeing of older people*, the Commission outlines that older adults require different mental health support based on their stage of life. Research on the patterns of alcohol and other drug use of older Australians (aged 65 years or older) by the National Drug Research Institute suggested that, in 2016, 25 per cent of men and 8 per cent of women were drinking more than two standard drinks per day (or more than 14 drinks per week, which is more than the healthy recommended amount).[116] The research suggested that alcohol use could occur as a result of distress caused by loss or grief, chronic pain or loneliness or homelessness experienced by older people.[117] Older adults may also use drugs to combat chronic pain, to cope with the symptoms of depression or anxiety, to manage the distress of social isolation or because they have a long-term substance use disorder for which they have not received appropriate treatment, care and support.[118]

People who access emergency departments and other crisis services

As described in Chapter 9: *Crisis and emergency responses*, people who experience a mental health or substance use crisis frequently require an immediate health response. This can be due to a range of reasons including intoxication, physical injuries, suicidal ideation or self-harm.

Data analysed by the Commission suggests that consumers who use both mental health and alcohol and other drug services are 25 times more likely than the Victorian population overall to use an ambulance for a mental health-related reason.[119] Consumers accessing both mental health services and alcohol and other drug services are 48 times more likely to go to Victoria's emergency departments for reasons relating to suicidal ideation and 40 times more likely to go to them for reasons relating to self-harm than other consumers (refer to Figure 22.7).

Figure 22.7: Estimated number of people who used mental health-related services and alcohol and other drug services who also accessed ambulance services and emergency department services, Victoria, 2014–15 to 2018–19

Sources: Department of Health and Human Services, Integrated Data Resource, Client Management Information/ Operational Data Store, Victoria Emergency Minimum Dataset, Victorian Ambulance Minimum Dataset, Victorian Alcohol and Drug Collection 2014–15 to 2018–19; Australian Bureau of Statistics, Australian Demographic Statistics, June 2020, cat. no. 3101.0, Canberra.

Note: In this instance, mental health consumers includes consumers who accessed mental health services in the public specialist system, private hospitals and emergency departments.

In response to the growing number of people with both mental health and substance use or addiction issues visiting emergency departments, the Victorian Government has committed to build six mental health and alcohol and other drug crisis hubs.[120] These six hubs are to be built at locations including Monash Medical Centre Clayton, Peninsula Health Frankston, Western Health in Sunshine and Barwon Health at University Hospital Geelong, and will include a total of 24–36 short-stay beds, which will enable consumers to spend 'up to 24 hours, or longer as clinically appropriate'.[121] These hubs are designed to be separate from the emergency department, in a low-stimulus environment and staffed by clinicians and practitioners with expertise in mental health and substance use or addiction, and are described in detail in Chapter 9: *Crisis and emergency responses*.[122]

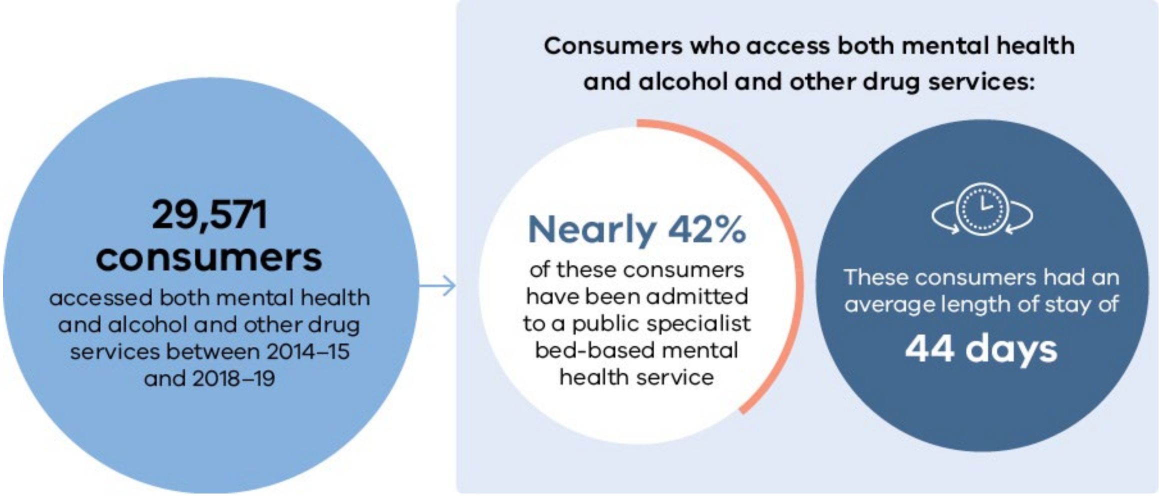
Emergency departments can be traumatic or stressful for people living with mental illness and co-occurring substance use or addiction, or they can be settings where people experience stigma and discrimination because of their use of alcohol and other drugs.[123] These hubs will respond to the needs of people with mental health and substance use or addiction who seek crisis services.

Consumers who use bed-based services

As described in Chapter 10: *Adult bed-based services and alternatives*, Victoria's bed-based services are in various residential settings, including hospitals and subacute facilities, where mental health treatment, care and support is delivered. In the future, bed-based services will make up a relatively small part of Victoria's mental health and wellbeing system and will be reserved for those consumers with complex and higher intensity support needs. Data analysed by the Commission suggests that a substantial proportion of mental health consumers who use bed-based services are also living with substance use or addiction or have a diagnosed 'substance use disorder'.[124]

Analysis of health service data suggests that in the five years from 2014–15 to 2018–19 approximately 29,571 consumers accessed both mental health and alcohol and other drug services.[125] Of this group, nearly 42 per cent (12,419 consumers) had been admitted to a public specialist bed-based mental health service an average of three times and had an average stay of 44 days (refer to Figure 22.8).

Figure 22.8: Estimated number of people who used mental health services and alcohol and other drug services, Victoria, 2014–15 to 2018–19



Sources: Department of Health and Human Services, Integrated Data Resource, Client Management Information/ Operational Data Store, Victorian Admitted Episodes Dataset, Victorian Emergency Minimum Dataset, Victorian Alcohol and Drug Collection 2014–15 to 2018–19.

Note: In this instance, mental health consumers includes consumers who accessed mental health services in the public specialist system, private hospitals and emergency departments.

Consumers who have complex support needs

As described earlier, research indicates that people with co-occurring mental illness and substance use or addiction can also have other complex support needs. These can include supports relating to housing and employment, physical health, family, interpersonal or sexual violence and the justice system.[126]

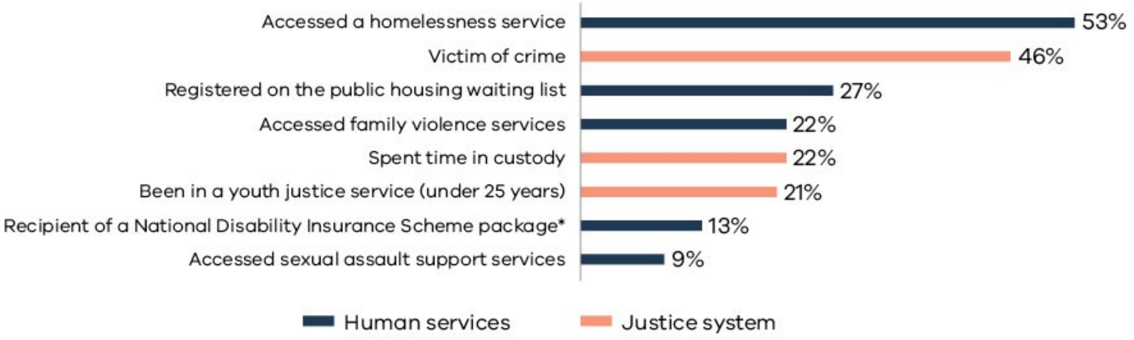
For example, First Step told the Commission that a snapshot of 100 consumers at first presentation to the service indicated that:

- 65 per cent were unemployed or not studying
- 15 per cent were homeless or were at risk of homelessness in the previous month
- 11 per cent had been arrested in the previous month
- 11 per cent had experienced sexual abuse in the previous month
- 7 per cent had attempted suicide in the previous month.[127]

Similarly, Turning Point, a national addiction treatment, education and research service based in Melbourne, submitted that 25 per cent of people seeking treatment from its services were consumers with what it defined as the 'most intensive support needs' due to experiencing multiple health and other life complexities.[128] This means that the consumer is experiencing drug or alcohol dependency, as well as other complex support needs related to mental and physical health or has previously experienced drug, alcohol or mental health treatment.[129] Further, 45 per cent of its consumers were assessed as having needs consistent with the second-highest tier of complex support needs, which includes having moderate mental health issues.[130]

This is consistent with data about the use of different government human services (for example, housing or homelessness services) and the justice system for people who made use of both specialist mental health and drug services over a five-year period, set out in Figure 22.9.

Figure 22.9: Proportion of consumers who accessed both mental health and alcohol and other drug treatment services, by interaction with human services and the justice system, Victoria, 2014–15 to 2018–19



Sources: Department of Health and Human Services, Integrated Data Resource, Client Management Interface/ Operational Data Store, Victorian Admitted Episodes Dataset, Victorian Emergency Minimum Dataset, Victorian Alcohol and Drug Collection, E-justice, Law Enforcement Assistance Program Extract, Specialist Homelessness Services Collection, Victorian Housing Register, Family Violence Support Services Data Collection, Sexual Assault Services, Disability—individual support packages 2014–15 to 2018–19.

Notes: Sample size n = 29,571 people. Includes consumers who accessed mental health services in the public specialist system, private hospitals and emergency departments. *Only includes people that were supported by the Victorian Government disability services that transitioned to the National Disability Insurance Scheme and does not include new consumers.

Mr Croton explained that this is why the Victorian Dual Diagnosis Initiative prefers the term 'complexity capability' over 'dual diagnosis capability'.[131] This is also the terminology used by integrated care experts Christie Cline and Kenneth Minkoff:

> Individuals and families not only have substance use and mental health issues, they frequently have medical issues, legal issues, trauma issues, housing issues, parenting issues, educational issues, vocational issues and cognitive/learning issues … we need to engage in a process of organizing everything we do, at every level … to be about all the complex needs of the people and families seeking help.[132]

22.4 Current services for mental illness and substance use or addiction in Victoria

In Victoria the mental health system and the alcohol and other drug sector are, with some exceptions, separate. The separation of mental health and substance use or addiction services occurred in the years after the deinstitutionalisation of Victoria's former mental health services in the 1990s. Prior to this, certain public hospitals provided both mental health and substance use or addiction treatment, care and support.[133] Mr Terry Symonds, the then Deputy Secretary, Health and Wellbeing, Department of Health and Human Services, explained that 'siloed research and clinical domains' have remained the norm in Australia.[134] In addition, '[w]orkforce shortages, problematic siloing of the two sectors and historical culture and practice approaches have led to limited opportunities for integrated care.'[135]

Victoria's alcohol and other drug services are largely delivered by non-government organisations and community health organisations and hospitals, and some services are commissioned by Primary Health Networks.[136] Alcohol and other drug services offer a range of different treatment, care and support options. They provide intake and assessment, counselling, residential and non-residential withdrawal services, residential and day rehabilitation services, care and recovery supports and pharmacotherapy such as opioid replacement therapy. They also offer harm-minimisation programs such as syringe exchange and safe injecting rooms and harm-minimisation education.[137] There are specific alcohol and other drug services for Aboriginal consumers, for young people and for people in forensic mental health care and correctional settings.[138] Services for Aboriginal consumers include healing centres for young people, which are described further in Chapter 20: *Supporting Aboriginal social and emotional wellbeing*.

22.4.1 Victoria's current statewide services for consumers living with mental illness and substance use or addiction

Victoria also has specific services in some health services for people living with mental illness and substance use or addiction who have more intensive needs. These include 28 'dual diagnosis' rehabilitation beds located in Bendigo (eight beds) and Sunshine (20 beds), which provide treatment, care and support for up to 12 weeks.[139] Another service is a statewide Addiction Medicine Unit, consisting of eight beds located at Box Hill Hospital, delivered by Turning Point. This service offers crisis support and withdrawal management, as well as treatment for co-occurring mental or physical health issues. The alcohol and other drug sector also provides beds for withdrawal and rehabilitation for people living with mental illness or psychological distress, including some that are specifically for young people.

Turning Point also has a Statewide Specialist Clinical Service, which is based at Eastern Health. Turning Point provides direct services to anyone in Victoria who meets relevant eligibility criteria. The services include addiction medicine, psychology, neuropsychology and other treatment services. Turning Point's services include a trial of an eight-bed subacute drug withdrawal and intensive rehabilitation service for people with addiction issues and complex mental and physical health needs, which commenced in 2018.[140]

Turning Point also has an important role as a research institution, auspiced by Eastern Health and affiliated with Monash University. Its activities include research, workforce and community training and education programs, providing population-level data through its research, policy advice to governments and expert comment.[141]

Victoria's 'dual diagnosis' rehabilitation beds are limited in the services they provide, including their small scale and an inability to provide withdrawal or non-residential options. They are also unsuitable for people with intensive support needs, such as those who have a substantial risk of suicide. Mr Symonds told the Commission that these 28 beds are 'not enough, and it is my view that the Royal Commission should consider a comprehensive approach to dual diagnosis'.[142] It is also clear that dual-diagnosis bed-based services are not equitably distributed across the state.

The Victorian Dual Diagnosis Initiative (VDDI) works with the alcohol and drug, mental health community support and clinical mental health sectors. It was established in 2002 by the then Department of Health. It aims to increase the capacity of clinicians, practitioners and services to recognise and respond effectively to people with co-occurring mental illness and substance use issues or addiction. The VDDI operates in metropolitan, regional and rural Victoria and is coordinated by the VDDI Leadership Group and the VDDI Rural Forum. Metropolitan health services are funded for a range of positions, including psychiatrists and youth practitioners who provide support to regional and rural VDDI workers. A 2011 evaluation of the initiative indicated that it had had some success, including in building awareness of co-occurring mental illness and substance use or addiction across sectors.[143] However, some stakeholders have informed the Commission that, due to insufficient support, the VDDI has been challenged to expand its remit across Victoria. For example, Mr Symonds stated that:

> the Victorian Dual Diagnosis Initiative made significant gains in the further development of mental health and [alcohol and other drug] workers, agencies and sectors' capacity to recognise and respond effectively to people experiencing co-occurring mental health and substance use concerns and related issues. However, this program has lost momentum and, as outlined in their submission to the Royal Commission, would require updating and refinement, co-design and implementation support were it to continue.[144]

22.4.2 Strengths of current approaches to treatment, care and support

The Victorian alcohol and other drug sector approach to providing treatment, care and support for consumers has several strengths. To some extent, the separation of mental health and alcohol and other drug services in Victoria has enabled the latter to offer treatment, care and support that often:

- puts consumers at the heart of decision making, with the tools, approaches and models of care in the alcohol and other drug sector, based on staff walking alongside people, hearing what their issues are, and developing interventions that work for them
- has a peer workforce that includes many people with a lived experience of substance use or addiction and recovery
- recognises the need to respond to the needs of consumers in a holistic way that understands the complexities of their support needs and their life circumstances
- acknowledges the relationship of trauma and distress and substance use or addiction
- offers therapeutic alternatives to medication and care and recovery coordination
- offers treatment, care and support that is compassionate and non-judgemental
- is proficient in partnerships with other systems and organisations.[145]

These strengths are entirely consistent with the Commission's aims for the future of mental health and wellbeing system in Victoria. Indeed, a recurring theme in the evidence received by the Commission is that the approaches of the mental health and alcohol and other drug sectors are not that different. Both aim to provide a person-centred approach to recovery and both sectors can learn from, and share knowledge with one another.[146]

Peer workers are central to the work of Victoria's alcohol and other drug services, which utilise peer supports when providing treatment, care and support more consistently than mental health services.[147] For example the Self Help Addiction Resource Centre, which has a model of practice grounded in peer support, started in 1986. It was formed when a group of people with lived experience decided to form a new organisation to support other people who needed help with substance use or addiction.[148] Self Help Addiction Resource Centre informed the Commission that:

> Much of the strength of [Self Help Addiction Resource Centre]'s approach is based on the spirit or ethos of self-help culture: Empowering ourselves to make those decisions that directly affect our lives, taking responsibility for ourselves, leading the development of models of support with professional champions and embracing the extraordinary value of mutual support, hope and moving towards recovery as defined by the individual.[149]

Dr Stefan Gruenert, CEO of Odyssey House Victoria, which offers alcohol and other drug treatment, training and support, explained that:

> We know that in sustainable recovery from both drug and alcohol and mental health issues … positive, strong relationships and relationship skills are one of the key predictors of long-term success … this is also why so many peer support programs work particularly well, because they can … go on that journey together with other people that have had similar experiences, at least as part of their treatment.[150]

A consumer at a focus group for people with lived experience of mental illness or substance use or addiction explained why peer workers are so important during the time of first seeking help from a service:

> Particularly in early recovery … it's a real rollercoaster ride mentally and emotionally, on any given day … having a place to touch base with basically on a daily basis for people who are going through the same thing as you or have been through … and are now in a more stable part of their lives … I just think it's invaluable … It can cause you to feel much less like an alien through a process, which at times feels very alien … just being able to touch base in that confidential space, where there is no agenda, where it's supported … that everybody there understands, without you even needing to say … no matter what state you're in.[151]

In addition, there are many strengths to Victoria's current mental health services that complement those of Victoria's alcohol and other drug sector. In particular, in comparison with Victoria's alcohol and other drug sector, Victoria's mental health services tend to have higher levels of specialisation of workforce in order to provide particularly high intensity supports for consumers with complex support needs. Noting the discussion in Chapter 36: *Research, innovation and system learning*, Victoria's mental health services also tend to have closer connections to research and the development of evidence-based approaches to treatment, care and support.

22.5 Challenges for people living with mental illness and substance use or addiction, and for Victoria's alcohol and other drug services

Despite the large number of people in Victoria living with co-occurring mental illness and substance use or addiction, too many consumers are currently unable to access sufficiently comprehensive and integrated care. This is largely because of the current separation of mental health and alcohol and other drug services, the limited capacity of alcohol and other drug services to provide treatment, care and support to people living with mental illness and related complex support needs, and a range of barriers to accessing integrated services that arise as a result of this.

22.5.1 Challenges in accessing integrated care and experiences of service exclusion

The Commission has heard that many consumers are not receiving sufficiently comprehensive treatment, care and support when they seek help because some mental health services currently do not provide this.[152] This situation is not unique to Victoria. The Productivity Commission's *Mental Health Inquiry Report* concluded that 'there was strong evidence' that integrated care is rare in Australia and that many Australians are not getting the treatment, care and support they need.[153] It is the current system, not consumers, that frequently approaches or treats mental illness and substance use or addiction as separate issues. Consumers identified this approach as inconsistent with the model of care they preferred:

> There are definite problems in the current system in dual diagnosis. So many people living with mental illness use alcohol and drugs to cope with the symptoms. They are not separate issues.[154]
>
> I became homeless, I had a couple of psych unit admissions … What I found during that time was there was a real disconnect between health services for … the alcohol and drug stuff, and … mental health and I require support in both those areas.[155]

In Victoria, as in other Australian states and territories, historic separations of mental health and the alcohol and other drug sector have resulted in separate service responses for issues that are interrelated. While there have been efforts to increase coordination between these separate services, it is clear that consumers experience multiple challenges to getting integrated care. These include limited access and long wait times for integrated care options, being shuttled between multiple services or being excluded from either mental health or alcohol or other drug services.

Being unable to get integrated care can impede recovery. In its submission, the Alcohol and Drug Foundation described how this approach affects consumers:

> A person with the co-occurring conditions of an anxiety disorder and an alcohol or other drug dependency can be locked in a 'catch-22' like state where a resolution seems impossible: consequently the treatment of both disorders is required or the one condition will undermine attempts to treat the second condition. This underlines the need for treatment for both conditions to be integrated rather than taking place in 'silos' independent of each other.[156]

Service fragmentation means that consumers can frequently find themselves triaged or 'shuttling back and forth' to different services.[157] They are then treated by separate workforces for interrelated and co-occurring issues.[158] This is consistent with the experiences of consumers described in a consumer focus group held in July 2020:

> [There is a] silo effect of mental health and [alcohol and other drugs] … I watched the crossover of people struggling with mental health and being told No, they don't fit into the [alcohol and other drug] service. So, they've [had] to go to the mental health [service] … the lack of combination between the two is something that I feel really passionately needs to be addressed.[159]

Consumers have told the Commission that this can mean they need to tell and then retell their story multiple times to practitioners at different services:

> Everyone ends up with their sort of own focus of where they think you should be. And how they think things should be handled … it might make things really difficult, when everything is so siloed … if we can start to integrate more services together … we need to be getting everyone working together on the one page.[160]

One mental health professional who participated in the mental health workforce survey, conducted by ORIMA Research on behalf of the Commission, explained that:

> There needs to be acknowledgement in the mental health system that mental illness and addiction happen concurrently, that it is difficult to separate, and the consumer should be treated for both their mental illness and addiction issues in one place, by the same clinician. There should be a 'no wrong door approach', and the consumer should not have to seek out separate services to address each issue, nor should they have to repeat their story to multiple services, especially if that story is traumatic and likely to cause the consumer more distress by repeating it.[161]

Submissions from peak addiction services emphasised that the barriers to getting integrated care can result in substantially poorer health and wellbeing outcomes for some people, particularly consumers with more complex treatment, care and support needs.[162] The VDDI stated that:

> There are several problems with the current systems approach to [people living with mental illness and substance use or addiction] … Integrated treatment can be difficult (e.g. the person with [mental illness and substance use or addiction] might be treated through disparate systems, which can impede treatment and diagnosis) … and the number of workers trained in [mental health and substance use or addiction] is limited.[163]

Personal story:

Kit

Kit lives in Melbourne but grew up in regional Victoria. They have experienced long-term mental health issues and dependence on methamphetamines. Kit said they were heavily dependent on drugs and not interested in engaging in treatment until they became homeless and had to find crisis accommodation. It was then that Kit started engaging with a non-residential withdrawal service. Kit said this service was very empathetic and helpful and assisted with a care plan.

The withdrawal service worked with Kit to get a psychological assessment, which recommended that a residential rehabilitation service would provide Kit with the extra support they needed to recover. Kit went to information sessions and found out about several different service options. During the process of referral and interviews with services, Kit recalls being told by an alcohol and other drug residential rehabilitation service not to disclose their history of mental illness, including previous admissions to mental health inpatient units.

> I'd been told to do that by counsellors, like, 'Do you really need to put that down? Because if you don't, it'll be easier for you to access treatment'. Essentially, because of my mental health, they believed that was going to be an impediment to access the service.

Kit was upfront during the interviews about their mental health issues and was subsequently referred for a psychiatric assessment, which recommended 'dual diagnosis' residential rehabilitation.

> I also felt that it would be the best option, but it meant that other rehabilitation services effectively turned me down.

There are a limited numbers of residential rehabilitation beds in Victoria that can treat people for both mental health issues and problems with substance use. After waiting about six months, Kit entered and completed a three-month 'dual diagnosis' residential rehabilitation program, which was able to treat both their mental health and substance use issues.

> This was the turning point for me, the beginning of my current life.
>
> I was also very sad to leave [my crisis accommodation]—the night before and the morning that I left I remember crying. I became very attached; it was a place I identified as saving my life. In the end I loved [the rehabilitation program] and cried a lot when I left there three months later. I experienced quite radical change in that time, and learnt that I had the capacity to change.

Kit explained what was different about the care provided in the residential rehabilitation service compared with other services and what had a positive impact for them.

> The nurse-to-patient ratio there was much better, with a high level of support, and there was a large multidisciplinary team. There was a real community feeling in the environment. I think the fact that it was built that way from the beginning made it really cool too. At no point did I feel like I was on a ward. It's a separate building to the hospital.

This program offered Kit their first regular contact with a psychiatrist. Before this, they had not had regular mental health treatment because they had not been considered eligible to access services like an adult mental health service. The psychiatrist also had a specialisation in addiction, which Kit said was very therapeutic in assisting their recovery in both mental health and substance use issues. The psychiatrist continued to provide treatment, care and support after discharge from the rehabilitation program.

> It was a pure fluke that I was able to continue to see this same psychiatrist after the rehabilitation, and I think this is something that should be embedded in the system.

Leaving a residential rehabilitation program can be a difficult transition, and this was particularly challenging for Kit. Having support as well as having stable housing after their discharge was really important.

> I've got a reasonably good support structure and a reasonably good routine. I'm living in transitional housing independently, with some support.

Source: Kit, *Correspondence to the RCVMHS*, 2020.

Personal story:

Michael Silva

Michael* and his family have been providing care and support to Michael's 55-year-old brother, Alan,* for more than 30 years. Alan has a diagnosis of bipolar disorder, including psychotic episodes, and experiences addiction to alcohol and other drugs.

Michael reflected that in his role as a carer he has not been able to find integrated treatment, care and support for Alan in the mental health system.

> We have never had an experience in the public mental health system of Alan being treated in an integrated way with respect to his dual diagnosis. Alan has eventually moved over to the private health sector, but even in the private health sector it's still only mental health and not integrated treatment.

Michael said he thought the mental health system was not equipped to respond to Alan's needs and found it 'rigid and inconsistent'.

> Alan's dual diagnosis meant that it was difficult for him to receive support. For example, we were once trying to give an explanation of Alan's dual diagnosis to a CAT [Crisis, Assessment and Treatment] Team. Their response was, 'We're not concerned about what the cause is. We just deal with the symptoms'.

Michael speaks of a stigma in the mental health system that Alan experienced because of his addiction and felt that he had to justify the need for Alan to be given mental health support.

> We felt that the mention of his use of illicit substances affected how people responded to the crisis. It was a situation of, 'Well, this is not really our domain. This is a drug and alcohol issue'.

The lack of integrated support for Alan has been an ongoing issue for Michael and his family. Michael said this has affected their own mental health.

> There is a lot of responsibility on the carers. My mother was not coping herself. For her, Alan's situation was a tragedy.
>
> There was a domino effect. It would start with Alan, and then my mother would become unwell herself, due to the stresses that she had. Then it would come through to me.

Michael believes access to a system providing integrated treatment, care and support would have been of great benefit to Alan and in turn help Michael and his family in their role as carers. Michael would like to see mental health and alcohol and other drug services more closely aligned.

> I think integrated treatment would give the family, us, something that we could work within … I feel that someone in a clinical role with training in dual diagnosis may have resonated with Alan.
>
> In the ideal world, there would be the one person, who understands both sides of the coin, working with a dual-diagnosis client.

Source: *Witness statement of Michael Silva*, 22 June 2020.

Note: *Names have been changed in accordance with an order made by the Commission.

Dr Cementon stated that, in certain cases, a failure to provide integrated care may lead to tragic outcomes for consumers:

> In the worst case scenario, there can be disputes over who takes clinical responsibility for patients with co-occurring mental illness and [alcohol and other drug] use, patients fall through these service 'gaps', and I've witnessed outcomes such as death as a consequence.[164]

Consumers and peak bodies described the experience of being 'bounced' between mental health and alcohol and other drug services, which can be detrimental to consumer wellbeing and mental health.[165] 'Bouncing' may occur because either a mental health service or an alcohol and other drug service has an exclusion policy affecting consumers.[166] One example of refusal of service is a consumer who wishes to go into alcohol and other drug rehabilitation but cannot do so because they take antipsychotic medication and the rehabilitation service has a strict no substances policy.[167] One submission summarised a common experience for consumers with co-occurring mental illness and substance use or addiction:

> A person assessed by mental health services receives feedback that before receiving any mental health service they first need to address their substance use—only then to be told by [alcohol and other drug] services that [they] first need to address their mental health concerns … thus falling through the gaps receiving no treatment from either service.[168]

Exclusion from treatment, care and support in Victoria's mental health services can occur for a range of reasons.[169] As a result of the separate service systems, mental health services tend to focus narrowly on a consumer's mental health needs and refer a consumer with substance use or addiction needs to an alcohol or drug service, particularly if they are actively using substances.[170] Dr John Reilly, Queensland's Chief Psychiatrist, said such referrals occur, not because providing integrated care is challenging, but because there is a perception that treatment, care and support for substance use or addiction is not the responsibility of mental health services.[171]

Dr Cementon explained that a narrow understanding of service delivery also acted as a barrier to people living with mental illness or psychological distress accessing support in alcohol or other drug services:

> Dual diagnosis is traditionally not considered to be 'core business', in either mental health or [alcohol and other drug] services, and it is often seen as a reason for exclusion from treatment programmes. This may lead to patients being referred to other services, or ultimately falling through service 'gaps'.[172]

Consumers, families, carers and supporters who participated in the Commission's community consultations shared their experiences of being excluded from services. For example, one person told the Commission:

> The assessment found that he had used marijuana and therefore he could not be admitted. He was denied access due to substance use.[173]

Mr Lawrence described how excluding consumers from services creates a barrier to recovery:

> [E]ven some tertiary outreach programs to homeless people with a mental illness will not see that person if they are drug affected. The question to ask here is 'How many homeless people with a mental illness are not illicit drug users?' Not many.[174]

The alcohol and other drug sector can also experience difficulties caused by a lack of access to mental health clinical support and services for consumers with acute needs. Mr Lawrence similarly stated that:

> Many specialist mental health services will not provide support to consumers if they have [alcohol and other drug] issues. In my view, a lot of specialist psychiatric services that could offer positive change through treatment will not see a person if they are drug affected or if there is an addiction component to their presentation.[175]

The Commission heard about experiences such as these from Kit, a consumer who experienced challenges accessing integrated care, before finding an integrated service that worked for them.

Families, carers and supporters told the Commission that they also felt excluded or unseen by services and that there was often a lack of care and compassion about their needs.[176] For example, during a focus group with families, carers and supporters of people who were living, or had lived with, substance use or addiction and mental illness, participants explained that families, carers and supporters can also experience feeling excluded from services:

> My son was wanting help and [was] looking [for it] everywhere, but we were not able to get it … alcohol [services] couldn't deal with his mental health. So we kept falling through the gaps … we lost count of the amount of ED [emergency department] presentations, where he's been labelled as a drug addict … but he actually wanted mental health help, because that was what was driving the drug use and the mental health, and we just couldn't get it.[177]

22.5.2 Experiences of stigma and discrimination

As described in Chapter 25: *Addressing stigma and discrimination*, people living with mental illness or psychological distress may experience stigma, where people are labelled, shamed or devalued because of negative and prejudiced stereotypes about their mental illness. They may also experience discrimination, which is unfavourable treatment on the basis of someone's personal attributes, including their mental health. People living with mental illness and substance use or addiction can be subjected to a compounded form of stigma because of pervasive negative stereotypes about people who use drugs.

Systematic reviews of Australian and international research indicate that stigma and negative attitudes about people who use substances is a well-recognised phenomenon.[178] Stigma and negative attitudes are held by society generally, and also among health professionals.[179] Common negative attitudes include that people who use substances are dangerous, unable to make decisions about their care or are to blame for experiencing addiction.[180]

As Turning Point stated in its submission to the Commission:

> the prevailing community thinking about addiction is that it is a moral condition that is self-induced, and this damaging paradigm is also applied to consumers with mental illness and co-occurring alcohol and other drug use.[181]

Stigma and shame are powerful barriers that can discourage people from seeking the treatment, care and support they need.[182] Australian research that analysed data from the National Survey of Mental Health and Wellbeing suggests that stigma is a major contributor to the delays of up to 20 years in seeking help for people with 'substance use disorders' compared with other diagnoses.[183]

Even when people do seek help and support from health services, some may experience discriminatory treatment by health professionals, undermining the treatment, care and support they receive.[184] Several witnesses described to the Commission the existence of stigma in Victoria's mental health workforce. For example, Dr Gruenert, said:

> There is particular stigma in the mental health workforce in relation to people who have problematic issues with [alcohol and other drugs]. This is depicted through the language that is often used to describe people with problematic [alcohol and other drug] issues (negative words such as 'addicts' or 'junkies' and reinforcing rare behaviour or incidences of violence).[185]

Negative stereotypes and moral judgements about substance use or addiction can undermine and influence the treatment, care and support that consumers receive in Victoria's mental health system.[186] For example, consumers described experiences of stigma and discrimination in Victoria's emergency departments:

> People say that, when they're in ED [an emergency department] … and they see that they're there for some kind of substance abuse issue, that their energy and their approach towards the patient changes … a lot of people feel very judged in those kind of settings … I think just having that integrated care and support that is specific to [alcohol and other drugs] in the ED, in that entry point, might really help just to educate people who don't work in the sector … for people who walk through the door to feel more understood and supported from the get-go, when they're in their most vulnerable state.[187]

Stigma and discrimination can no longer have any place in mental health and wellbeing services that provide integrated care. The future mental health and wellbeing system has the ability to change the way consumers access and receive mental health and alcohol and other drug services, to make it a positive experience and not one where they feel judged or ostracised for having a concurrent mental illness and addiction challenge.

The Commission's reforms relating to discrimination and stigma have a particular focus on the cultural and behavioural changes needed to eliminate such experiences in mental health services, including those that relate to people who are living with substance use or addiction.

22.5.3 Victoria's alcohol and other drug services provide treatment, care and support for consumers with complex support needs

Submissions to the Commission highlighted that severely limited access to mental health services and a lack of integrated care is placing pressure on Victoria's alcohol and other drug sector to provide treatment, care and support for consumers living with complex support needs and mental illness.[188]

Victoria's alcohol and other drug sector sees an increasing number of consumers who have complex support needs, including those relating to mental illness and psychological distress.[189] Submissions from Victoria's alcohol and other drug services have identified a range of challenges to providing treatment, care and support for people living with mental illness of psychological distress. This can cause challenges for the mental health system and other services:

> There remains a cohort of people living with [mental illness and substance use or addiction] who do not fit into either service system. These people are often too unwell to be supported in an AOD setting and not unwell enough to get access to acute or community mental health services, often leading to greater demand on emergency services, police (and corrections) or the coronial system.[190]

Submissions from Victoria's alcohol and other drug sector have stated that the sector is not resourced to provide treatment, care and support to people with complex mental health needs. Further, the alcohol and other drug sector finds it particularly challenging to gain access to specialist mental health or medical expertise such as addiction specialists or psychiatrists.[191] As a result, some services must rely on care provided by private GPs or emergency departments for consumers with complex mental health needs.[192] Windana, a drug and alcohol recovery service, identified in their submissions that:

> The [alcohol and other drug] sector would greatly benefit from more ready access to [a]ddiction [m]edicine [s]pecialists and [a]ddiction [m]edicine [p]sychiatrists.[193]
>
> [Alcohol and other drug] funding models are insufficient to support multidisciplinary teams that include more highly skilled and credentialled staff.[194]

Highlighting the challenge facing the alcohol and other drug sector to provide integrated care for consumers with complex support needs, Turning Point stated that:

> Currently, there is overwhelming demand for provision of assessment and treatment in areas of medical and psychiatric complexity, such as co-occurring pain, anxiety and addiction, heroin and depression, prescription opioid and other pharmaceutical misuse, complex trauma, alcohol and liver disease, methamphetamine and psychosis … The relative absence of a tertiary [alcohol and other drug] sector, and associated multidisciplinary team management, has a critical impact on recovery and outcomes for individuals with complex alcohol and other drug use and co-occurring mental illness.[195]

In 2018–19 the Victorian Government spent $260 million on alcohol and other drug services, compared with almost $1.6 billion on mental health services.[196] The then Department of Health and Human Services acknowledged that the current funding and service model in Victoria does not enable alcohol and other drug services to provide this integrated care unless the service is specifically designed to do so.[197] It acknowledges that this challenge is exacerbated by the barriers that consumers face when trying to access Victoria's mental health system.[198]

22.5.4 Barriers to mental health workforce capability relating to substance use or addiction

A consequence of separating alcohol and other drug services in Victoria has been reduced capability of the mental health workforce to provide treatment, care and support for people living with co-occurring substance use or addiction.[199] For example, Dr Reilly explained that Victoria's separation of mental health and alcohol and other drug services has meant that the mental health practitioners within them have not maintained the requisite skill set to offer integrated care.[200] This 'knowledge gap' means that practitioners and clinicians may not have the skills and knowledge to comprehensively deliver treatment, care and support to people with co-occurring substance use or addiction within mental health services.[201]

Professor Lubman stated that this skill deficit extends to a broad range of practitioners and clinicians, including GPs, and is due to the limited number of opportunities for the broader mental health workforce to undertake training in substance use or addiction:

> Since the 1990s across Victoria, there has been a generation of medical, nursing and allied health practitioners who have not had the opportunity to train in addiction settings or interact with Victorians in recovery, and as such, do not have the skills or knowledge to provide evidence-based care to this population, irrespective of setting. This gap in knowledge and experience has led to health practitioners having little confidence in [alcohol and other drug] interventions or the treatment system and being pessimistic, even nihilistic, in their views around treatment and recovery.[202]

Mental health services are challenged both by the capability of mental health practitioners and limited capacity to create multidisciplinary teams including alcohol and other drug or addiction-trained staff. For example, Ms Gail Bradley, Interim Operations Director of the NorthWestern Mental Health Service, stated:

> in relation to alcohol and other drugs, probably about 40 per cent of people who have a severe mental illness also have a substance misuse or dependence problem … helping them with that problem if they want the help is a really … important thing to be able to do, but we don't really have the capability amongst our mental health workforce … [we] employ alcohol and other drug clinicians …. [but] in the other area mental health services within NorthWestern Mental Health [there is only] access to a 0.3 position … It's simply not adequate.[203]

A particular challenge is the current under-supply of addiction specialists in Victoria. It is estimated that, in 2020, Victoria's fulltime-equivalent addiction specialist capability is only 16 fulltime-equivalent staff across five health services (Western Health, Turning Point at Eastern Health, St Vincent's, the Alfred, Monash Health and Ballarat).[204] Addiction specialists are medical doctors (both physicians and psychiatrists) who have advanced training in addiction, including drug and alcohol addiction. By comparison, as at June 2019, the estimated number of addiction specialists in New South Wales was 81.75 fulltime-equivalent positions, comprising 7 per cent of total alcohol and other drug workforce fulltime-equivalent roles.[205] While New South Wales has many more addiction specialists than Victoria, it is noteworthy that the Special Commission of Inquiry into Crystal Methamphetamine found that even the current levels of addiction specialists were not sufficient to meet demand for these services in that state.[206]

22.6 The case for integrated treatment, care and support for mental illness and substance use or addiction

There are many benefits to offering integrated treatment, care and support for people living with mental illness and substance use or addiction.

22.6.1 Removing the barriers to comprehensive mental health care

One of the Commission's guiding principles is that Victoria's future mental health and wellbeing system will ensure that:

> Comprehensive mental health treatment, care and support services are provided on an equitable basis to those who need them.[207]

Equitable access to health care is recognised as a human right that allows people to enjoy the best health possible.[208] Realising this right requires continuous work from governments to ensure barriers to care for certain groups of consumers are identified and dealt with.[209] This is particularly important where people with lived experience of mental illness or psychological distress are marginalised or excluded—for example, due to discrimination—from accessing health care. Barriers to accessing health care also include services that do not provide integrated care for people with more complex support needs.

In the future, Victorians who experience both mental illness and substance use or addiction will receive integrated and comprehensive treatment, care and support. Substance use or addiction will not be a barrier to getting mental health treatment, care and support. Mental illness will not be a barrier to getting treatment, care and support for substance use or addiction. This will help to realise the right to health for this group of consumers and will be necessary to fulfill the Commission's vision for Victoria's mental health and wellbeing system.

Case study:

Te Wairua (Odyssey New Zealand)

Odyssey New Zealand runs residential and community services that offer supportive peer environments for adults, young people and extended families to build on their existing strengths and learn new skills that enable long-term recovery from drug, alcohol and other addiction challenges.

Odyssey operates Te Wairua, a residential service for adults seeking support with mental health and addiction issues. There are three Te Wairua services, two in Auckland and one in Whangarei, and each offers a hopeful, compassionate environment in a small residential setting accommodating 11–19 people. During their stay, residents are supported to develop skills and strategies to manage their emotional, spiritual, physical and social wellbeing to help with their recovery.

Jenny Boyle, General Manager of Operations at Odyssey, said Te Wairua provides services to people who require specialised mental health support in addition to general alcohol and other drug services.

> Te Wairua offers an option for people who may be living with moderate to severe mental health issues, who would benefit from a residential stay to support them with their addiction challenges.

Ms Boyle said the program is based on a treatment approach called a therapeutic community, with the service provided in a home-like environment in a residential area.

> Everyone who lives or works in our therapeutic community lives by a set of shared values, known as our pillars. These are trust, honesty, responsibility, concern and love. Learning occurs in the way everyone lives and works together as residents and staff, and in the roles and responsibilities shared across the community. It's all about helping people gain skills to be more in control of their life, free from drug, alcohol or other addiction challenges.

Ms Boyle said routine is critical to the success of the program. Each house follows a timetable of scheduled jobs, activities and group sessions, as well as time for recreation or relaxation.

> We offer a range of supportive, evidence-based interventions, as well as creative, social, cultural and outdoor activities, such as kapa haka [traditional Māori performance] or other tikanga Māori [customary practices or behaviours] study and practice. There are also work training programs available.

Photo credit: Odyssey New Zealand

Residents are able to stay in the program for a number of months and Odyssey works in partnership with other community agencies to ensure they are supported before, during and after their stay.

Residents have noted the program has helped them recover and to change their behaviour. One resident said:

> All the connections I need in my life to have a healthy lifestyle are back in my life and I'm starting to see the person I used to be, but an even better version. I'm a better mother, a better person. I've found that love and acceptance of myself. I like that.

Source: Odyssey, 'Te Wairua' <www.odyssey.org.nz/our-services/pakeke/te-wairua> [accessed 19 October 2020]; *Visit to Odyssey House with Commissioner Armytage*, 17 September 2019.

Case study:

ReGen (Uniting)

Uniting's ReGen service aims to reduce the harm from problematic alcohol and other drug (AOD) use and promote health and wellbeing. ReGen has grown from being a specific AOD service into an integrated AOD and mental health service.

Laurence Alvis, Uniting's General Manager, Alcohol and Other Drug and Mental Health, spoke of the importance of integrating both services:

> We previously were an AOD specific service which found it very frustrating not to have integrated mental health services. There is a strong interaction of our clients, around 70 per cent would have both mental health and AOD issues.

The integration of support services at both service delivery and governance levels is an area that continues to be a focus for Uniting more broadly. Mr Alvis said:

> The exciting part of Uniting merging AOD and mental health, is that in solving AOD issues, you can address the co-existing issues for clients. That is where we see the key opportunities going forward.

ReGen determined that without joint treatment, care and support people would pass through the treatment for AOD but would return repeatedly. Mr Alvis said the integration breaks down siloed approaches to services, and when they started working with everyone together, 'normal stresses under normal life circumstances didn't push people into addiction again'.

The provision of an integrated AOD and mental health service also supports a good relationship with local clinical mental health services, again supporting a more holistic service for consumers.

A psychiatric registrar comes into ReGen's youth and adult residential withdrawal programs to support consumers and staff and for secondary consultation. Mr Alvis notes the importance of leadership in both organisations recognising the links between AOD and mental health services:

> This partnership is based on a strong relationship with Northern and NorthWestern Mental Health services. It has been great having leaders who recognise that AOD is a critical part of mental health and see there is a benefit to the clientele of continued collaboration.

ReGen also offers a long-term non-residential program that is targeted at those with severe AOD, mental health and homelessness issues. This supports consistency of clinicians throughout a person's rehabilitation journey. According to Mr Alvis, this builds trust, reduces the risk of dropping out and enables ReGen to comprehensively address a range of issues over a longer period of time.

In addition, ReGen is a registered training organisation that offers training opportunities for AOD workers and provides free courses for consumers and carers, including court and drink drive referrals.

To support ReGen's integrated approach, staff are trained across both AOD and mental health sectors. All AOD workers complete three mental health competencies, as well as forensic and family violence competencies, in order to provide holistic support.

Source: Uniting ReGen meeting with Commissioners Armytage, Cockram and Fels, 16 April 2020.

22.6.2 Integrated care for better mental health and wellbeing outcomes

Several witnesses who gave evidence stated that, in their professional experience, integrated approaches to treatment, care and support are internationally recognised as delivering the best consumer outcomes, including increased likelihood of recovery and improved mental health.[210] The Commission has heard that:

> People should expect to receive treatment that reflects their needs, rather than conceptualising them as an assortment of conditions that need to be compartmentalised and referred off to multiple providers for treatment.[211]

Consumers who engaged with the Commission also expressed a preference for integrated care.[212] Consumers, families, carers and supporters commonly expressed a preference for compassionate, empowering and stigma-free service delivery that is welcoming, recognises co-occurring needs, is person-centred and has a strong focus on peer and lived experience support.[213]

For many consumers, integrated treatment, care and support is likely to support better health and wellbeing outcomes.[214] Mr Symonds told the Commission that integrated care can:

> ensure internally consistent treatment with common objectives, which can explore the complex relationship between conditions. This single point of contact reduces the burden on the individual, along with potential communication problems and discordant treatment philosophies, reducing the chance of clients falling through treatment gaps.[215]

In addition to being a recommendation of the Productivity Commission *Mental Health Inquiry Report*, integrated treatment, care and support is also recommended by Australia's Fifth National Mental Health and Suicide Prevention Plan.[216] The National Drug Strategy has also emphasised the importance of service collaboration and coordination to ensure that the most appropriate treatment and support is offered to consumers.[217]

Integrated care for mental health and substance use or addiction is an approach widely adopted in other countries (such as Canada) as well as certain services in Queensland, a state where mental health and alcohol and other drug services are integrated at the policy and governance levels.[218]

One such service, profiled in a case study in this chapter, is New Zealand's Te Wairua (Odyssey House), which offers integrated care for people with addiction and mental illness.

Another international example of integrated service delivery is a new centre for mental health, addiction treatment and research that will open in 2021 in British Columbia, Canada, to treat people who live with the most severe, complex mental illness and substance use or addiction. The service, which is called the Red Fish Healing Centre, is in part a response to British Columbia's opioid crisis. The 105-bed facility will offer a therapeutic, trauma-informed space and healthcare model to respond to the many needs of a person's recovery journey. It is envisaged that people will usually stay in the centre for six to nine months. The new service will help people learn how they can live a life that is meaningful to them and help with their eventual transition to care in their home communities.[219]

The therapeutic design of the centre features private single rooms with bathrooms, adjustable lighting to help people who don't have standard sleep cycles, and a considered use of textures and colours to support a calm, healing environment. The facility will also feature dedicated spaces for research and education, as well as virtual technologies to provide specialised services. The entire centre will be virtually enabled, including a multipurpose room for community events, allowing patients, families, caregivers and educators across the province to connect.[220]

Trauma-informed practice has been integrated at every level of the centre's design so the multidisciplinary teams of physicians, clinical and support staff are all sensitive to the effects of trauma, and work to avoid re-traumatisation. The centre was developed in close consultation with staff, clients and their families.[221]

In the United States, the influential work of Christie Cline and Kenneth Minkoff has emphasised the need for health services to provide a 'welcoming, accessible, integrated, continuous and comprehensive system of care that can support an array of evidence-based and consensus-based best practices for individuals'.[222]

Several systematic reviews have indicated that integrated care offered in different settings is associated with better outcomes for consumers in certain situations, including:

- better participation in care and treatment programs and interactions with services[223]
- less substance use and improvements in mental health symptoms[224]
- other indicators of wellbeing, including improved quality of life and decreased risk of homelessness or interaction with the justice system.[225]

22.6.3 Integrated services in Victoria

The Commission has observed that a number of services in Victoria currently provide integrated treatment, care and support. In addition, some area mental health services employ clinicians and other practitioners who provide 'dual diagnosis services' or other coordination roles.[226] There are also partnerships between alcohol and other drug and mental health services, services that employ multidisciplinary teams, or services that have merged their mental health and alcohol and other drug units.[227] Often, these services are in the community health or non-government sectors. One such service is Uniting ReGen (refer to Uniting ReGen case study).

22.7 The future system: providing integrated treatment, care and support for mental illness and substance use or addiction

Victoria's future mental health and wellbeing system will be a responsive and integrated system that focuses on providing treatment, care and support through new models of care in the community. Integrated care for substance use or addiction will be a core function of mental health and wellbeing services for young people, adults and older adults. It will also be an expectation of Victoria's emergency departments, including the new Mental Health and Wellbeing Crisis Hubs located in each region. For consumers who need to find community or hospital bed-based care, integrated care for co-occurring substance use or addiction will be provided alongside mental health treatments and therapeutic interventions.

Stakeholders from a broad range of sectors have recommended that the Commission create the necessary reforms to provide consumers with integrated treatment, care and support.[228] However, the Commission acknowledges that different stakeholders have different perspectives about *how* integration should be achieved. Broadly, these perspectives are:

- **full system integration**—integration of mental health services and the entire alcohol and other drug sector in Victoria, including shared governance and funding[229]
- **service integration**—integration of treatment, care and support offered in mental health services while retaining a separate alcohol and other drug sector in Victoria[230]
- **increased service linkage**—enabling increased coordination and collaboration between mental health and alcohol and other drug services, such as stronger referral pathways.[231]

These differences were also apparent in a public hearing panel on how to support people living with mental illness and substance use or addiction, where expert participants advocated for different approaches to achieving greater integration of care.[232] Although there are diverse views about how this should be achieved, the Commission notes that, overall, there is agreement that a greater degree of integration of care is critical for people living with mental illness and substance use or addiction.

The Commission has therefore chosen to focus on which reforms can deliver an experience of integrated care for consumers in Victoria's mental health and wellbeing system. This approach to integration focuses on how services can best respond to the needs of consumers and aligns with the approach recommended by global experts on mental illness and substance use or addiction:

> Any process by which mental health, and alcohol and other drug services are appropriately integrated or combined at either the level of direct contact with the individual client with [co-occurring needs] or between providers or programs serving these individuals … Integrated services can be provided by an individual clinician, a clinical team that assumes responsibility for providing integrated services to the client, or an organised program in which all clinicians or teams provide appropriately integrated services to all clients.[233]

As set out in Figure 22.10, in the future system consumers will access treatment, care and support across a variety of settings, in accordance with the intensity of their needs and preferences. The figure shows that the future system retains an important role for the standalone alcohol and other drug sector, separate to the mental health and wellbeing system. However, the future system would not expect alcohol and other drug providers to be supporting people with high-intensity mental health support needs generally, and certainly not without support from mental health and wellbeing services. Instead people requiring high-intensity mental health treatment, care and support (who are sometimes described as having 'severe' mental illness) will have their comprehensive needs met by Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services. Specifically, the Commission expects that Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will offer integrated treatment, care and support that includes support for substance use or addiction.

This approach aligns with the thinking in the 'quadrant of care approach' used by Queensland Health.[234] It is also used by the United States Department of Health and Human Services in planning its services for people living with mental illness and substance use or addiction.[235] It is designed to assist different services across an entire health system by providing 'guidance for the level of service coordination (defined as consultation, collaboration, or integration) needed to improve consumer outcomes' and to 'facilitate improvements in coordinated care across the mental health and alcohol and other drug treatment sectors'.[236] Although they have limitations, such models can help in planning a system that can respond to the different needs of people living with mental illness and substance use or addiction.[237] In Queensland, which integrates mental health and substance use or addiction care at the system-wide level, the model has been accompanied by an expectation that the mental health system offers treatment, care and support for people living with substance use or addiction.[238]

The approach also shows that at several points in the system, secondary consultation should be used to support people to continue to get treatment, care and support without them having to be referred or 'handed over' to a different provider. This includes Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services providing support to alcohol and other drug providers and the new statewide service for mental health, substance use or addiction (described in this chapter) providing support to Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services.

Figure 22.10: Continuum of care for people living with mental illness and substance use or addiction in the responsive and integrated care system

People living with mental illness and substance use or addiction will be supported in different settings depending on the intensity of their mental health and wellbeing support needs and their need for integrated treatment, care and support. At any point in time, consumer needs will fall into one of five categories:

Consumers with limited need for integrated treatment, care and support, primarily supported by alcohol and other drug services

Consumers primarily supported by alcohol and other drug services or primary or secondary mental health providers, with need for occasional integrated approaches to care, accessed through secondary consultations from Local Mental Health and Wellbeing Services or Area Mental Health and Wellbeing Services

Consumers needing moderate- to high-intensity integrated treatment, care and support across mental health and wellbeing and substance use or addiction, to be provided by Local Mental Health and Wellbeing Services, with inreach support from Area Mental Health and Wellbeing Health Services

Consumers needing high-intensity integrated treatment, care and support across mental health and wellbeing and substance use or addiction, to be based in Area Mental Health and Wellbeing Health Services, with some support provided potentially through Local Mental Health and Wellbeing Services

Consumers needing the highest intensity integrated treatment, care and support across mental health and wellbeing and substance use or addiction, supported by Area Mental Health and Wellbeing Services, with inreach support from new statewide service for mental health, substance use and addiction

22.7.1 Approaches to implementing integrated treatment, care and support

Victoria has existing mental health and alcohol and other drug services across the state. These services have developed to meet the needs of local communities over time. With this in mind, the Commission has determined not to prescribe a single model of integrated care. This choice also recognises that in Victoria there are already existing integrated services of the kinds described in Table 22.1, currently offering integrated treatment, care and support.

Different models can successfully deliver integrated care through configurations that respond to the needs of local communities. Adapting services to the local context is essential when designing and implementing responsive mental health and wellbeing services.[239]

The Commission's expectation is for integrated care to be provided by all Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services, for people of all ages. This includes young people who access Youth Local Mental Health and Wellbeing Services and the service stream of Youth Area Mental Health and Wellbeing Services, which is a substantial shift in the current model of mental health treatment, care and support for young people and is described in Chapter 13: *Supporting the mental health and wellbeing of young people*. To decide the approach taken by each Local Mental Health and Wellbeing Service and Area Mental Health and Wellbeing Service, services will be assisted by Regional Mental Health and Wellbeing Boards, described in detail in Chapter 5: *A responsive and integrated system*. Regional Mental Health and Wellbeing Boards will commission the providers of those services using set criteria, which will allow local providers to assess the best of the above integration approaches for their community and service context.

The Commission expects that regardless of the model of integration adopted by each service, each will deliver integrated treatment, care and support that comprehensively meets the needs of consumers in those services specifically. This will be care that is simultaneous, empathetic and matched to the level of need of the consumer and delivered in a timely and coordinated way.

This includes the expectation that Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will provide culturally appropriate treatment, care and support that is responsive to the needs of diverse consumers, and is described in further detail in Chapter 21: *Responding to the mental health and wellbeing needs of a diverse population*. In particular, these services will provide integrated treatment, care and support that is appropriate to the needs and preferences of Aboriginal consumers. This may include models of integrated care formed through partnerships with Aboriginal controlled community health organisations, or alcohol and other drug services for Aboriginal Victorians.

In order to implement the delivery of integrated treatment, care and support, the Commission expects that Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will achieve integration through one or more of the three models outlined in Table 22.1. Importantly, consumers should not be 'bounced' between different services or practitioners.[240] As the World Health Organization states, '[t]ruly integrated care involves more than co-locating health workers with diverse specialties into the same building.'[241] Therefore, across all three approaches, care coordination will play a vital role in delivering integrated care. While Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will have the flexibility to decide which implementation model best meets the needs of their local communities, mental health and wellbeing services will be accountable for delivering integrated treatment, care and support for substance use or addiction.

Table 22.1: Models for implementing integrated treatment, care and support in Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services

Model 1: Multidisciplinary teams Practitioners and clinicians, as well as peer workers, provide integrated care in a single service setting. There is a high degree of collaboration and coordination to deliver consumer care.	For example, in an acute bed-based service, multidisciplinary teams such as mental health nurses, addiction medicine specialists, psychiatrists, lived experience workers, social workers and other allied health workers work together in an integrated way to deliver treatment, care and support. An example of care provided by multidisciplinary teams is that delivered by First Step (mentioned throughout this chapter). First Step's model of care involves multidisciplinary practitioners and clinicians working together to deliver care in a single setting. The team includes GPs, an addiction specialist physician, nurses (including mental health nurses), lawyers, clinical and counselling psychologists and a psychiatrist.[242]
Model 2: Co-location and care coordination partnerships Different services physically co-locate and deliver coordinated care.	For example, in a community mental health service, a mental health service and a non-government provider of alcohol and other drug services physically co-locate. Through care coordination and single care planning, they deliver the integrated services needed to meet the consumer's needs. Regular case conferencing and shared consumer records and information enable seamless and coordinated care, where all care providers work towards joint care goals. Care coordination and shared information systems are critical components in this model.
Model 3: Service delivery partnerships A mental health service partners with another care provider, such as a non-government organisation, to deliver some aspects of the consumer's care within the mental health service.	For example, in a community bed-based service, the mental health service could partner with a non-government organisation to provide peer-support workers or counselling for consumers with substance use issues or addiction, delivered in the mental health service. An example of this is community health organisation cohealth's Homeless Outreach Mental Health Service. This service is located at cohealth's Melbourne CBD site and involves a range of partner organisations (Inner West area mental health service, Launch Housing and McAuley Services for Women) that work together to deliver integrated care to people experiencing homelessness, mental health and other complex support needs.[243] Cohealth itself offers a range of services for people who use substances: health care, drug and alcohol counselling, needle exchange and non-residential withdrawal nursing services.

The Commission also acknowledges that some contributors, particularly those representing Victoria's alcohol and other drug sector, have cautioned that where mental health and alcohol and other drug services are integrated 'mental health becomes the dominant approach and services become more clinical. This does not work for [alcohol and other drug] services'.[244]

It will be critical to ensure that the strengths of Victoria's alcohol and other drug sector are retained in any future integration, including within individual services. Integration should not come at the expense of the consumer-centred model of care that Victoria's alcohol and other drug sector has been able to develop over many years. This will require the leaders of mental health services to recognise and support integrated care as core business:

> The first thing that is required in order to achieve integrated care is clinical leadership to drive cultural change. Responding to people with dual diagnosis with integrated care must be recognised as 'core business'.[245]

The Commission intends that the strengths of the alcohol and other drug sector be retained and suggests that integration through partnerships and consortiums be considered as ways to enable this.

22.8 Supporting the system to provide integrated treatment, care and support for mental illness and substance use or addiction

Achieving integrated care for consumers in some mental health services will be relatively straightforward because integrated care is already provided. Other services will deliver integrated care through newly created partnerships with alcohol and other drug service providers, while others will choose to expand their workforce to create multidisciplinary teams. Each of these approaches to integrated care is valid, provided that all Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services:

- comprehensively meet the needs of consumers living with mental illness and substance use or addiction at that service by offering integrated care to consumers of all ages by the end of 2022
- ensure no consumers are excluded from getting mental health treatment, care and support on the basis that they also need support for substance use or addiction
- have the right practitioners and clinicians to provide integrated care, which can be achieved through multidisciplinary teams, partnerships between services or co-location of services.

The transition of Victoria's mental health services to providing integrated care to consumers will require support, including:

- establishing, funding and supporting a new statewide service for mental health, substance use or addiction to provide expert support to mental health services and alcohol and other drug services—this should be built on the foundations established by the Victorian Dual Diagnosis Initiative
- ensuring the strengths of the Victorian alcohol and other drug sector's approach to care are adopted and retained in mental health services that provide integrated care, including the role of peer workers
- responding to the under-supply of addiction specialists in Victoria, including by increasing the number of addiction specialists and exploring joint Commonwealth–state opportunities for funded addiction specialist trainee positions in Victoria.

22.8.1 A new statewide service for mental health and substance use or addiction

Victoria currently has two statewide services for co-occurring mental illness and substance use or addiction, as well as a statewide service that provides 'dual diagnosis' support to both mental health and alcohol and other drug services (described earlier).

However, the Commission considers that it is necessary for the Victorian Government to establish a new statewide service to support the future responsive and integrated system.

It is the Commission's view that this service be built on the foundations established by the Victorian Dual Diagnosis Initiative.

This statewide service will work closely with the Collaborative Centre for Mental Health and Wellbeing, in particular in relation to translational research and workforce training and education. The main functions of this service are to support Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services across age-based systems to deliver integrated treatment, care and support. It will also provide secondary consultation to alcohol and other drug services, who will continue to play an important role in supporting some consumers with less complex mental health support needs. However, it is also expected that for a very small number of consumers with the most intensive and complex support needs, the statewide service will provide direct treatment, care and support through primary consultation.

This new statewide service will provide the necessary support to mental health and wellbeing services and play an important role in increasing Victoria's capability to support people with mental illness and substance use or addiction. Chapter 5: *A responsive and integrated system*, outlines the Commission's approach to statewide services in the future. In line with the service delivery models outlined in that chapter, the new statewide service will adopt a combination of 'capability uplift', 'direct service provision' and 'hub-and-spoke' models, in order to perform the following functions:

- **research**—this will ensure continuous improvement and best practice. It is expected that the new statewide service will lead research into substance use or addiction and mental health, as well as research into optimal ways of delivering integrated care in Victoria for people who have mental health needs and substance use or addiction needs
- **training and education**—this will increase the substance use or addiction and mental health capability of practitioners and clinicians across Victoria's mental health and alcohol and other drug services. It is expected that a broad range of practitioners and clinicians will be able to take training in substance use or addiction and mental health, with a focus on optimal delivery of integrated care
- **supporting consumers with the most complex support needs**—the service will provide primary consultation to consumers with the most complex support needs in Area Mental Health and Wellbeing Services. Primary consultation can be done in person, or virtually if appropriate.
- **supporting practitioners and clinicians**—the service will provide secondary consultation to mental health and wellbeing practitioners and clinicians working in Local Mental Health and Wellbeing Services, Area Mental Health and Wellbeing Services, as well as in alcohol and other drug services. This can be in person or virtually, particularly when considering the needs of rural or regional services.

The Commission highlights the role that the Victorian Dual Diagnosis Initiative has played over many years in increasing coordination and collaboration between mental health and alcohol and other drug services.[246] This initiative was designed to create links with related agencies including primary care, family violence and homelessness services.[247] The initiative has been central to building 'dual diagnosis capability' across services in Victoria.[248]

The Commission considers that the expertise of practitioners and clinicians who deliver the initiative will be invaluable to supporting the transition to integrated care delivered in mental health services and suggests that the expertise of those involved in the initiative continue to be a feature in the new statewide service.

22.8.2 Increasing the number of addiction specialists in Victoria

Victoria's 2015 *Ice Action Plan* identified a need to strengthen Victoria's addiction medicine capability.[249] Since 2016, Turning Point has undertaken work to increase the number of addiction specialists.[250] This work has included a review of Victoria's addiction specialist workforce and its sustainability, as well as analysing workforce models that may assist this process, such as that used in the Hunter New England region of New South Wales.

Addiction specialists are medical doctors (both physicians and psychiatrists) who have advanced training in addiction, including drug and alcohol addiction. For physicians, this is Advanced Training in Addiction Medicine and for psychiatrists, this is Advanced Training in Addiction Psychiatry. Addiction specialists provide care to consumers with complex needs, such as alcohol or opioid dependence. They also play an important role in training, mentoring and advising other health professionals, such as general practitioners or other physicians and psychiatrists about addiction medicine, including through secondary consultation.[251] Addiction specialists also provide consultation liaison services in hospitals, where they provide advice on care and best clinical management for people with substance use issues, such as in emergency departments, and enhance the knowledge of general hospital staff in addiction and substance use.[252]

The Commission has heard that to increase the number of addiction medicine specialists, more trainees are needed. Several submissions noted that Victoria has more limited addiction medicine training opportunities than any other state:

> **The numbers of trainees and qualified addiction specialists are particularly low in Victoria due to a chronic lack of investment in training and specialist positions: New South Wales, by way of contrast, has almost six times the numbers of addiction doctors in training as Victoria, as well as funded addiction specialist positions within each health service.**[253]

The project run by Turning Point has resulted in an increase in the number of addiction specialists and trainees. Turning Point has estimated that due to an increase in the number of addiction medicine trainees, by 2021 Victoria's capability will increase to 18 trainees.[254] Turning Point's project has also increased the number of accredited training sites for addiction medicine trainees from four to 11 hospital sites.[255]

The Commission acknowledges the outcomes of this project, which have demonstrably increased both the number of training sites and the number of trainees in addiction medicine. Victoria's new approach to providing integrated care requires that there are enough addiction specialists in its public health system. In light of this, and Victoria's current under-supply of addiction specialists, the Commission recommends that the Victorian Government, as a priority, increases the number of addiction specialists in Victoria.

The Victorian Government should also work with the Commonwealth to explore options for funding trainee positions, as well as funded opportunities for GPs to increase their addiction knowledge and skills through training. The importance of collaboration between the Victorian Government and the Commonwealth to secure the appropriate workforce supply, including of addiction specialists, is explored in Chapter 33: *A sustainable workforce for the future*.

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Chapter 23

Improving mental health outcomes across the criminal justice, forensic mental health and youth justice systems

Recommendation 37:

Supporting the mental health and wellbeing of people in contact with, or at risk of coming into contact with, the criminal and youth justice systems

The Royal Commission recommends that the Victorian Government:

1. expand the Assessment and Referral Court to each of the 12 headquarter Magistrates' Courts to meet demand at both existing and new locations.
2. expand the existing forensic community model to:
    - a. enable Adult and Older Adult Area Mental Health and Wellbeing Services and Infant, Child and Youth Area Mental and Wellbeing Services (refer to recommendation 3(2)(c)) to provide consistency in treatment, care and support to people in contact with, or at risk of coming into contact with, the criminal justice system; and
    - b. establish the specialist behaviour response team described by the Royal Commission in its final report.
3. establish a program of supports for people in prison living with mental illness who require ongoing intensive treatment, care and support to transition the delivery from correctional settings to the mainstream mental health and wellbeing system upon their release.
4. expand specialist youth forensic mental health programs to a statewide model, including across the 13 Infant, Child and Youth Area Mental Health and Wellbeing Services (refer to recommendation 3(2)(b) and (c)), to provide consistent and appropriately specialised treatment, care and support to children and young people in contact with, or at risk of coming into contact with, the youth justice system.

Recommendation 38:

Providing safe and appropriate mental health treatment, care and support at Thomas Embling Hospital

The Royal Commission recommends that the Victorian Government:

1. in line with master planning for Thomas Embling Hospital and the proposal of the Victorian Health and Human Services Building Authority:
   - **a.** refurbish the existing 136 beds; and
   - **b.** by the end of 2026, provide an additional 107 beds, a small number of which should be allocated for people living with mental illness whose treatment, care and support requirements cannot be safely and appropriately met in acute inpatient settings or through the forensic community model (refer to recommendation 37(2)).
2. provide up to 20 beds, in addition to the 107 beds referred to in recommendation 38(1)(b) and the additional beds in recommendation 11(3), to support people living with mental illness whose treatment, care and support requirements cannot be, or are unlikely to be, safely and effectively met in other extended rehabilitation settings.

23.1 Improving mental health outcomes across the criminal justice system

The Royal Commission has been tasked with inquiring into and reporting on how to improve mental health outcomes for people in contact, or at greater risk of contact, with the criminal justice, forensic mental health and youth justice systems. These three systems comprise:

- the adult criminal justice system—including police, courts, prison and community-based management of offenders
- the forensic mental health system—including community and inpatient services for people living with mental illness who have offended or are at risk of offending
- the youth justice system—including police, the Children's Court, youth justice centres and community-based management of young people.

These three systems present unique opportunities to improve mental health outcomes. People living with mental illness are over-represented throughout the criminal justice system, including in prisons. For some people, interactions with the criminal justice system may be the first time they can access mental health treatment, care and support. In a well-functioning system, this access can be facilitated through police, courts, prisons and in community-based services. The Commission has a unique opportunity to improve service access for people living with mental illness who are often excluded from mainstream service delivery.

In examining this issue, the Commission has considered evidence about best practice treatment and current research and has listened to the experiences and views of people with lived experience of the justice system.

Like other members of the community, those in contact with the criminal justice system need continuity and consistency in mental health treatment, care and support. As Dr Emma Cassar, Commissioner of Corrections Victoria at the Department of Justice and Community Safety, articulated:

> **The mental health care of those in contact with the justice system, or at risk of contact, should be a part of a lifetime continuum of care responsive to their health needs. Access to and quality of mental health care should not change based on a person's legal status.**[1]

This is currently not the case in Victoria. Evidence received by the Commission paints a picture of a mental health system under strain, which is in turn placing pressure on police, courts and prisons. While there are pockets of progress, these systems and services are not structured and resourced to adequately support people living with mental illness.

Ms Peta McCammon, Associate Secretary at the Department of Justice and Community Safety, described the interface between the justice system and the mental health system as fragmented, poorly coordinated and impeded by capacity constraints.[2] Specifically, Ms McCammon highlighted:

- poor coordination between justice and community services
- capacity constraints in community-based mental health services that result in the justice system becoming mental health treatment providers of last resort
- lack of continuity in how people transition out of the criminal justice system and back into the community.[3]

The Commission has made recommendations directed at improving outcomes for people living with mental illness who are involved in the criminal justice system. Specifically, these recommendations seek to:

- improve coordination between justice and mental health and wellbeing services through increased access to problem-solving courts
- ensure that community-based Area Mental Health and Wellbeing Services have capacity to offer forensic mental health services to people who need it
- improve transitions out of the criminal justice system for people living with mental illness.

23.1.1 Rates of imprisonment and community-based supervision orders

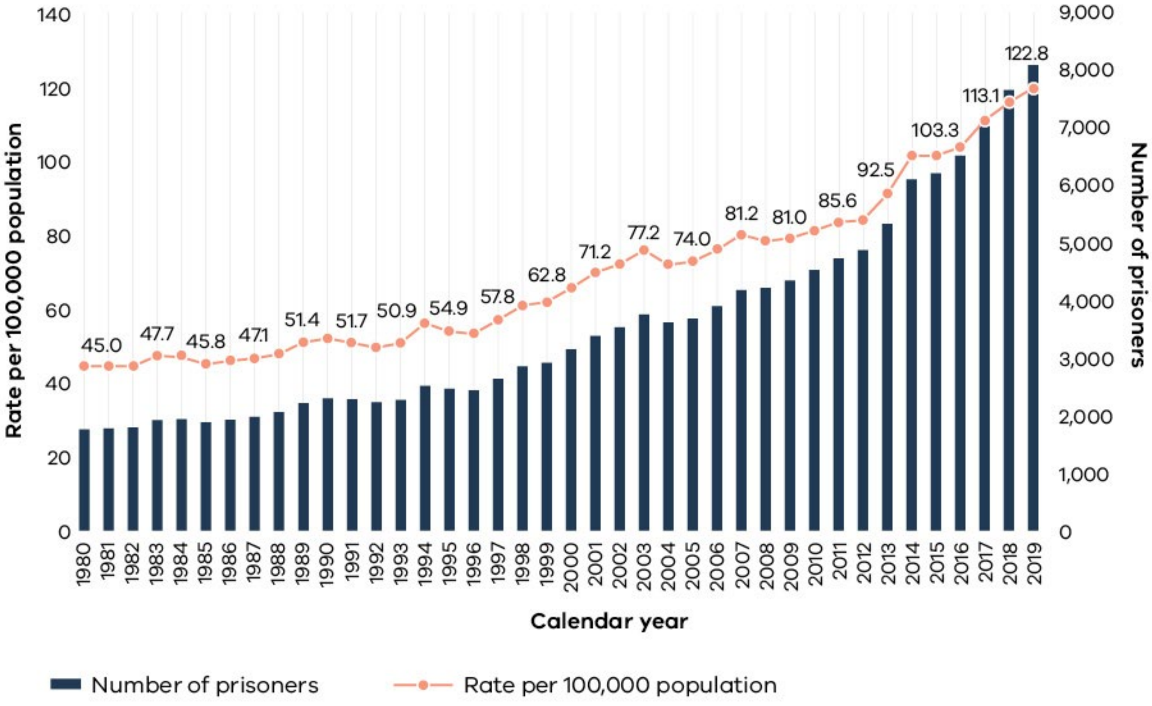
For the past 20 years there has been a consistent upward trend within Victoria in the proportion of the adult population in prison.

In Victoria the imprisonment rate has almost doubled over the past 20 years. In 2019 the rate was 123 prisoners per 100,000 people compared with 62 per 100,000 in 1998 (and 38 per 100,000 people in 1977).[4] The Aboriginal imprisonment rate more than doubled between 2009 and 2019, from 839.4 to 2,267.7 per 100,000 adults.[5] The increase in the number and rate of Victorian prisoners since 1980 is shown in Figure 23.1.

This increase is not explained by increasing crime rates, which have mostly declined over the same period.[6] Rather, it is primarily explained by reporting rates, policing practices, sentencing laws and bail laws.[7]

As the Commission delivers its report it is not entirely clear what the ongoing impact of the COVID-19 pandemic will be on prisoner numbers. Between 31 January 2020 and 30 November 2020 there was a 13 per cent decrease in the sentenced prisoner population (from 5,017 to 4,381) and a 13 per cent decrease in the remand population (from 3,143 to 2,728).[8] Remand is when an accused person does not get bail and is held in custody in the lead-up to finalising their charges. For all sentenced and unsentenced prisoners, there has been a 12 per cent decrease for male prisoners and a 19 per cent decrease for female prisoners.[9] The Commission does not have access to data to explain this decrease, but it may be attributable to the increased access to—and size of—Commonwealth benefits and support, programs to reduce rough sleeping and homelessness by the Victorian Government, and a reluctance of judicial officers (judges and magistrates) to place more accused people on remand due to current delays in the criminal justice process and the increased health risks of closed environments.

Figure 23.1: Number of prisoners and rate of prisoners per 100,000 population, Victoria, 1980 to 2019



Source: Sentencing Advisory Council, 'Victoria's Imprisonment Rates' <www.sentencingcouncil.vic.gov.au/statistics/sentencing-trends/victoria-imprisonment-rates> [accessed 6 November 2019].

Similar growth patterns are evident in people subject to Community Correctional Services supervision. Community Correctional Services oversees delivery of community corrections in Victoria. Community corrections involves managing and supervising people who have offended and are serving court-imposed orders either as part of a sentence or as a condition of their release from prison. This includes people subject to supervision in the community through court, administrative and parole orders. This group of people increased by 50 per cent between 2009 and 2019, following a period of sustained growth between 2014 and 2017.[10] Since 2017 the number of people subject to supervision has decreased slightly. This was primarily driven by a 39 per cent decrease in the number of people on a reparation order.[11] Offenders with reparation orders must only undertake unpaid community work.

Between 2009 and 2019 the number of people:

- on a supervised court order increased from 55 to 80 per cent of the total population of people subject to Community Correctional Services supervision
- on reparation orders decreased by 28 per cent
- on parole decreased by 43 per cent, from 17 to 7 per cent of the total population of people subject to Community Correctional Services supervision
- aged under 25 years decreased from 23 to 14 per cent of the total population of people subject to Community Correctional Services supervision.[12]

Similar to the trends in imprisonment evident during the COVID-19 pandemic, on 30 November 2020 there were 8,531 Victorians under Community Correctional Services supervision, which is a 30 per cent decrease since 31 January 2020 when 12,197 Victorians were under supervision.[13]

23.1.2 Over-representation of people living with mental illness in the criminal justice system

Imprisonment

Increasing rates of imprisonment disproportionately affect people living with mental illness. In its interim report, the Commission referenced the most recent survey of prisoner health, which reported that 61 per cent of people entering Victorian prisons had a diagnosed mental illness and 35 per cent of Victorian prisoners were referred to a prison mental health service.[14] Prisoners are also two to three times more likely to have a mental illness and 10 to 15 times more likely to have a 'psychotic disorder' than someone in the community.[15]

The Australian Institute of Health and Welfare reported that around 40 per cent of prison entrants and 37 per cent of people released from prison, sometimes referred to as 'dischargees', reported a previous diagnosis of a mental illness, including alcohol and other substance use disorders.[16] This report also stated that 65 per cent of female prison entrants reported a history of a mental illness in comparison with 35 per cent of male prison entrants.[17] An investigation conducted by the Victorian Ombudsman found that, in 2015, 54 per cent of people in prison had a history of suicide attempts or self-harm.[18]

Dr Cassar reported that of the 8,156 prisoners in Victorian prisons (public and private) on 1 March 2020, there were 2,351 prisoners (29 per cent) with a mental health diagnosis.[19] Depression, substance use disorders and 'anxiety disorders' accounted for 72.8 per cent of all diagnoses for this cohort.[20]

Community Correction Orders

It is estimated that a high proportion of people subject to Community Correction Orders are living with mental illness.[21] This conclusion is drawn from looking at the percentage of people on Community Correction Orders who have a mental health treatment rehabilitation condition.[22] Mental health treatment rehabilitation conditions may require people subject to a Community Correction Order to get psychological, neuropsychological, or psychiatric treatment, or other treatment a court considers necessary including, for example, personal development programs (*Sentencing Act 1991* (Vic), section 48D). Dr Cassar reported that as 'at 30 June 2019, 10,063 offenders were subject to a [Community Correction Order] with a supervision condition, and of those, 56 per cent (5,625) had a [mental health treatment rehabilitation] condition'.[23] This proportion has remained fairly consistent over time—in 2015–16, 51.4 per cent of Community Correction Orders had a mental health treatment rehabilitation requirement.[24]

The imposition of a mental health treatment rehabilitation condition does not necessarily mean treatment is received. Ms McCammon observed that the lack of services in the community may make it difficult for people to comply with Community Correction Orders.[25] For example, some offenders may not be eligible for referral to specialists, may not be able to afford the costs of complying with their orders, or bulk-billed services available through a GP may not be sufficient.[26] Dr Cassar observed that before implementation of the Forensic Mental Health in Community Health Initiative, which connects people to treatment when they have a mental health treatment requirement on their Community Correction Order:

> the majority of offenders in the community had significant difficulties accessing and completing treatment to fulfil their [mental health treatment requirement] condition. This was because their mental health needs were not sufficiently severe or acute to engage an [area mental health service]; or Commonwealth funded psychological counselling as part of a GP referral was not intensive enough, or suitable.[27]

With specific reference to mental health programs, the Victorian Auditor-General's Office concluded:

> Lack of access to services to enable offenders to fulfil the conditions of their [Community Correction Orders] is a significant concern. Further steps are needed to develop a permanent and viable solution to meet this gap in service provision.[28]

The Victorian Auditor-General's Office identified the Neighbourhood Justice Centre's integrated model as an effective model for supporting compliance with Community Correction Orders.[29] The elements of the centre's model that were found to be beneficial include 'collocation of a range of services at court including [Community Correctional Services], active judicial monitoring and effective integration of all support and services'.[30] The Neighbourhood Justice Centre is Australia's first community justice centre and is based in Collingwood. It is only available to people who live in the City of Yarra, or who are homeless or Aboriginal and if the offence occurred in the City of Yarra.[31]

Box 23.1 examines the over-representation of Aboriginal people in Victoria's criminal justice system.

Box 23.1: Over-representation of Aboriginal people

Aboriginal people are significantly over-represented in Victoria's criminal justice system. Between 2009 and 2019, the imprisonment rate for Aboriginal people was significantly higher than the imprisonment rate for the total Victorian population. In 2019 the imprisonment rate for Aboriginal Victorians was 2,267.7 per 100,000 adults compared with 157.1 per 100,000 adults for all Victorians.[32] The Victorian Aboriginal Legal Service stated that as of May 2019, the Victorian imprisonment rate for Aboriginal people was higher than in any other Australian state or territory, with 10 per cent of the total prison population (812 people) identifying as Aboriginal.[33] The Victorian Aboriginal Legal Service also reported that in 2017–18, 32 per cent of their criminal law matters involved clients who reported mental health concerns.[34]

For Aboriginal prisoners, over-representation is 'inextricably linked to the intergenerational consequences of dispossession, disruption of culture and kinship systems and high rates of socioeconomic disadvantage'.[35] Aboriginal-led research from New South Wales and the Northern Territory discussed how over-policing and high rates of imprisonment can have a further negative impact on Aboriginal people's mental health.[36] This research indicated that 'institutionalised racism, the taking of land, forcible removal of children, poor education, over-crowded housing, a lack of appropriate health care, early loss of family and community members, over-policing and high rates of incarceration' all have a negative impact on the mental health of Aboriginal people and contribute to their over-representation in the criminal justice system.[37]

23.1.3 Mental illness, victimisation and perpetration

High-profile incidents involving people diagnosed with mental illness have contributed to a public perception that there may be a causal relationship between mental illness and offending. The true relationship between mental illness and offending is complex and multifaceted, and a mental illness diagnosis is not an accurate predictor of potential offending. As highlighted in the evidence below, 'some relationship appears to exist between certain severe mental health conditions and offending behaviours, but the nature and extent of the association remains in doubt'.[38] The existing body of research on mental illness and offending can be summarised in this way: 'most people with mental illnesses are not violent, most violent offenders are not mentally ill, and the strongest risk factors for violence (e.g. past violence) are shared by those with and without mental illnesses'.[39]

People living with mental illness are more likely to be a victim of crime than a perpetrator[40] and are more likely to be a victim of crime than people without a mental illness.[41] Research based on the American National Crime Victimization Survey found that people living with severe mental illness were about 11 times more likely to be a victim of violent crime compared with the general population.[42] In Victoria a 2013 study of people diagnosed with 'schizophrenic-spectrum disorders' found a significantly higher likelihood of being the victim of violence, including sexual violence, compared with the general population.[43] Distinguished Professor James Ogloff AM, Executive Director at Forensicare, Distinguished Professor at the Centre for Forensic Behavioural Sciences at Swinburne University and Expert Advisory Council member for the Commission, noted in his statement to the Commission that, '[t]he risks of victimisation were greatest among people living with schizophrenia who have criminal offending histories themselves, and who experience substance misuse.' [44]

In relation to the perpetration of violence, several systematic reviews have shown a modest association between violence and schizophrenia and other psychoses.[45] One study of 130 male offenders who had contact with Forensicare, Victoria's statewide specialist provider of forensic mental health services, found that co-occurring mental illness and 'substance use disorders' had a greater association with offending than mental illness alone.[46]

A recent review, conducted in Norway, suggests that the major factor linking schizophrenia and violence is substance use.[47] Another study that looked at common assumptions and misconceptions regarding the association between mental illness and violence acknowledged that research has consistently shown substance use is a strong predictor of violence and that it reduces the association between schizophrenia and violence.[48] The authors concluded that 'there is limited evidence that mental health problems are independent predictors of violence when accounting for other factors, such as substance use or previous violence'.[49]

Predicting the risk that people living with mental illness may commit violent offences is extremely difficult. A study on schizophrenia risk categorisation found that 'in order to prevent one homicide of a stranger, 35,000 high-risk patients with schizophrenia would require completely successful individual risk management'.[50] This research found that 'proper consideration of the patient's situation, symptoms, strengths, and disabilities'[51] would be better for consumers than focusing on risk assessment and predicting future behaviour.

A study published in 2020 concluded that receiving psychiatric treatment is associated with a decrease in the likelihood of offending.[52] There was, however, a three-fold increase in the likelihood of offending for people who became disengaged from treatment post-imprisonment or hospitalisation compared with those who did not.[53] Of those who did reoffend, two-thirds committed another offence within one year of leaving treatment.

This body of research indicates that dealing with mental illness alone will not reduce rates of offending or increase community safety. Distinguished Professor Ogloff told the Commission:

> **Although necessary, however, psychiatric treatment is not sufficient in reducing the risk of offending. Rather, interventions must also address the factors that relate to offending in order to significantly decrease the likelihood of offending, while increasing community safety. Indeed, the same … risk factors exist in people with mental illnesses who offend, and those who offend but do not have a mental illness.[54]**

23.1.4 Investment in corrections, police and custodial mental health services

The Victorian Government has made significant recent investments in corrections, police and custodial mental health services. The 2018–19 Victorian Budget included $1.8 billion funding for 1,600 new prison beds, including a new prison in Geelong and adding beds to existing prisons (for example, Ravenhall Correctional Centre).[55] This budget also included $6 million to plan a new custody and courts complex in light of increasing remand numbers.[56]

In 2016 the Victorian Government announced 'the biggest ever investment in law and order in our state's history'.[57] This included funding for an additional 3,135 police officers and, more recently, has also included 100 additional protective services officers to work across the public transport network.[58]

There has also been an increased focus on building specialist mental health units within prisons, rather than providing mental health treatment, care and support in secure hospital settings.[59] Recent investments include:

- Ravenhall Correctional Centre, a medium security prison for sentenced and remanded male prisoners, opened in 2017. As of 30 June 2019, Ravenhall had capacity for 1,300 prisoners, as well as 75 dedicated forensic mental health beds across four units.
- The Marrmak and Rosewood units at the Dame Phyllis Frost Centre were refurbished and expanded in 2018. Dame Phyllis Frost Centre is a maximum security prison for women. As of 30 June 2019, the prison had capacity for 604 prisoners. Marrmak Unit is a 20-bed mental health residential program, intensive outreach program and a therapeutic day program for women.
- The Acute Assessment Unit at the Melbourne Assessment Prison was refurbished in 2019.[60] This is 'a 16-bed short stay unit for patients thought to be mentally ill and requiring psychiatric assessment and a range of recovery-oriented short-term interventions and support. The assessments determine future treatment needs both in and out of custody. The Acute Assessment Unit also accommodates patients requiring compulsory treatment and awaiting admission to Thomas Embling Hospital.'[61]

There has also been increased spending on primary and specialist mental health services in prisons to meet demand.[62] The Commission has been told that there are no publicly available data on demand for mental health services in Victorian prisons.[63] Dr Cassar explained that a range of factors are taken into account to ensure services meet demand, with growth in prisoner population not necessarily being the driving factor.[64] As an illustration, the total annual expenditure on specialist mental health services across public prisons doubled from $6.9 million in 2012–13 to $13.9 million in 2018–19. And while the prison population increased over this period, it was at roughly half the rate of the funding increase.[65]

Forensicare provides specialist mental health services at the following prisons:

- Melbourne Assessment Prison (Acute Assessment Unit)
- Dame Phyllis Frost Centre (Marrmak Unit)
- Ravenhall Correctional Centre (Ballerrt Yeram-boo-ee Forensic Mental Health Service)

- Metropolitan Remand Centre (a Mobile Forensic Mental Health Service that also provides outreach to other prisons and incorporates satellite psychology services at Barwon Prison and Marngoneet Correctional Centre)
- Port Phillip Prison (St Paul's Unit)
- visiting consultant psychiatric and nurse practitioner sessions at the larger state-managed regional prisons.[66]

Figure 23.2 provides a summary of services provided by Forensicare across the prison system in 2018–19.

Figure 23.2: Activity at Forensicare's prison services, 2018–2019

	Reception assessments	Average length of stay	Admissions	Mobile Forensic Mental Health Service
Melbourne Assessment Prison	9,063 reception assessments	7.50 days in the Acute Assessment Unit	16 admissions to the Acute Assessment Unit	-
Dame Phyllis Frost Centre (Marrmak Unit)	-	43.74 days	142 admissions	-
Metropolitan Remand Centre	1,214 reception assessments	-	-	3,748 occasions of service 782 clients seen by the service
Ravenhall Correctional Centre	915 reception assessments	45.14 days in the Aire Unit 66.37 days in the Erskine Unit 119.69 days in the Moroka Unit 151.50 days in the Tambo Unit	375 admissions to Ballerrt Yeram-boo-ee Forensic Mental Health Service	-
Port Phillip Prison (St Paul's Unit)	-	204.67 days	37 admissions	-

Source: Forensicare, *Correspondence to the RCVMHS: CSP.0001.0108.0001, Forensicare Service Plan*, 2020, p.27.

There have not been similar funding trends for community-based mental health services or diversion, rehabilitation and reintegration programs. In the budget that allocated $1.8 billion for new prison accommodation, $42.7 million was allocated to services focused on keeping people out of the justice system and $22.7 million to diversion, rehabilitation and reintegration programs.[67] This total allocation to diversion programs is equivalent to 3.6 per cent of the investment in prisons.

Mr Grant Todd, a witness, described his experience of community and forensic mental health services. Mr Todd noted the difference between community and inpatient services, and the need for increased funding of community services:

> There needs to be more funding for mental health services. In my view, there is a vast difference between community services and the forensic system. I understand that community workers have caseloads of between 30 and 40 people. It must be hard for them to stay on top of all their patients, and I'm sure their appointments aren't frequent enough. There needs to be more funding for case managers, and infrastructure and mental health services in the community.[68]

Victoria Police and Dr Cassar highlighted the impact of inadequate investment in community-based mental health services on police and the corrections system. Victoria Police stated:

> patterns of investment over the past twenty years (an almost exclusive focus on numbers of police and police stations) will not meet the challenges faced by police and the community's expectations.
>
> Police increasingly deal with the consequences of a variety of social ills, such as family violence, abuse of alcohol or illicit drugs, mental illness or underemployment. They depend on the effectiveness of other services to resolve a situation fully, and they are expected to work with other agencies to find ways to deal with the causes of harmful behaviours.[69]

Dr Cassar said 'there are too many people coming into the corrections system who have not received adequate treatment and support in public specialist mental health services'[70] and that 'the corrections system is too often acting as a mental health provider of last resort because people are unable to access mental health services in the community'.[71]

Prisons as the 'catchall solution to social problems'

Limited investment in mental health services has meant that some people are unable to get mental health services until they enter the criminal justice system. Forensicare commented that, '[s]adly, it is not uncommon for some people to have the first opportunity to access mental health assessment and services when they enter the justice system'.[72] The Magistrates' Court of Victoria similarly concluded that 'prisons have in some circumstances become front line mental health care providers by default'.[73] At the Commission's community consultation in Box Hill, a participant spoke about her experience trying to find support for her son:

> There is no treatment, the doors have all closed, [my son is] self-medicating – not a single private hospital will take him and the last public hospital had him arrested. I have been told by a clinician that 'the best thing for your son is the criminal justice system'.[74]

In their submission, Caraniche, a specialist provider of psychological services, discussed the impact of differences in access to care in custody and the community. Some Caraniche clients experience a cycle of arrest and placement in supervision (either through a Community Correction Order or in custody), stabilisation due to consistent access to treatment, release to the community, disconnection from care and subsequent relapse and rearrest.[75]

Ms Mary Pershall, a witness before the Commission, reiterated Caraniche's observation that prison mental health services can achieve stabilisation and positive mental health outcomes. Ms Pershall told Commission that as a result of the routine, structure and community within prison, as well as the access to mental health care, her daughter's 'mental health is better than it has been since she started school'.[76]

The Commission also heard that prison can have detrimental impacts on a person's mental health. Mental Health Victoria and the Mental Health Legal Centre told the Commission that '[f]or many people living with mental illness prison is a challengingly restrictive environment and incarceration can have a debilitating impact on their mental health and well-being'.[77] The Human Rights Law Centre stated that prisons fail 'to provide adequate health care to people denied community-based interventions and supports. Prisons are increasingly being used as the 'catchall solutions to social problems'.[78]

While prison mental health services achieve positive outcomes for some people, it is not appropriate that some Victorians are excluded from receiving mental health treatment until they enter the criminal justice system. It is anticipated that the Commission's suite of reforms across crisis and emergency responses, Area Mental Health and Wellbeing Services and community mental health will go some way to ameliorate the demand pressures currently facing the prison system. The recommendations of this chapter will build on these reform areas by improving service delivery across the criminal justice system.

23.1.5 The net of the criminal justice system

The Senate Select Committee on mental health identified a number of causes for the over-representation of people living with mental illness in the criminal justice system.[79] This included homelessness, substance use or addiction, a lack of early intervention and limited mental health services in the community. The Commission has made recommendations to respond to these issues for all Victorians living with a mental illness, not only those engaged with the criminal justice system, which are outlined in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*, Chapter 16: *Supported housing for adults and young people* and Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction*.

A lack of mental health services in the community combined with a criminal justice system that is not sufficiently resourced to support recovery is a key cause of current over-representation in Victoria.

Dr Cassar said a significant number of prisoners with acute needs had not received the treatment, care and support they required in the community:

> prisoners with acute needs requiring compulsory treatment while in custody have generally been clients of one [area mental health service] or more previously, but have been disconnected from the service for a period before they entered custody. In my opinion, this indicates that the public specialist mental health service system appears to be identifying but not meeting the needs of people at risk of offending.[80]

Mr Dan Nicholson, Executive Director of Criminal Law at Victoria Legal Aid, agreed that inadequate community-based supports may lead to engagement with police and subsequent entry into the criminal justice system:

> Because of a lack of other services, Victoria Police are too often first responders when people are experiencing mental health issues. Once contact is made, our current settings mean that people are too often caught in the net of the criminal justice system. These settings include: police practices including in respect of charging, cautioning, bail and remand; ongoing criminalisation of minor offending such as begging and drug use; and the consequences of bail laws.[81]

Mr Nicholson went on to describe the impact of being caught in the 'net of the criminal justice system':

> the net is cast too wide, then once people experiencing mental health issues are propelled into the criminal justice system, it is not sufficiently therapeutically oriented and resourced to support them to recover and return to stable lives. They find themselves unable to get out of the system which is often harmful for their mental health and hinders recovery.[82]

The Magistrates' Court of Victoria reiterated the flow-on effect identified by Dr Cassar and Mr Nicholson. Regarding the over-representation of people living with mental illness within the justice system, the Magistrates' Court recognised 'it as a critical problem caused by, in part, community-based services and responses being limited and under-resourced'.[83] The Magistrates' Court went on to say that limited access to community-based services can increase:

> the likelihood of Victoria Police being called out to respond to people with mental health symptoms manifesting in difficult behaviours. Police contact increases the probability of criminal charges. When mental health behaviours are criminalised, clients are likely to remain in custody where they do not have access to services that address their health and wellbeing needs.[84]

The Commission has identified three key elements of the criminal justice system that have contributed to the net widening and subsequent over-representation of people living with mental illness:

- minor offences that disproportionately affect people living with mental illness
- use of police as first responders when a health response is required
- use of remand as a 'method of safe management and containment'[85] for people living with mental illness.

Minor offences and infringements

People living with mental illness are more likely to be charged with minor offences and infringements than people without mental illness. Submissions to the Commission have variously pointed to the potential of reforming minor offences in reducing the disproportionate impact on people living with mental illness including begging, public space offences (like obstruction of footpaths or relating to directions to move on), offensive language and some drug offences including possession.[86] The 1993 *Burdekin Report* also found that 'mentally ill people are especially likely to fall foul of laws concerning drunkenness, offensive behaviour, disorderly conduct, loitering or vagrancy (which commonly coincides with homelessness)'.[87]

More recent evidence received by the Commission shows these trends are still evident. Inner Melbourne Community Legal told the Commission they have 'assisted many clients charged with low-level offences which are a direct consequence of a mental health episode'.[88] Springvale Monash Legal Service reported that 'certain kinds of behaviour can be deemed 'anti social' and can cause people with a mental illness to be an easy target for policing practices'.[89]

In his statement to the Commission, Mr Nicholson called for minor offences reform:

> Offences that penalise poverty and addiction should be repealed or decriminalised to reduce the overcriminalisation of people with complex needs, such as the offences of begging and low-level possession of drugs of dependence for personal use. Enforcement of minor offences does not address the underlying circumstances of mental health, disability, homelessness and social marginalisation, and can further entrench these issues.[90]

This is a view held consistently across organisations and agencies that work with people living with mental illness who have come into contact with the criminal justice system.[91]

Receiving fines—for example, public transport, parking or toll road fines—also disproportionately affects people experiencing homelessness, living with mental illness or who are on low incomes.[92] Springvale Monash Legal Service stated that these groups may be 'more vulnerable to receiving fines, [and] … more likely to accumulate larger debts through multiple fines and additional penalties'.[93]

Illustrating the impact of infringements on people living with mental illness, data analysis conducted by the Commission indicates that registered clients of area mental health services are 10 times more likely to be charged with fare evasion than the general Victorian population.[94] The Northern Community Legal Centre stated that of the 568 people it assisted in 2018–19 who identified as having a 'diagnosed mental illness', 20 per cent (115 people) were assisted with infringements issues.[95] WEstjustice told the Commission that when they assist clients with mental illness to deal with fines, they are routinely withdrawn and the corresponding debts and penalties waived.[96]

The Fines Reform Advisory Board was established in September 2019 to review the fines system following reforms made under the *Fines Reform Act 2014* (Vic) which came into force in early 2018). The board submitted its report to the Attorney-General in April 2020, and in December 2020 it, along with the Victorian Government's response, was published.

Relevant to the work of this Commission, the board found that '[s]ocial justice initiatives delivered under Fines Reform are providing more support for vulnerable fine recipients'.[97] The board went on to recommend improvements to the way the fines system treats vulnerable people:

> the Advisory Board recommends that the eligibility test for persons who shouldn't pay their fine ('the special circumstances or nexus test') should be reformulated in two ways to make it fairer: the threshold to meet the existing test should be reduced and a second, narrow limb, requiring no causal link between the infringement offences and a person's condition or circumstances, should be available to those with a substantially diminished capacity to pay or otherwise manage a fine for the foreseeable future.[98]

The board goes on to note that one such example of diminished capacity to pay would include 'a person subject to long-term involuntary treatment under the Mental Health Act 2014.'[99] The Victorian Government has indicated it accepts in principle the board's recommendation.[100] The Commission notes the wealth of evidence it has received in relation to the impact of infringements on people living with mental illness that may be of assistance to the government in the implementation of the recommendations of the board.

Health justice partnerships

In addition to advocating for reform to minor offences, submissions to the Commission highlighted the potential benefits of health justice partnerships as a way to respond to the impact of minor offences and fines on people living with mental illness.[101] There are a number of health justice partnerships currently or recently operating in Victoria, including:

- Melbourne Legal Care—a partnership between the Royal Melbourne Hospital and Inner Melbourne Community Legal
- Rumbalara Therapeutic Justice Practice—a partnership between the Goulburn Valley Community Legal Centre and Rumbalara Aboriginal Cooperative Limited
- St Vincent's Hospital Melbourne health justice partnership—a partnership with Justice Connect, Seniors Law
- Sunshine Hospital Family Violence Project, Sunshine—a partnership between Brimbank Melton Community Legal Centre and Western Hospital
- First Step Legal—embedded and co-located within First Step, an addiction and mental health services clinic.

The health justice partnerships case study provides an overview of the health justice partnership between WEstjustice and Werribee Mercy Hospital.

Police engagement with people living with mental illness

The Victorian Government told the Commission that a lack of mental health services is leading to an increased reliance on police to be first responders for people experiencing mental illness.[102] The Commission's interim report stated that between 2014 and 2018, mental health transfers, where police transfer a person experiencing a mental health crisis to hospital, increased by 13 per cent annually, and 'psychiatric crisis' or 'suicide attempt or threat' computer-aided dispatch events increased by 10.9 per cent annually.[103] In comparison, non-mental health computer-aided dispatch events increased by 3.6 per cent each year.[104]

Case study:

Health justice partnerships

Health justice partnerships are collaborations embedding legal assistance within health care services. They support people who are at risk of poor health and unmet legal need. They can identify and address people's legal problems that may otherwise not be addressed and would have a continuing impact on a person's health, including their mental health. There are more than 60 health justice partnerships in Australia, with more than 30 operating in Victoria.

WEstjustice and Mercy Mental Health
In 2016, WEstjustice and Mercy Mental Health (MMH) established a Fines and Debt Clinic, Victoria's first health justice partnership focusing on people with a disability that may arise from mental ill-health. The clinic operated until 2020, but is currently on hold while the service model is being evaluated and future funding is confirmed.

The Fines and Debt Clinic supports people living with mental ill-health by providing legal services to inpatients of MMH's adult inpatient unit, as well as clients of MMH's community care unit. Social workers identify people with legal issues and refer them to the clinic's lawyer, who sees clients in the hospital while they are inpatients or in MMH's community care services.

Shifrah Blustein, Program Manager of the health justice partnership, said it has assisted 242 clients since 2016.

> Working with clients in the Mercy Mental Health setting provided many valuable insights into the complexities of clients facing significant mental health issues. It afforded us the opportunity to forge client relationships with a cohort that were very much in need of legal assistance but would likely not find their way to our centre if it were not for our health-justice partnership with the hospital.

Ms Blustein said a recent evaluation of the program showed that some staff believed that the assistance greatly reduced stress for clients and reduced readmissions to hospital.

> Clients surveyed attested to the sometimes life-changing nature of the assistance provided, aiding them to rein in financial problems and reduce stress and poor health outcomes.

Source: Health Justice Australia <www.healthjustice.org.au> [accessed 16 November 2020]; WEstjustice, *Diverting vulnerable offenders away from the traditional criminal justice system, Submission to the RCVMHS: SUB.1000.0001.5694*, 2019; WEstjustice, *Health Agency to Court, Tackling the Fines System Evaluation Report*, September 2020.

In 2017–18 Victoria Police attended 43,000 events relating to a psychiatric crisis or suicide attempt or threat and conducted 14,000 transfers to an emergency department or designated health facility for an urgent mental health response.[105] Police responded to mental health callouts on average once every 12 minutes in that year.[106]

Victoria Police observed that 'for many of these callouts, a health based intervention, rather than a law enforcement one, would have likely been the most beneficial response'.[107] In his evidence to the Commission, Assistant Commissioner Glenn Weir, Victoria Police, noted that 'unnecessary contact between police and people experiencing mental health issues should be minimised as this can compound stigma and add to the person's trauma, leading to suboptimal outcomes'.[108] Fitzroy Legal Service described the current approach of sending police as first responders as failing to 'meaningfully engage people with appropriate community services' and that it causes harm through the 'trauma and stigma of a public, at times violent arrest, further criminalisation, and potentially imprisonment'.[109]

The Productivity Commission's *Mental Health Inquiry Report* recommended changes to how police respond to mental health incidents in line with a co-responder model:

> State and Territory Governments should implement a systematic approach for responding to mental health related incidents to support all parties involved. Mental health professionals should be embedded in police communication centres and police, mental health professionals and/or ambulance services should be able to co respond to mental health related incidents.[110]

The demands placed on Victoria Police to support people living with mental illness are considerable. The need for health-based interventions in many of these circumstances is clear. Chapter 9: *Crisis and emergency responses*, sets out the Commission's findings in relation to Victoria Police's role as first responder. This includes the recommendation that, wherever possible, emergency services' response to people experiencing mental health crises is led by health professionals rather than police.

Police response to minor offences

In addition to the role of police as first responders, another area of significant interaction between police and people living with mental illness is through minor offences. Submissions to the Commission discussed how these interactions could be improved to ensure people receive health-based interventions where required.

Police decision making is pivotal in determining whether or not a person enters the justice system.[111] For some offences, police have the ability to recommend diversion or issue a caution as an alternative to charging an individual 'where it would not be in the public interest to proceed with criminal charges'.[112]

Despite this capacity, the Commission heard that the use of diversion has declined in Victoria in recent years. Emeritus Professor Arie Freiberg AM, Chair of the Sentencing Advisory Council, observed in his personal capacity that:

> One notable trend is what seems to be an overall decline in the use of diversion in Victoria in recent years. The Council is generally supportive of diversion. This is largely due to a decline in the use of police-ordered diversion; however, there has been a significant increase in the use of court-ordered diversion.[113]

Fitzroy Legal Service reiterated this observation and stated that for their clients, 'arrest and criminal charge is the predominant police response' and that this decision means 'a health issue is transformed into a criminal justice issue'.[114] The Magistrates' Court of Victoria advised that 'providing a law and order response to an episode of mental illness that requires medical intervention is not appropriate'.[115] Fitzroy Legal Service recommended that Victoria Police policy be updated to expand the circumstances in which a 'pre-charge' diversion could be granted. Fitzroy Legal Service advised:

> This could allow police officers to redirect a person into therapeutic and rehabilitative services instead of prosecuting them for low-level offences attributable to drug addiction and/or mental health issues.[116]

There are examples of cautioning and pre-charge diversion programs currently operating in Victoria. The Aboriginal Youth Cautioning Program, funded through the Victorian Government's Community Safety Statement, seeks to respond to the over-representation of Aboriginal young people in the criminal justice system through greater use of cautioning and diversion options.[117] There is also the Koori Women's and Adult Pre-Charge Diversion Programs that operate in Mildura and Latrobe.[118] Ms Marion Hansen, Co-Chair of the Aboriginal Justice Caucus, said the Koori Women's Diversion program was developed with extensive Aboriginal involvement,[119] providing 'practical support to ensure women are connected to the services they need, supported to get to appointments, and reconnected to culture as a source of therapeutic strength, healing and self-esteem'.[120]

Ms Hansen noted the benefits of diversion programs developed in close consultation with Aboriginal communities:

> Diversion schemes or services, including mentoring, that are facilitated by Aboriginal community controlled organisations, community members or Elders are more positive for strengthening cultural connection, re-establishing broken relationships and community building.[121]

The fourth Aboriginal Justice Agreement recommended expanding these programs. The Aboriginal Justice Agreement was developed in response to recommendations from the 1991 Royal Commission into Aboriginal Deaths in Custody.[122] The agreement is now in its fourth phase and aims to improve Aboriginal justice outcomes and reduce over-representation in criminal justice settings. It is yet to be completed.[123]

In one of the Commission's roundtables, Assistant Commissioner Luke Cornelius at Victoria Police reflected on the capacity of cautioning and pre-charge diversion programs to achieve positive outcomes for young people: 'we know the evidence is very clear, that effective cautioning, effective diversion, with appropriate supports in place actually is the best way of supporting young people in changing behaviour'.[124] Assistant Commissioner Cornelius highlighted the Aboriginal Youth Cautioning Program as a positive example of police and community services working closely together.[125]

Jesuit Social Services supports the broader use of cautioning models that involve police and support services working together:

> Jesuit Social Services would like to see a youth social worker working alongside police because we consider a caution issued by police to a young person could trigger an opportunity for a social worker to engage with a young person and refer the young person to necessary supports—without further engagement in the criminal justice system.[126]

At the Commission's roundtable, Assistant Commissioner Cornelius added the caveat that the success of these models relies on the quality of services that young people are referred to:

> one of the particular challenges we face, is many of the services out there are not fit for purpose when it comes to being able to deal with particularly complex cases. And so the standard suite of offerings from service providers oftentimes fall short, in terms of being able to address some of the particular complexities that come with some of the mental health issues that young people ... are living with.[127]

It is anticipated that the Commission's recommendations to significantly expand community-based mental health services, as outlined in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*, will enable cautioning and pre-charge diversion programs to refer people to services that have the resources and capacity to provide appropriate supports.

Use of remand and its impact on people living with mental illness

Recent bail reforms are likely to have had a significant impact on people living with mental illness due to their over-representation in the prison system. In 2013 there were significant reforms to bail legislation in Victoria. These included creating offences for contravening a condition of bail and committing an indictable offence (a more serious offence) while on bail. In 2017, in the aftermath of the Bourke Street tragedy, the Honourable Paul Coghlan QC reviewed the bail laws. Following this review, further legislative changes were implemented, which made it more difficult for people to obtain bail.

Since these reforms, the number of people held on remand in the adult prison system has increased. On 30 June 2013, prior to the bail reforms, 18 per cent of all prisoners were remandees (954 from a total of 5,340 prisoners).[128] By 31 July 2016 this proportion had increased to 30 per cent of all prisoners and has remained above 30 per cent since then.[129] On 30 November 2020, 38 per cent of all prisoners were remandees (2,728 from a total of 7,109 prisoners).[130] This increase can also be seen in the numbers of prisoners who are remanded but do not receive a sentence of imprisonment when their matter is finalised by a court. On 30 June 2013, 144 prisoners on remand (29 per cent of all prisoners on remand) were discharged without being sentenced.[131] On 30 November 2020 this had increased to 455 prisoners, or 45 per cent of all prisoners on remand.[132]

Mr Nicholson discussed how increasing remand rates have particularly affected people living with mental illness. Bail laws may require people to prove there are strong reasons or exceptional circumstances for not remaining in custody (even for minor offending), and this has been particularly challenging for people living with mental illness 'who may have difficulty complying with bail conditions or desisting from minor offending'.[133] Mr Nicholson further proposed that remand rates may be contributing to the recidivism (subsequent interactions with the criminal justice system) rate among people living with mental illness because 'time in custody is criminogenic—people are much more likely to go back to prison once they have been there, even for short periods'.[134]

The Commission heard about the use of 'therapeutic remand'—'where a person is denied bail in order to ensure they receive treatment in prison'.[135] Dr Cassar reported that she is 'anecdotally aware that "therapeutic" remand continues to occur'.[136] In her witness statement, Ms McCammon cited data to support this. Among prisoners with a 'serious or significant mental health condition' in custody on 30 June 2019, almost two-thirds (63 per cent) were on remand (324 of 515 prisoners).[137] Ms McCammon concluded that '[w]hile not conclusive, this data aligns with various submissions to the Royal Commission indicating the continued use of 'therapeutic remand''.[138]

Mr Coghlan also made recommendations for bail reform that were not implemented. These recommendations were directed towards removing some lower-level offences from the bail and remand system and establishing a 'Notice of Charge' to allow people to be charged with these lower-level offences without entering the bail and remand system.[139] Mr Coghlan noted:

> **The use of bail in cases of minor offending causes broader problems for the criminal justice system. It can lead to accused persons who pose a low risk to the community being remanded in custody for offences for which they would be unlikely to receive a sentence involving imprisonment. This creates pressure on the remand system, which requires places to be available for people charged with more serious offences and those who pose a greater risk to the community. Even a remand overnight puts pressure on the system. Resource pressures on the police and the courts are exacerbated when warrants are issued for accused who fail to appear, rather than cases being determined in the accused's absence.**[140]

The impact of the bail reforms on people living with mental illness can be reduced through the Commission's recommendations to improve diversion, rehabilitation and reintegration programs. This will enable people living with mental illness to avoid appearing before the courts, and if they do appear, they will have the supports in place to assist them to comply with their bail conditions. These recommendations include the police and ambulance co-responder model referred to in Chapter 9: *Crisis and emergency responses*, expansion of problem-solving courts, significant investment in community mental health and wellbeing services and reforms to community-based forensic mental health services.

23.1.6 Problem-solving courts

Problem-solving courts have been developed to deal with the underlying causes of crime.[141] By responding to the factors that contributed to an offence, it is hoped that the person will be less likely to reoffend. Through this mechanism these courts aim to deal with patterns of repeated involvement with the justice system. Problem-solving courts are, to some extent, based on the principles of therapeutic jurisprudence.[142] Those principles emphasise that better outcomes can be achieved by having a positive impact on the psychological wellbeing of the accused. These courts aim to address issues related to offending (such as mental illness or substance use or addiction) through service referrals, treatment provisions or supervision requirements.[143]

The history of problem-solving courts at the Magistrates' Court of Victoria is outlined in Box 23.2.

Box 23.2: Problem-solving courts at the Magistrates' Court of Victoria

The Magistrates' Court of Victoria sits at 51 locations around Victoria. There are 12 headquarter courts (Geelong, Broadmeadows, Dandenong, Frankston, Latrobe Valley, Ballarat, Heidelberg, Shepparton, Bendigo, Melbourne, Ringwood and Sunshine). The remaining 39 courts are satellite courts.

The Magistrates' Court has developed a range of problem-solving courts and related services. Problem-solving approaches were introduced in Victoria in 1994 with the Mental Health Court Liaison Service in the Magistrates' Court.[144] The interest in problem-solving approaches grew in the early 2000s with an increased policy focus on reducing offending. In 2005 the Victorian Government published *A Fairer Victoria*, which committed to reducing offending and reoffending by tackling the underlying causes of crime and improving access to justice for targeted disadvantaged groups.[145] In 2006 the Senate Select Committee on mental health recommended:

> That there be a significant expansion of mental health courts and diversion programs, focussed on keeping people with mental illness out of prison and supporting them with health, housing and employment services that will reduce offending behaviour and assist with recovery.[146]

In 2008 Mr Rob Hulls, the then Victorian Attorney-General, published his second 'justice statement'—a Ministerial Statement that outlined the government's plans for the Victorian criminal justice system. This statement endorsed the use of problem-solving approaches to respond to the underlying causes of offending behaviour.[147] One of the 25 initiatives of the statement was:

> Develop and implement a framework for problem-solving approaches in the Magistrates' Court to consistently address the underlying causes of offending behaviour by people from groups who are over-represented in the criminal justice system. The Koori Court program will be extended to Mildura and Gippsland and a Koori Children's Court will be established.[148]

Around this time, a number of problem-solving courts and related services began, including the Drug Court, the Neighbourhood Justice Centre, the Court Integrated Services Program and the Assessment and Referral Court. The Koori Court was also established around this time. There is also a Koori Court in the County Court of Victoria jurisdiction.

Established in 2010, the Assessment and Referral Court (ARC) is a problem-solving court that operates as part of the Magistrates' Court. The ARC focuses on clients living with 'a mental illness or cognitive impairment due to intellectual disability, acquired brain injury, autism spectrum disorder and/or neurological impairment'.[149] It is a specialist therapeutic court that shifts 'the focus of the court from determining a legal contest between opposing sides to being actively engaged in addressing the underlying causes of offending and the therapeutic needs of the individual'.[150]

The Magistrates' Court summarises the functions of the court this way:

> The ARC List combines active court supervision or judicial monitoring with clinical case management. A team of advanced, clinically-trained and court-based case managers, including social workers and psychologists, develop and support clients to engage with tailored treatment and support plans. The primary focus of the program is to scaffold and support clients to engage with appropriate treatment and services to ensure they manage their functional and/or social disabilities (including mental illness, intellectual disability, acquired brain injury, autism spectrum disorder and neurological impairment).[151]

The court aims 'to address the needs and circumstances of the individual to bring about recovery and stabilisation'.[152] This can include assisting a person to get mental health, disability, drug treatment, housing, physical health and other services as required.[153]

The ARC is currently available at three headquarter courts (Frankston, Melbourne and Latrobe Valley) and two satellite courts (Moorabbin and Korumburra). Given the limited geographic coverage of the ARC, many Victorians do not have access to the court.[154]

ARC participants are people who have been charged with one or more criminal offences within the jurisdiction of the Magistrates' Court for either summary (minor) or indictable (more serious) offences that are capable of being heard as summary offences.[155] Offenders who have been charged with a serious, sexual or violent offence (as defined in section 6B (1) of the Sentencing Act) are not eligible for participation in the ARC list.[156]

To be eligible for the ARC, offenders must remain out of custody, consent to participate in the ARC, and meet diagnostic, functional and needs criteria including:[157]

- having a mental illness, intellectual disability, acquired brain injury, 'autism spectrum disorder' and/or neurological impairment, including (but not limited to) dementia—the diagnostic criterion
- having substantially reduced capacity in self-care, self-management, social interaction or communication due to the condition—the functional criterion
- being likely to benefit from receiving coordinated services and participating in a problem-solving court process—the needs criterion.[158]

These criteria ensure the 'ARC provides a dedicated justice pathway for a small number of people with mental health conditions and cognitive or neurological impairments'.[159]

On acceptance into the ARC, participants receive supervision, assessment and case management for up to 12 months.[160] Ensuring each participant encounters the same court staff is a core component of the program. The same magistrate, case manager and police officer are involved throughout the program and interact with the participant in a less formal setting than is usual in the Magistrates' Court.[161] The Magistrates' Court observed that:

> the presence of a sworn police member creates a relationship between the offender and Victoria Police, which can change perceptions, and assist in the client's rehabilitation, further reducing engagement or contact with the Victoria Police in the community.[162]

Personal story:

Whitney Dwyer

Whitney has had numerous contacts with the mental health and criminal justice systems. When she heard about the Assessment and Referral Court (ARC), she asked her lawyer if she would be suitable.

> my lawyer got me to see a professional psychologist … [who] diagnosed me with borderline personality disorder and severe depression, among other things, which got me into the program.

Whitney says her experience with ARC was very positive and she does not think she would be where she is today if she had not had this experience.

> I was skating on thin ice but the Judge kept giving me chances. She saw a lot more than I saw in myself, and she believed in me.
>
> ARC offered me a second chance at life. They were very patient—I wouldn't even be that patient with me! They don't look down on you, they sit at your level.

Whitney said it is critical that services care about their clients.

> You need someone who is not going to give up on you.
>
> when I got out of prison, even though I went straight back down the same old road, my housing worker really cared about me. … Usually if you don't engage with workers, they close your case, but she didn't even though she didn't hear from me for ages. The next minute she was rocking up at my shared accommodation door with a bag and she was like 'I just wanted to check how you are'. I honestly started crying and I gave her a hug and I felt like 'wow, she actually cares'.

It has taken time for Whitney to find the mental health services and practitioners that work well for her.

At her current mental health service, Whitney is able to decide which services to access at her own pace. With these supports, she is now positive about the future.

> After seeing a psychologist for two years, I have learnt to open up and respect everything. It's been a long journey, but if I didn't go through all that I wouldn't be who I am today.

Whitney said the most important factor for a successful future mental health and wellbeing system is a passionate and caring workforce.

Source: *Witness Statement of Whitney Dwyer*, 12 June 2020; Whitney Dwyer meeting with Commissioner Cockram,, July 2020.

> After seeing a psychologist for two years, I have learnt to open up and respect everything. It's been a long journey, but if I didn't go through all that I wouldn't be who I am today.

Whitney Dwyer

Positive outcomes for participants

The ARC is achieving positive outcomes for participants and is well regarded by police, participants and the legal system. Victoria Police highlighted the ARC as evidence that a health-based approach can respond to the factors that lead to offending and 'can often be more beneficial than a traditional criminal justice pathway'.[163] Victoria Legal Aid reported that such courts 'can have strong therapeutic benefits for participants' and that it has 'assisted many clients in ARC and has seen a number of people transform their lives over the time they have been participating in the program'.[164]

A 2016 study sought to determine whether the ARC had reduced the number of offenders with a 'mental impairment' received into custody.[165] The study concluded that 'successful program completion was the most significant predictor of non-reoffending or a longer time to reoffending'.[166] This research also indicated there was a significant difference in the 'time to reoffending' between those who completed the program and those who did not. The average time to the first proven offence post-program for program completers was 21.87 months, and for non-completers this was 4.87 months.[167] For those who did reoffend, their offences after they had completed the program were less severe than those committed before entering the program. Severity of offending during the program was also significantly lower than post-program severity of offending.[168]

Support across the justice sector and from participants

The ARC has received support from across the justice sector and from participants. Whitney Dwyer, a witness before the Commission, said:

> I can't think of many improvements for ARC, I think they are doing an excellent job. I don't think anything needs to be changed with the program itself. It might be good if they could give the program more workers because I think last time I was there, they only had two main support workers. They could also try to promote more caring work and how to help people with mental health issues so it carries less stigma.[169]

Inner Melbourne Community Legal reported that while therapeutic courts such as the ARC 'provide welcome alternatives for people in mental health crisis', access to these lists is currently limited.[170] This service regularly has clients who are unable to access the ARC because the court in which their charges are to be heard does not have an ARC.[171] Inner Melbourne Community Legal recommended an increase in funding for the ARC and related programs 'to ensure that all suitable matters can be heard in the therapeutic system and that this is not determined by whether the court where a person's matter is listed has ARC'.[172] Support for the expansion of problem-solving courts, and specifically for the expansion of the ARC, was also expressed by participants in the Commission's panel hearings.[173] Youthlaw recommended that funding for the ARC list should 'be made available in all major courts'.[174]

In 2015 the Victorian Ombudsman made a recommendation to expand the:

> successful models of the Drug Court of Victoria, the Court Integrated Services Program, the Neighbourhood Justice Centre, the Assessment and Referral Court List, the Criminal Justice Diversion Program and the CREDIT/Bail Support Program and the Koori Court.[175]

The Ombudsman defined success as reducing reoffending. This report stated that the ARC provided an estimated benefit of between $2 and $5 for every dollar spent.[176] Ms McCammon referenced an evaluation of the ARC that forecast that, over five years, the 'ARC List would generate savings of $2.24 for every $1 invested in it'.[177] These savings were attributed to reduced reoffending as well as fewer days in prison or under community correction supervision.[178]

The Ombudsman concluded that expanding diversion, rehabilitation and reintegration programs requires a 'whole-of-government' approach to improve accessibility:

> Although there is some good practice across the justice system in diversion, rehabilitation and reintegration, these are often uncoordinated, as well as demographically, geographically and financially constrained. A whole-of-government approach is needed to shift the focus: to reduce offending and recidivism and to promote the rehabilitation of offenders. This requires a common intent and set of shared objectives across justice agencies, health, education and housing, and stronger links to community service organisations.[179]

The Productivity Commission's *Mental Health Inquiry Report* made four recommendations regarding diversion, rehabilitation and reintegration services for people living with mental illness who are engaged with the criminal justice system (refer to Box 23.3).

Box 23.3: Productivity Commission recommendations for diversion, rehabilitation and reintegration services for people living with mental illness who are engaged with the criminal justice system

1. 'An early intervention approach should be introduced to identify people with mental illness at high risk of contact with the criminal justice system, and provide supports to reduce the risks of them offending.'
2. 'State and Territory Governments should work to ensure that people with mental illness who would benefit from mental health court diversion programs, are able to access them.'
3. 'State and Territory Governments should develop disability justice strategies and work towards integrating legal and health services (including through health justice partnerships) so that people with mental illness are better supported to resolve legal matters and participate in the justice system.'
4. 'Supported decision making by and for people with mental illness should be promoted through improved access to individual non-legal advocacy services … and mental health advance directives.'[180]

23.1.7 Expanding the Assessment and Referral Court

The Commission recommends expanding the ARC to improve opportunities for directing people living with mental illness away from the criminal justice system. This reform will contribute to addressing the over-representation of people living with mental illness in Victorian prisons and increase access to support services. It is anticipated that these benefits will contribute to improved mental health outcomes for people living with mental illness who are in contact with the criminal justice system. It is expected that this reform will also contribute to improved cohesion between the mental health, justice and broader support service systems. This recommendation is aligned with the findings of the Productivity Commission's inquiry into mental health.

Regarding the ARC, Victoria Police told the Commission that a health-based approach 'can often be more beneficial than a traditional criminal justice pathway'[181] and that 'the existence of the ARC is positive … as it works to more effectively support the needs of … individuals'.[182] However, Victoria Police also noted that the success of the ARC depends on capacity across referral services.[183] That is, if the court refers a participant to a drug treatment service, but this service has no capacity to take on new clients, the effectiveness of the ARC approach may be compromised. Victoria Police reported that 'due to the increasing demand on the mental health service system there can be difficulty for individuals to access the support services they need'.[184] The proposed expansion of the ARC into new geographic areas must consider the accessibility of mental health, disability, drug treatment, housing, physical health and other services. It is anticipated that the new community model recommended by the Commission and described in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*, will improve access to mental health and other services throughout Victoria.

The Commission does not have access to data on how many applicants are expected to apply for the ARC in the coming years. Analysis of this expected demand will be required to inform the scale of expansion. Given the recent investment to expand the ARC, there should be a strong basis available to government on which to model the expansion as recommended by the Commission.

23.2 Improving mental health outcomes across the adult forensic mental health system

Forensic mental health services provide treatment, care and support to people living with mental illness who have come into contact with the criminal justice system. In Victoria these services are primarily delivered by Forensicare in three settings:

- community-based mental health services
- inpatient care at Thomas Embling Hospital, the state's forensic mental health hospital
- prison-based specialist mental health services (refer to section 23.1.4).

23.2.1 Community forensic mental health services

The adult community-based forensic mental health system aims to meet the needs of people with a mental illness who have committed a criminal offence or are at risk of doing so. Consumers may have had repeated involvement with police, a matter before the court, been sentenced to a community-based order, or been recently released from custody. The system includes any forensic mental health service that is provided outside of a hospital or prison setting.

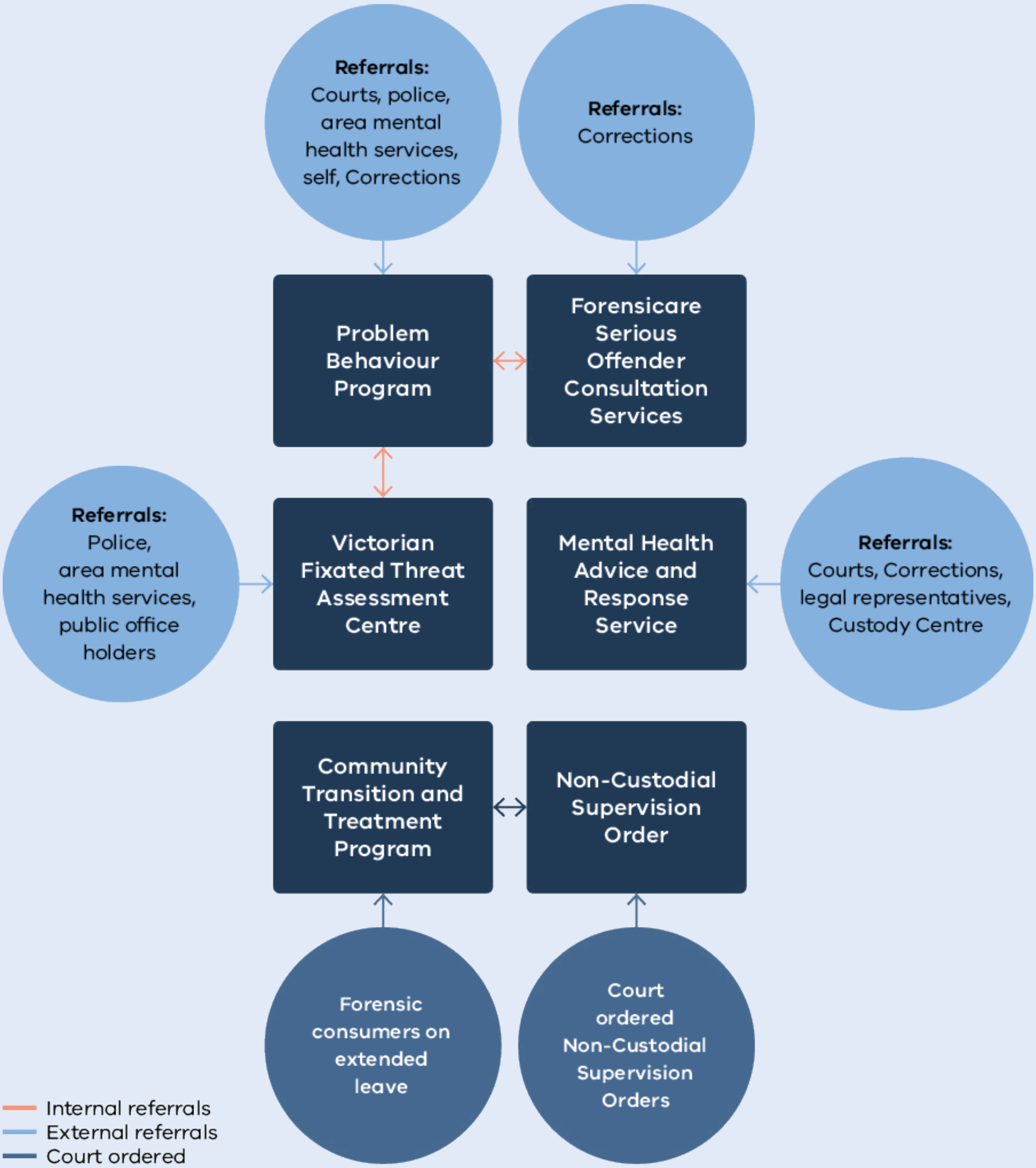
Forensicare's Community Forensic Mental Health Service is a small suite of community-based programs for people living with mental illness who have offended or are at high risk of offending. These programs provide clinical advice and consultation services. Forensicare's service plan provided an overview of current programs:

- The **Court Reports Service** provides psychiatric and psychological pre-sentence reports to courts at the request of magistrates and judges.
- The **Community Integration Program** provides short-term support and linkage assistance to people with severe mental illness who require ongoing treatment when they leave prison. This program has 3.5 fulltime-equivalent positions and has the capacity to support 35 people at any one time.[185]
- The **Community Transition and Treatment Program** oversees the treatment, care and supervision for forensic and civil consumers transitioning from Thomas Embling Hospital to the community.
- The **Forensic Clinical Specialist Program** builds forensic mental health expertise and capacity in Victoria's mental health services. Forensicare provides central coordination of the program, which is delivered in partnership with local specialist mental health service providers. There are currently 23 forensic clinical specialists employed across area mental health services.[186]
- The **Forensicare Serious Offender Consultation Service** aims to support Community Correctional Services and mental health services to manage people who have a severe mental illness and a history of serious violent and/or sexual offending. In 2018–19 this program had 1,420 contacts with Community Correctional Services.[187]

- The **Mental Health Advice and Response Service (MHARS)** provides clinical mental health advice within the court to reduce delays in proceedings and remands and to improve the appropriateness of mental health interventions and referrals for people appearing before the court. In 2018–19 this program provided 4,232 court liaison assessments.[188]
- The **Non-Custodial Supervision Order Consultation and Liaison Program** supervises the monitoring and direct treatment of people placed on a Non-Custodial Supervision Order. A Non-Custodial Supervision Order is an order made by a court following a finding that a person is permanently unfit to plead or not guilty by reason of mental impairment. The order allows the person to live in the community subject to conditions such as restrictions on where they can live or travel and that they obtain medical, psychiatric or psychological treatment. In 2018–19 this program supported 68 consumers.[189]
- The **Problem Behaviour Program** provides psychiatric and psychological consultation and treatment for adults aged 18 years or older with a range of behaviours associated with offending. In 2018–19 this program supported 323 consumers.[190]
- The **Victorian Fixated Threat Assessment Centre** 'provides a structured and coordinated approach to serious threats of violence posed by people with complex needs'.[191] This program is a significant recent investment in community-based forensic mental health care—in 2017–18 the program was established with $31.6 million in funding.[192] It is a partnership between specialist police and Forensicare that aims to 'identify high-risk people who may pose a serious threat to the community, including terrorists and lone actors who have made ongoing threats to others'.[193] In 2018–19 this program received 60 referrals.[194]

Figure 23.3 provides a summary of consumer pathways into these services.

Figure 23.3: Community Forensic Mental Health Service consumer pathways (internal and external referrals)



Source: *Forensicare, Correspondence to the RCVMHS: CSP.0001.0108.0001, Forensicare Service Plan*, 2020, p.33.

Further detail as to the current state of some of these programs is set out in the following sections, as the Commission ultimately recommends their expansion.

Forensic Clinical Specialist Program

Currently, the Forensic Clinical Specialist Program provides specialist forensic services to area mental health services. Dedicated forensic clinicians are embedded within area mental health services to provide specialist clinical, training and service development functions. Through this program, forensic clinical specialists are employed by local area mental health services to 'improve the expertise and capacity of the workforce in [these] services to optimally assess and manage offending and problem behaviours'.[195] Specifically, forensic clinical specialists aim to:

- improve clinical outcomes for consumers
- reduce consumer contact with the justice system
- improve management of offence-related risk
- improve worker safety and reduce violence and aggression in the workplace
- improve coordination and referral pathways between specialist mental health services and correctional services
- focus on people released from custody in need of mental health follow-up
- improve oversight of people subject to Non-Custodial Supervision Orders.[196]

When the program began in 2010, there were between six and eight forensic clinical specialists; there are now 23.[197] Despite this increase, the program is not responding effectively to high levels of demand and the increasing complexity of consumers.[198] Dr Margaret Grigg, CEO of Forensicare, identified 'workload and the limited support currently available to [forensic clinical specialists] from Forensicare' as the major barriers to the effectiveness of the program.[199] The significant workload means that forensic clinical specialists are currently only able to focus on primary and secondary consultation, and 'there is limited opportunity … to work directly with complex clients.'[200] Distinguished Professor Ogloff told the Commission that a crucial challenge to the program's effectiveness was that 'there is largely only one forensic clinical specialist for an entire area mental health service'.[201] Similarly, Mr Peter Kelly, Director of Operations at NorthWestern Mental Health, reported that 'forensic clinical specialists are spread very thinly across services' and that this creates 'a situation whereby recommendations may be made but which staff may or may not be able to implement'.[202] Distinguished Professor Ogloff observed that the program cannot currently meet sector demand for forensic expertise:

> **From my experience interacting with and teaching the Forensic Clinical Specialists since their inception, many become highly experienced but all typically lament the inability to meaningfully address all of the needs in their home services. Although the current model has begun to bridge a gap in services, it has not filled that gap. Only with expanded services, can the broader needs of the area mental health service and their consumers with forensic histories and contact be met.**[203]

Despite these barriers, an evaluation of the program found statistically 'significant improvements in the competency, confidence and skill of the clinical workforce' in area mental health services to work with the target client group between August 2010 and April 2013.[204] This evaluation also found that area mental health service staff were 'working together and communicating more effectively around risk as a result' of the program.[205]

There is support for the expansion of the Forensic Clinical Specialist Program. Dr Shaymaa Elkadi, Executive Director of Strategy, Planning and Performance at Forensicare, told the Commission that 'expansion of [the forensic clinical specialist] role is much needed to enable area mental health services to cope with the growing acuity [severity of illness] and risk complexity of presenting cases'.[206]

Distinguished Professor Ogloff recommended that the Forensic Clinical Specialist Program be expanded 'such that it can be a conduit between Forensicare and the area mental health services'.[207]

Dr Elkadi further identified the need for more integration between Forensicare and the area mental health services, particularly to support people living in rural and regional areas:

> There is significant merit in supporting Forensicare to provide regional outreach and to operate satellite clinics across metropolitan and regional areas by collocating with area mental health services to provide shared care (particularly for high risk clients). This would support the regional model of Community Corrections, creating a stronger interface between justice and forensic mental health.[208]
>
> there is also need for a shared care model with area mental health services. This may require Forensicare to co-locate with area mental health services and have satellite clinics in regional areas. It would assist Forensicare to proactively build relationships with stakeholders and provide assertive outreach.[209]

Dr Grigg identified a shared care model as an important opportunity to improve community-based forensic mental health care:

> I do think that the issue of having regional forensic mental health community teams is important, really intensive treatment to a small number of consumers potentially through a shared care model, where Forensicare doesn't just provide advice to area mental health services, on what the risk is, but potentially helps work with them and hold that risk with them ...[210]

Area mental health services are not currently adequately supported, and the workforce does not always have the skills to respond to consumers' behaviour symptoms when they are 'experiencing an acute mental health episode'.[211] This may include consumers who are extremely agitated, distressed and placing the safety of themselves, other consumers and staff at risk. Queensland Health's *Violence Risk Assessment and Management Framework—Mental Health Services* provides a pathway for mental health services to get forensic expertise and advice on consumer care (refer to Box 23.4). The Commission has considered this when contemplating the expansion of the current system.

Box 23.4: Queensland's Violence Risk Assessment and Management Framework—Mental Health Services

Queensland's Violence Risk Assessment and Management Framework—Mental Health Services sets out guidance on how to identify, assess and manage service consumers who may pose a risk of violence towards others. This framework was recommended by the 2016 report *When Mental Health Care Meets Risk: A Queensland Sentinel Events Review into Homicide and Public Sector Mental Health Services.*[212] This review was initiated in response to a number of high-profile fatal events involving people with a known or suspected mental illness in Queensland. In reviewing these fatal ('sentinel') events, the review aimed to provide recommendations for improving the delivery of public and forensic mental health care.

The review found that risk of violence was not well understood or managed in mental health services in Queensland. Specifically, risk assessments and management plans did not consider a consumer's previous history of violence. There was limited 'senior staff involvement in the provision of treatment, management and supervision of high risk consumers', and this resulted in an unclear escalation process for assessing and managing risk.[213] The review also found there had been limited access to specialist forensic mental health advice and support for 'generalist clinicians [who are] managing forensic consumers or other consumers who pose a high risk of violence'.[214]

In response to these findings, the sentinel events review recommended developing a violence risk assessment framework. This framework aimed to improve access to specialist forensic mental health advice for the highest risk consumers.

The framework provides a pathway for mental health services to access forensic expertise and advice on consumer care. It uses a structured three-tiered approach to risk assessment and management. Each tier represents an escalation in the risk of violence and an associated increase in the service response. The tiers are:

- **Tier 1—screening** focuses on 'all people receiving mental health services'
- **Tier 2—assessment and response** focuses on people 'identified through the Tier 1 screening process as having an elevated risk profile' (this is conducted by 'senior clinicians and consultant psychiatrists with training and experience in violence risk assessment')
- **Tier 3—specialist assessment and response** focuses on people 'identified through the Tier 2 risk assessment and response process as having a significantly elevated risk profile that is unable to be managed without specialist forensic input and meets specialist forensic mental health services referral criteria'. This process is undertaken by specialist forensic mental health services.[215]

Community Integration Program

Forensicare's existing Community Integration Program provides assertive case management before and after release for prisoners with severe mental illness and complex needs who are at high risk of discontinuing treatment in the community.[216] It 'provides short term support and linkage assistance for people with serious mental illness who need ongoing treatment when they leave prison'.[217] This program involves discharge planning six to eight weeks before discharge and assertive community outreach immediately following release. During the outreach stage, clinicians facilitate linkages to area mental health services or community health services.[218]

This program is very small. Currently, there are 3.5 fulltime-equivalent clinicians in the Community Integration Program. Given the current cap of one fulltime-equivalent clinician per 10 consumers, the program 'only has capacity to service 35 clients at any given time'.[219] Forensicare estimates that this is less than 0.5 per cent of all Victorian prisoners.[220]

Community Integration Program clinicians therefore have limited capacity to support consumers with other needs beyond connecting them with mental health treatment in the community. Forensicare reported that clinicians are often asked to assist in 'non–mental health, yet essential, needs such as accessing legal advice, assistance with accommodation, guidance and access to financial assistance, obtaining essential items, supporting reconnection with family and physical health care needs'.[221] The inability of the program to deal with these broader factors due to resourcing limitations is an impediment to achieving positive outcomes for consumers.

23.2.2 Transitions from custody to the community

The importance of continuity of care

The Commission recognises the importance of continuity of care when people move between custody and the community. 'Continuity of care' means:

> health services in the community being integrated and closely aligned with the health services provided in prisons such that there is no gap or interruption in the services and support a person receives as they transition from prison to the community.[222]

A Victorian Alcohol and Drug Association report to the Commission goes on to note that '[e]nhanced continuity of care reduces the risk of poor [mental] health outcomes, the need for expensive emergency healthcare contact after release from prison'.[223] Forensicare advised that many people 'quickly lose any health gains made in prison within a few months of release' in part through their disengagement from treatment with poor outcomes for, 'not only the individual, but the entire community'.[224] Lack of access to consistent mental health treatment can also lead to reoffending and ongoing involvement in the justice system.[225] Distinguished Professor Ogloff informed the Commission that there is particularly poor continuity of care for people living with mental illness who are leaving prison.[226] He concluded that this cohort is 'more likely to deteriorate very rapidly in their mental state and re-offend before they get mental health care if not engaged with mental health services'.[227]

The Victorian Alcohol and Drug Association argues that:

> continuity of care between the criminal justice, mental health and [alcohol and drug] systems is essential before, during and after release from prison to redress inequality and build on any health gains made during incarceration. … Ideally, planning for reintegration into the community should begin as soon as someone enters prison, with service provision continuing seamlessly after they return to the community.[228]

These sentiments about the importance of continuity of care have been echoed to the Commission by multiple experts.[229]

Lack of integration between prison and community services

The health care experienced by 'people released from prison in Victoria is neither well integrated nor continuous with community services.'[230] Forensicare's service plan identified 'limited community transition planning for people leaving prison' as a key challenge for the community-based forensic mental health system.[231] The service plan stated:

> Transition to community from prison is a time of great complexity, anxiety, and risk for the individual and community. Currently post release support for prisoners is limited. … This cohort often experiences multiple assessments, misdiagnosis, lack of tailored support and continuity of care, and episodic service engagement, leading to relapse or increased substance use.[232]

Forensicare said that 'due to a lack of comprehensive assessment and discharge planning, many prisoners without family or community support leave prison without any post-release support'.[233] Forensicare also described communication systems between prisons and community services as 'prohibitive, exacerbating the tyranny of distance experienced by them; increasing risk and subsequent stress on practitioners'.[234] Dr Danny Sullivan, Executive Director of Clinical Services at Forensicare told the Commission that:

> the coordination of care as justice-involved persons enter the community provides a sharp disjunction between previous care in prison and the availability and access of subsequent care in the community.[235]

Many prisoners held on remand are bailed and released directly into the community, most often with very little notice and planning. For these prisoners there are no formal pathways into community forensic mental health services.[236] This is also the case for straight release prisoners (prisoners who are not released on parole), who do not have obligations to start or continue forensic mental health treatment but who do in contrast to the above have a known planned release date.

In her witness statement, Ms Julie Edwards, CEO of Jesuit Social Services, highlighted the importance of continuity of care to ensure people do not 'fall through the gaps when they transition between services'.[237] Ms Edwards stated that a case or 'key' worker can be integral to supporting continuity of care,[238] along with information sharing[239] and embedding mental health services within other services.[240] Forensicare highlighted the importance of discharge planning in ensuring effective continuity of care.[241] Effective planning is required to ensure people have access to housing, support resources and general mental health and health services once they leave prison.[242]

Dr Sullivan supported creating 'integrated care in prison that then follows people back into the community'.[243] Ms McCammon advised that people in custody would:

> benefit from in-reach services which allow them to commence treatment with community mental health providers prior to release, to deliver continuity of care and build connections with the mental health provider they will use in the community.[244]

Dr Cassar recommended creating an 'assertive in-reach model where dedicated clinicians work with the prisoner and [area mental health service] prior to their release to ensure a suitable discharge plan is in place'.[245]

Release from custody straight into emergency departments

Some prisoners reach the end of their term of imprisonment 'but [continue] to experience acute mental illness'.[246] This is typically due to a prisoner refusing treatment, as is their right, while in custody. Due to prolonged wait times or other factors, these prisoners have not been transferred to Thomas Embling Hospital to receive compulsory treatment before the end of their sentence. In such cases, at the time of discharge prison health services may seek an Assessment Order under the *Mental Health Act 2014* (Vic).[247] An Assessment Order authorises the compulsory assessment of a person to determine whether the person requires compulsory mental health treatment. It is the required precursor to any order which authorises compulsory treatment. Once an Assessment Order is made, a prisoner is transported via ambulance to the nearest designated mental health service.

Mr Kelly expressed concern that Assessment Orders are being used as a 'mechanism of convenience' to transfer care from the justice system to the mental health system. Mr Kelly stated, '[w]hat we find most commonly is that the released person is homeless and has no funds, and under these circumstances the mental health service is left to sort out these issues'.[248] Mr Kelly estimated that 50 per cent of Assessment Orders do not result in a recommendation for compulsory treatment from the attending psychiatrist.[249]

For prisoners who are acutely unwell, and an Assessment Order is therefore appropriate, Mr Kelly says there is poor communication between prisons and emergency departments:

> We often have very little warning that these people are going to be released and consumers often arrive at the emergency department in a state that is unmanageable, for example a consumer who is floridly psychotic and in restraints.[250]

Eastern Health and NorthWestern Health similarly reported that there have been some instances of aggression and violence in inpatient units from this cohort.[251]

The Commission's recommendation to increase forensic bed capacity will ensure many more prisoners receive the treatment they need before their release. This change should reduce the role of emergency departments in treating recently released prisoners. The Commission's recommendation to improve transitional supports when leaving custody will ensure there is appropriate communication and planning between prisons and hospitals when an Assessment Order is required. It should be noted that Assessment Orders and transfer to emergency departments may still be needed when a person is released on bail at short notice, or released directly from court.

23.2.3 Inpatient care at Thomas Embling Hospital

Thomas Embling Hospital provides specialist mental health treatment for consumers transferred from prison or ordered by courts to be detained for psychiatric assessment and treatment. Treatment is provided under the *Mental Health Act 2014* (Vic)*,* the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* (Vic) (CMIA) or the *Sentencing Act 1991* (Vic) for the following cohorts:

- security consumers, who are people transferred from the criminal justice system for psychiatric assessment, treatment and care under the Mental Health Act
- civil consumers, who are admitted under the Mental Health Act (sections 45 and 52), including consumers transferred from other area mental health services for treatment
- forensic consumers, who are people who have been found not guilty by reason of mental impairment and are admitted under the CMIA.

If a person is found not guilty because of mental impairment they may be placed on a supervision order (custodial or non-custodial) or may be unconditionally discharged. Forensic consumers at Thomas Embling Hospital have been placed on a Custodial Supervision Order. Both Custodial and Non-Custodial Supervision Orders are of indefinite length, but the court must set a nominal term for the order that is set out under the CMIA. The orders can be very long-lasting depending on the person's response to treatment.

Figure 23.4 provides a summary of the consumer pathways for each of these cohorts.

Thomas Embling Hospital has 136 beds across seven units contained within a high-secure precinct, and one low-secure unit.[252] Since opening in 2000, Thomas Embling Hospital inpatient infrastructure has expanded very slowly despite the concurrent very significant expansion of the Victorian population and the prison population. Thomas Embling Hospital opened with 65 beds, before becoming fully operational with 100 beds by the end of 2002. Over the past 18 years an additional 36 beds have been created. The eight-bed Apsley Unit opened in March 2019 to provide acute treatment to consumers transferred from prison under the Mental Health Act, particularly those with challenging behaviours.

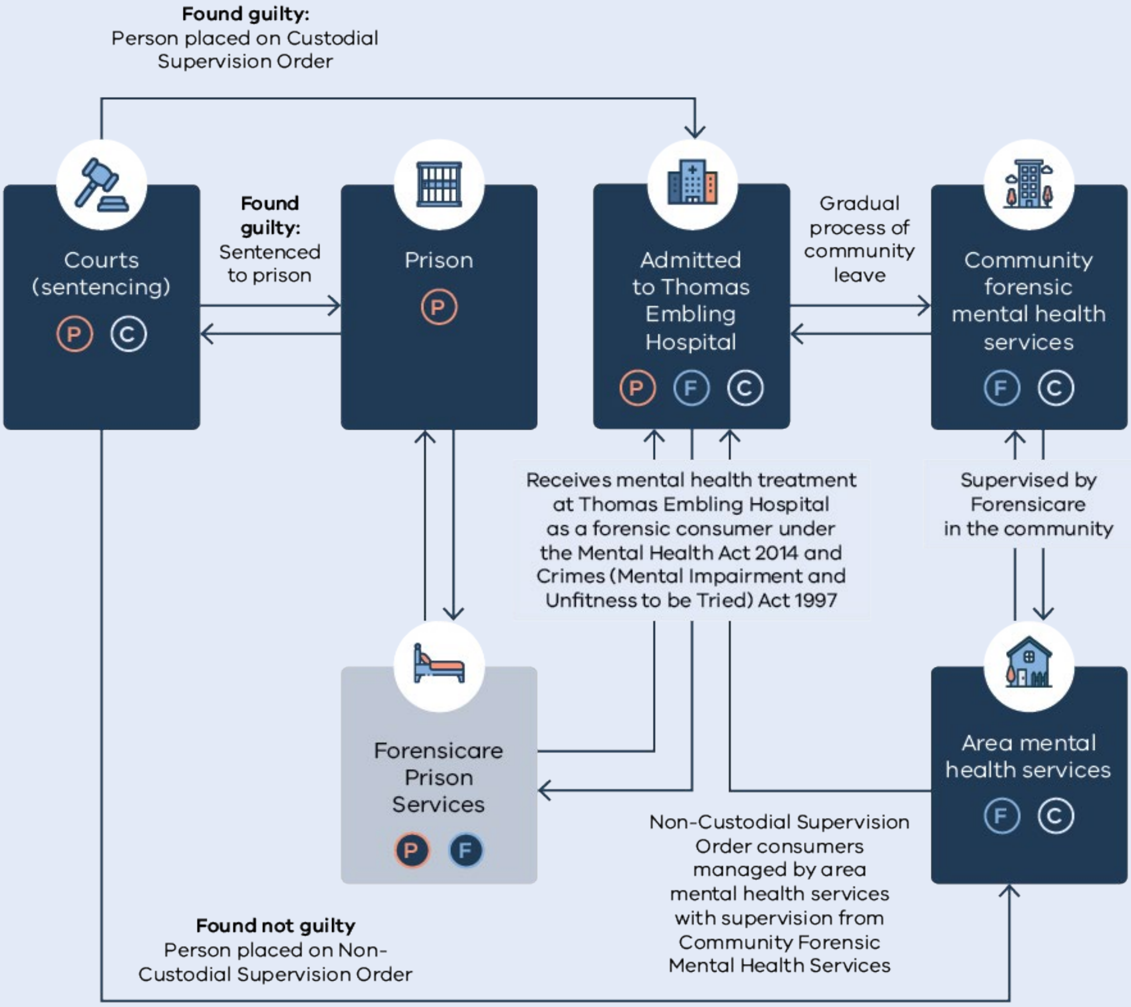
In a roundtable with representatives from the Forensicare Consumer Advocacy Group, the Commission heard about both positive and negative experiences at Thomas Embling Hospital. One consumer stated:

> The service was brilliant. It took a long time. But I think with a lot of people with mental illness, it does take time to sort things out. So, having been afforded the time to get well again yes, I do approve of the service and I think it's been very helpful for not just me but for all that use it.[253]

Another roundtable participant discussed limited bed numbers and the impact this had on consumer flows: 'the biggest concern is beds available because it's very slow moving'.[254]

Another consumer said: 'They look after me, they want the best for me, they don't want you to be upset and I find that very welcoming environment'.[255]

Figure 23.4: Summary of consumer pathways



Ⓟ **Prison & security consumers**	Ⓕ **Forensic consumers**	Ⓒ **Civil consumers**

Source: Forensicare, *Correspondence to the RCVMHS: CSP.0001.0108.0001, Forensicare Service Plan*, 2020, p.33.

Note: In some cases, forensic and security consumers may be on remand.

Personal story:

Tommy

Tommy* had multiple hospital admissions for mental illness starting from the age of 19. He was admitted to Thomas Embling Hospital when he was 30, where he stayed until recently.

> I have been in and out of hospital many times. I must have had over 20 admissions to public units. For about 10 years, until I came to Thomas Embling, I was never really well. I was never what I'd call stable or recovered or anything like that.

Tommy said his experience of stays in mental health inpatient units were always too short to allow him to fully recover and that the system needs places where people can stay for longer.

> I've been on clozapine for about 12 years now. And even then, it's probably only the last four or five years that I've really become stable. Which is incredible, because you think of the public system where you are in and out in three or four weeks. That's not nearly enough time to get someone stable and well, and to the point where they don't have to come back to the hospital anymore. It's important to not just patch someone up but actually get them stable—it's a thing that only time can really do.

Tommy said it took a long time with stable medication and other supports for him to recover.

> It was only when I got to Thomas Embling that with time and consistent medication taking and all the therapy and all that sort of thing, that I started to get well again. I think now I am fully recovered and managing a very good mental state. It took about 15 years in Thomas Embling to get my head right.

When Tommy was younger, he said it was hard to understand the help he needed. He was put on a compulsory treatment order when he was 20.

> I had difficulties with taking medication consistently. I think I never really took it seriously enough and drug use was another problem.
>
> The [community treatment order] was a bit of a kick in the guts. I never really understood the gravity of the situation. I never thought anything was wrong. The hard part is identifying that there's something wrong when you don't think there is.

'Insight' is a big word for Tommy—he said he did not have insight into his mental illness and the impact of his offending until he got to Thomas Embling.

> I wish I had access to Thomas Embling without committing an offence. If there were a Thomas Embling in the community, for the public before you commit an offence, I think that would be a real positive. If that existed, then I might have gotten back the 20 years that I've lost.
>
> I've lost a good 20 years of my life because of poorly managed mental health. The frustration was crushing. I just couldn't shake it. I couldn't shake the illness. I tried, and there were no quick fixes. When you've got a headache you take Panadol and then an hour later it's gone. But mental illness isn't like that. It's a war of attrition.

Tommy found peer support and the group sessions at Thomas Embling helpful. He said this was not something he had access to in other hospital settings.

> For me, one of the best things I did was talking to my peers about similar things that have put us here, how mental illness has affected us. When I was in the acute units in the public system, they had art therapy and music groups which were more distracting people from their illness. I don't remember having a room full of peers talk about their illness and how that affects them, and that would have been a really big help.
>
> If I could tell my story to someone who's just starting to get unwell, point out the things that work and what helps and what doesn't, maybe that might help them. I wish I could say that to young people—listen, if you don't fix this now, you're gonna lose all that time. It's going to cost you time off your life. If you don't address it and do it well, do it right early, it's just gonna consume your life.

Source: *Personal Story of 'Tommy' (pseudonym), Collected by Victoria Legal Aid.*

Note: *Name has been changed to protect privacy.

One representative discussed the need for improved services for women:

> the women need more facilities where they can actually have some space to get well instead of all being put in a corridor where you're all on top of each other … there's really not much there for women at all and it's actually quite disappointing when you look at the facts because there's a lot of women waiting in jail and this was my experience when I went through this system and you know, you can just get lost in it and it's really not fair actually.[256]

Forensicare observed:

> Despite recognition of the specific needs of women across the spectrum of forensic mental health services, they do not have the same options as men for a staged transition through security levels to support recovery and community integration.[257]

The Commission did, however, hear of the positive experience of recovery and integration of witness, Leona Coleman.

As discussed in the Commission's interim report, the demand for beds at Thomas Embling Hospital has increased for several reasons, including the growing prison population, recent changes to bail laws that have increased the number of people held on remand, and the introduction of the CMIA.[258] Since the Act's introduction, many more people have received supervision orders than before, and this has added to the demand for beds at Thomas Embling Hospital.[259] This increase in demand has not been met with increased investment to expand service capacity, with consequent restrictions on access and poorer quality of care.[260] A number of reviews have highlighted the service capacity challenges at Thomas Embling Hospital and the risks of not providing enough mental health services to acutely unwell prisoners.[261]

Growing proportion of forensic consumers

In 2002, 31 of the 100 beds at Thomas Embling Hospital were occupied by forensic consumers and the remainder by security and civil consumers.[262] Since 2002 the proportion of forensic consumers at Thomas Embling Hospital has increased. The hospital now has 136 beds, of which approximately 90 beds (66 per cent) are occupied by forensic consumers.[263] Figure 23.5 has been reproduced from the Commission's interim report and shows the change in the proportion of total occupied bed days by each consumer cohort, from 2002–03 through to 2019–20.

Despite this focus on forensic consumers, this cohort still commonly long wait times to be admitted to Thomas Embling Hospital from prison.[264] That is, these consumers—found not guilty by reason of impairment—are on average being kept in prison for more than a year before a bed at Thomas Embling Hospital becomes available. In 2019–20 this was an average of 392 days for men and 88 days for women.[265] This delay in receiving mental health treatment, care and support often results in a severe deterioration in mental health. This delay and subsequent deterioration may constitute a violation of a person's human right to humane treatment when deprived of liberty. Figure 23.6, reproduced and updated from the Commission's interim report, shows the increase in the average wait time for forensic consumers to be admitted to Thomas Embling Hospital over time.

Personal story:

Leona Coleman

After experiencing mental health and addiction issues for some time, Leona* committed a serious offence. She was found not guilty due to mental impairment and placed on a custodial supervision order at Thomas Embling Hospital.

Prior to the commission of the offence, Leona had been admitted to a mental health facility four times, including a two-month stay in the year the offence was committed. Despite trying a range of medications, Leona had been quite unwell in the lead-up to the offence.

> When I think about my offence I feel like I had hit rock bottom, like the light inside me went out. It felt like I had charcoal in my chest and I lived like that for years and years. It was not me that night. It was a different person. I know I have to live with what I did and that really hurts.

During her time at Thomas Embling Hospital she was put on a combination of medications which she said have 'kept me well for a number of years now'. At Thomas Embling Hospital, Leona was able to access a range of treatments including a psychologist, group therapy, and a drug and alcohol group, which she said was very helpful.

Leona was able to transition slowly back into the community and now lives independently with the help of some community-based supports. Leona lives in stable accommodation, which has also been a great way for her to maintain her health and wellbeing.

> I still receive treatment and support in the community. I am on medication and see a counsellor who is really great … I also see my local area mental health service who have worked with me to help me identify my early warning signs. It is my responsibility to keep myself well. I have a good National Disability Insurance Scheme package. I do singing lessons and art classes once a week. I have a cleaner and a gardener that helps me with my plants out in the courtyard. I also have a kitten which has changed my life. I am hoping to start a family soon.

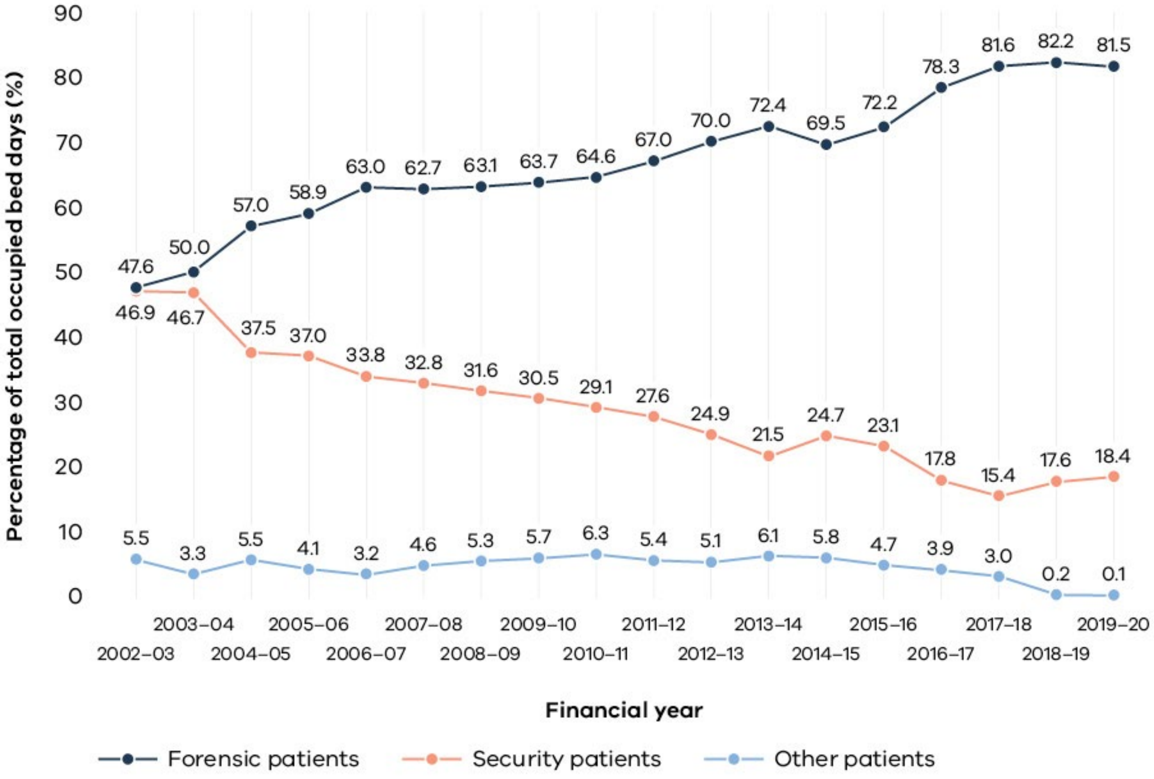
Leona advocates for more facilities to support people to stay well in the long term.

> There should be a Thomas Embling in the community. A facility where you can check in and constantly get support, medication, group therapy, workshops and courses. All these things help you learn more about yourself and what you are feeling.

Source: *Witness Statement of 'Leona Coleman' (pseudonym)*, 4 May 2020.

Note: *Name has been changed in accordance with an order made by the Commission.

Figure 23.5: Proportion of total occupied bed days by consumer type, Thomas Embling Hospital, Victoria, 2002–03 to 2019–20



Source: Department of Health and Human Services, Client Management Interface/Operational Data Store 2002–03 to 2019–20.

Notes: Classification of consumer legal status for the purposes of calculating the percentage of total occupied bed days by consumer legal status is as follows:

- Forensic consumer included anyone on a forensic order at any time during their episode.
- Security consumers included anyone who was not on a forensic order, but on a security order at any time during their episode.
- Other consumers included all other consumers not listed above.

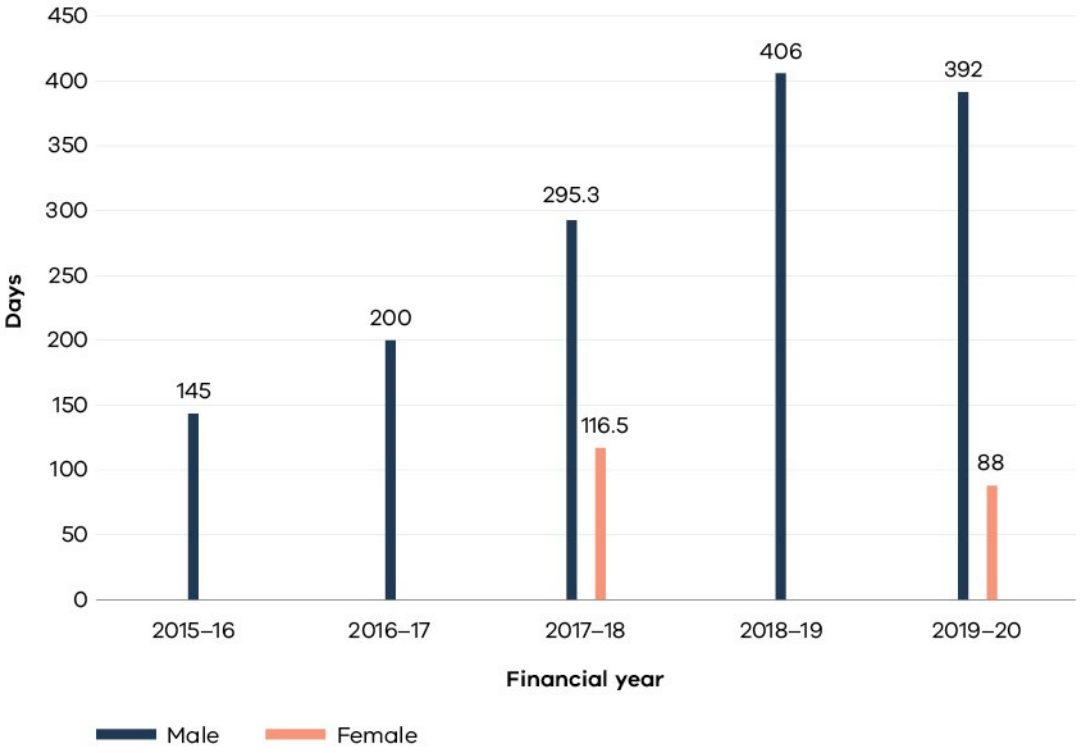
Limited capacity to treat civil consumers

The target population of Thomas Embling Hospital includes 'people with a serious mental health disorder in mainstream mental health services who are … a danger to their carers or the community'.[266] This means that Thomas Embling Hospital can provide inpatient services for civil consumers. These consumers are involuntary consumers who are not subject to forensic or sentencing orders—that is, who have not committed an offence or been placed under an order issued under the CMIA.[267]

In practice, Thomas Embling Hospital has rarely been able to provide treatment, care and support to these consumers. Distinguished Professor Ogloff said 'the capacity to assist the broader area mental health services by admitting complex and challenging patients for assessment and intervention has been lost'.[268]

Dr Neil Coventry, Victoria's Chief Psychiatrist, observed that civil consumers requiring high-intensity support in a higher security, safe environment at Thomas Embling Hospital cannot be admitted because of bed constraints.[269]

Figure 23.6: Average wait time (days) for forensic consumers in prison to be admitted to Thomas Embling Hospital following a recommendation to the court for a custodial supervision order, 2015–16 to 2019–20



Sources: Forensicare, *Yanith Bilang Quality Account 2017–18,* p.49; Forensicare, *Annual Report 2018–19,* p.39; Forensicare, information provided to the Royal Commission, 1 December 2020.

Notes: Wait time on average is for forensic consumers in prison to be admitted to a bed at Thomas Embling Hospital. There were no female prisoners in 2015–16, 2016–17 and 2018–19 who had to wait for a bed at Thomas Embling Hospital on a Custodial Supervision Order.

In some cases these consumers may instead access treatment, care and support in secure extended care units, which provide extended bed-based rehabilitation in the current system.[270] As the Mental Health Tribunal has suggested, changes over time, and a growth in the number of people who may present in secure extended care units with aggressive behaviours, has altered 'the milieu of a [secure extended care unit], arguably requiring it to provide a service it was not intended to provide'.[271] One outcome of this change is a reduced therapeutic environment for other consumers accessing treatment, care and support in secure extended care units, for example, because of heightened security requirements that may be applied to all rather than only for those who may need it.

The need for additional civil capacity was identified by Distinguished Professor Ogloff in his witness statement to the Commission, and in research undertaken by the University of Melbourne for the Commission. Distinguished Professor Ogloff stated:

> consistent with the principle of least restriction under the [Mental Health Act], consumers currently at [secure extended care units] may benefit if they are in a [secure extended care unit] in [Thomas Embling Hospital] instead.[272]

The University of Melbourne research also concluded:

> We suggest that a statewide system of secure units could be developed and linked with Forensicare, separate to the afore-mentioned inpatient rehabilitation units. These would operate similarly to the Forensicare rehabilitation model but in community locations and/or within Thomas Embling Hospital (TEH) itself. They would effectively serve a step-up/step-down function within a high level of security and assist consumers unable to leave Forensicare without a high level of support to transition to the community. They would also re-create a statewide capacity to assess and treat consumers with very complex needs from area mental health services, including those not subject to forensic or sentencing orders but who are likely to be subject to compulsory orders.[273]

Figure 23.7 provides a summary of Thomas Embling Hospital consumers as of July 2020.

Compulsory treatment for people in custodial settings

Currently in Victoria, people living with mental illness in prison cannot receive compulsory mental health treatment under section 67 of the Mental Health Act. Compulsory treatment means that a person may receive treatment and medication without their consent, though their treatment must adhere to a legislative framework. In order to receive compulsory treatment, a prisoner must first be transferred to a designated mental health service. For adults, the designated mental health service is Thomas Embling Hospital, while young people are transferred to an intensive care area of the Orygen Specialist Program. This program provides specialist mental health services for young people aged 15–25 years who live in the western and north-western regions of Melbourne.

This approach is consistent with 'a long-established principle in Victoria that compulsory mental health treatment must not be provided in correctional settings'[274] and with the *National Statement of Principles for Forensic Mental Health*.[275] The expected outcome of a course of compulsory treatment is that the person's illness is stabilised, enabling them to return to the prison environment for voluntary treatment.

The shortage of beds at Thomas Embling Hospital means that prisoners who may need compulsory treatment are waiting for long periods in prison before they can be admitted.[276] In 2018–19 female security consumers waited an average of nine days before admission and male security consumers waited 38.8 days on average.[277] This delay in care may have serious consequences for the health of consumers as well as safety risks for staff. To address these wait times, some have suggested that Victoria introduces compulsory treatment in custodial settings.

Figure 23.7: Current activity at Thomas Embling Hospital

		Security		Forensic		Civil	
Overall Thomas Embling Hospital occupancy (as at end of July 2020)		22%		76%		2%	
Gender mix based (as at end of July 2020)		**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
		88%	12%	85%	15%	100%	0%
Average length of stay	**Acute**	2.4 months	3.5 months	3.5 months	-	2.1 years	-
	Subacute	-	-	2.0 years	-	8.6 years	-
	Rehab	-	-	4.1 years	6.5 years	-	-
Discharges (per year)		146	27	19	1	5	-

Source: Forensicare, *Correspondence to the RCVMHS: CSP.0001.0108.0001, Forensicare Service Plan*, 2020, p.22.

Note: Data above is for the period 1 July 2017 to 30 June 2019 inclusive.

Associate Professor Ruth Vine, Director at Forensicare, supports introducing compulsory treatment in prisons, given long wait times associated with bed shortages at Thomas Embling Hospital. Associate Professor Vine argued:

> until there is sufficient capacity in the forensic mental health system, there needs to be a way to provide more intensive mental health care (including the use of compulsory treatment) in prisons; it is untenable that we provide 19th century treatment to people living with mental illness in prisons in the 21st century. Ideally, there should be greater investment in the amenities and capacity of the forensic mental health system, so that there is a reduced number of prisoners living with untreated mental illness.[278]

The Commission heard opposition to compulsory treatment in custodial settings from multiple witnesses.[279] In a position statement, the Royal Australian and New Zealand College of Psychiatrists opposed compulsory treatment in custodial settings, '[i]nvoluntary mental health treatment in custodial settings compromises clinical care, encourages inappropriate management of prisoners, and breaches human rights'.[280]

The Commission heard that compulsory treatment in custody compromises the 'principle of reciprocity', as set out in the United Nations *Standard Minimum Rules for the Treatment of Prisoners*.[281] Dr Coventry explained:

> This principle holds that society has no right to remove civil liberties from individuals for the purpose of treatment if resources for that treatment are inadequate. If a prisoner experiences psychiatric symptoms that are so acute that compulsory treatment is needed, they should receive it from a specialist multidisciplinary team at a hospital; the care available in prison is not an adequate substitute, particularly in situations where prisoners require treatments with the potential for serious side effects.[282]

Despite this interpretation of the principle of reciprocity, New South Wales and South Australia do provide compulsory treatment in custodial settings.[283] In New South Wales, this is the result of mental health facilities within correctional centres being declared as designated health services under the *Mental Health Act 2007* (NSW) for the purposes of providing involuntary treatment.[284] In South Australia, this is expressly enabled under legislation.[285]

The weight of evidence before the Commission indicates that compulsory treatment should not be provided in Victorian correctional settings. It is anticipated that the recommended increase in bed numbers at Thomas Embling Hospital will provide enough capacity for prisoners to gain timely access to compulsory treatment.

23.2.4 Expanding the existing community forensic model

Multiple witnesses have highlighted the need for forensic mental health experts to better support area mental health services.[286] The Commission recommends improving supports for Area Mental Health and Wellbeing Services to care for consumers who have either:

- committed or are at risk of committing an offence, or
- engaged in threatening or violent behaviours towards others.

This will occur in two ways:

- increase the workforce of the Forensic Clinical Specialist Program—in line with current arrangements, these specialists will be employed by and based at Area Mental Health and Wellbeing Services
- establish a specialist behaviour response team to support Area Mental Health and Wellbeing Services in responding to the needs of consumers in mainstream adult inpatient services.

The Commission further recommends that the Department of Health conducts a review of forensic community-based services two years after implementation. This review will focus on the interaction between the Forensic Clinical Specialist Program, the specialist behaviour response team and other community-based programs. This review will identify and respond to any opportunities to further improve community-based forensic service delivery in Victoria's new mental health and wellbeing system.

Expand the Forensic Clinical Specialist Program

The Forensic Clinical Specialist Program will receive funding to increase the workforce across Area Mental Health and Wellbeing Services. The program will employ people with expertise in social work, psychology, occupational therapy and psychiatry to provide the area mental health and wellbeing workforce with training, clinical advice and co-case management as required.

The new specialist behaviour response team will provide the forensic clinical specialists with support from Forensicare, increasing their capacity to work directly with complex consumers.

The implementation of this recommendation will be informed by data analysis of demand for the service based on consultation with Forensicare, Area Mental Health and Wellbeing Services and the existing forensic clinical specialist workforce.

The Commission has recommended improving the forensic capacity of the Area Mental Health and Wellbeing Services by expanding existing programs and creating a new service that focuses on consumers who act in threatening or violent ways. In implementing these recommendations, the relationship between these programs and service providers should be informed by some aspects of Queensland's Violence Risk Assessment and Management Framework—Mental Health Services (as detailed in Box 23.4).

Create a specialist behaviour response team

In addition to the Forensic Specialist Clinical Program, Forensicare will provide a specialist behaviour response team to support Area Mental Health and Wellbeing Services strengthen their capacity to respond to consumers who are extremely agitated, distressed and placing the safety of themselves, other consumers or staff at risk. The specialist behaviour response team will help ensure consumers receive highly specialised care responses in the least restrictive way and build on other initiatives to improve inpatient settings.

The explanation and rationale for creating a specialist behaviour response team, along with the description of its functions and purpose, is contained in Chapter 10: *Adult bed-based services and alternatives*.

23.2.5 Supporting transitions between prisons and mental health services

The Commission recommends that the Victorian Government establishes a program to transfer the supports people living with mental illness receive in prison to mainstream mental health services on their release. Targeted to people who need ongoing intensive treatment, care and support the program will be based on the Community Integration Program and will support people leaving prison to begin or continue their treatment with Area Mental Health and Wellbeing Services.

Between December 2019 and November 2020, 13,103 people were discharged from Victorian prisons.[287] This includes people who may have had multiple short stays in prison during this period. Almost half of these (46 per cent), or 6,009 people, were not sentenced during their episode of imprisonment.[288] The high proportion of prisoners released while on remand reflects the need to enable remandees to be referred to this program. *The Health of Australia's Prisoners* report found that, in 2018, 18 per cent of Victorian prison dischargees reported experiencing a high or very high level of psychological distress, as measured by the Kessler 10 scale (a simple measure of psychological distress).[289] The very small sample size for this study should be noted—only 83 prison dischargees from Victoria were included in the study.[290] This proportion is equivalent to 2,359 prisoners released between December 2019 and November 2020. Additionally, 26 per cent prison dischargees reported being distressed about mental health issues.[291] Applied to the number of people discharged between December 2019 and November 2020, this is 3,407 prisoners.

The recommended transition program will provide three key services:

- discharge planning six to eight weeks before discharge from prison
- facilitate connections to Area Mental Health and Wellbeing Services
- facilitate access, whether through the pre-release planning conducted by the Department of Justice and Community Safety, or directly to community support services such as housing, legal assistance, physical health care, the National Disability Insurance Scheme and Commonwealth benefits.

Remandees and sentenced prisoners living with mental illness may be referred to the program by Forensicare staff providing specialist forensic mental health services in prisons.

The following prisoners should be referred to the program:

- prisoners leaving prison from a custodial unit dedicated to mental health service requiring referral to an Area Mental Health and Wellbeing Service
- prisoners leaving prison from a Forensicare outpatient service requiring referral to an Area Mental Health and Wellbeing Service
- prisoners leaving prison from a primary mental health care outpatient service requiring referral to an Area Mental Health and Wellbeing Service.

Referrals from Forensicare will be provided to the Sentence Management Unit within each prison so the program can begin in line with expected release dates.

It is recommended that the program be initially rolled out in the major prisons where Forensicare currently provides specialist mental health services. These are Dame Phyllis Frost Centre, Ravenhall Correctional Centre and Melbourne Assessment Prison. Following an evaluation of the effectiveness of the program, it could be expanded to other prisons if appropriate.

The Commission estimates that when implemented across all locations, the expanded transition program will support around 500 prisoners each year. The implementation of this recommendation should include robust data analysis on expected demand for the service.

This program will be developed in partnership with Aboriginal community-controlled organisations to ensure culturally appropriate transitional support is provided to Aboriginal prisoners.[292] The Aboriginal Social and Emotional Wellbeing Centre, a recommendation of the Commission's interim report,[293] is well placed to facilitate the required connections between prisoners and community-based Aboriginal health providers.

The expanded program will require a multidisciplinary workforce that can provide prisoners with: mental health treatment, care and support; appropriate wellbeing supports; supervision in the community adapted to a person's presentation and needs; and assertive outreach visits where staff visit consumers.

Proposed model of care

As discussed above, there is strong evidence that continuity of care is required to ensure good outcomes during the transition from prison to the community. However, evidence about the specific components of transition support programs is less clear.[294] The implementation of this recommendation will require careful consideration of the specific elements of this transition support program, in consultation with experts and consumers.

In many instances people living with mental illness who transition out of prisons have ongoing, intensive mental health treatment, care and support needs. The Commission's recommendation that people living with this high-intensity level of need will be supported through Assertive Community Treatment is described in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services* and in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults*. Assertive Community Treatment involves care delivered where a person needs it by multidisciplinary teams with low caseloads and is a model of care that may be adapted to best support people who have been involved with the justice system.[295]

23.2.6 Expanding the capacity of Thomas Embling Hospital

The Commission recommends expanding the bed capacity at Thomas Embling Hospital. An expansion of bed numbers will enable consumers to receive appropriate care throughout their recovery.

The expanded capacity of Thomas Embling Hospital is also intended to support the extended rehabilitation needs of people who cannot safely and appropriately be provided with treatment, care and support in secure extended care settings and other extended rehabilitation settings. As well as being briefly described in section 23.2.3, the impact of the expanded capacity of Thomas Embling Hospital to support the extended rehabilitation needs of civil consumers is described in Chapter 10: *Adult bed-based services and alternatives*.

This recommendation seeks to:

- increase capacity for civil consumers—this will ensure these consumers receive the specialist forensic support they need and relieve pressure on community-based inpatient services
- decrease the wait time for compulsory treatment among prisoners—this will ensure prisoners receive compulsory treatment in a timely manner in line with service delivery in the community
- improve consumer streaming—being able to organise the hospital based on security needs, gender and level of need will improve consumer care as well as safety for consumers and staff
- improve services for women—currently women do not have the same options as men for a staged transition through security levels to support recovery and community integration.[296]

Mr Robert Fiske, CEO of the Victorian Health and Human Services Building Authority, submitted to the Commission a statement on service planning for Thomas Embling Hospital. This statement provided secure forensic bed demand projections until 2036 informed by Forensicare's bed-based service plan. The current modelling was completed in November 2019 and is based on population forecasts from Census data and prisoner number forecasts.[297] Table 23.1 and Table 23.2 summarise Mr Fiske's projected forensic bed requirements until 2036 by consumer cohort.

Stage 1A of expansion works includes a 48-bed men's medium security building and 34-bed women's precinct.[298] The Victorian Health and Human Services Building Authority has advised the Commission that this stage has an estimated program timeframe of four years once funding is secured. The exact timeframe depends on when government gives final approval and on the need to modify any planning to meet the final recommendations of the Commission.[299]

The Commission recommends that the Victorian Government commits to meeting required capacity until 2026. The Commission expects that further expansion of Thomas Embling Hospital will occur in line with demand following 2026, noting the Commission's recommendation that the Victorian Government establishes a process for assessing the Victorian population's need for mental health and wellbeing services, including forensic mental health and wellbeing services discussed further in Chapter 28: *Commissioning for responsive services*. It is anticipated that prevention elements, in particular a better resourced and targeted community mental health and wellbeing system, will affect demand for forensic beds. The precise level of impact is unknown, and the Building Authority's projections may need to change to reflect this. The need to adjust projections following the introduction of the reformed system is discussed in Chapter 5: *A responsive and integrated system*.

Table 23.1: Secure forensic bed demand projections and shortfall 2018–2036

	Current capacity	Required capacity 2018	Required capacity 2021	Required capacity 2026	Required capacity 2031	Required capacity 2036
Total beds	136	189	213	239	257	275
Bed shortfall		53	77	103	121	139

Source: RCVMHS calculation of *Witness Statement of Robert Fiske*, 15 October 2020, para 14; Forensicare, Review of Forensic Bed numbers (based on the bed forecast model) endorsed by the VHHSBA/Forensicare Steering Committee in 2019.

Table 23.2: Secure forensic bed demand projections and shortfall by consumer cohort, Victoria 2018–2036

Consumer cohort	Current capacity	Required capacity 2018	Required capacity 2021	Required capacity 2026	Required capacity 2031	Required capacity 2036
Security consumers	27	77	99	116	125	134
Forensic consumers	107	101	102	109	117	125
Civil consumers	2	11	12	14	15	16
Total	136	189	213	239	257	275

Source: *Witness Statement of Robert Fiske*, 15 October 2020, para 14; Forensicare, Review of Forensic Bed numbers (based on the bed forecast model) endorsed by the VHHSBA/Forensicare Steering Committee in 2019.

23.3 Improving mental health outcomes across the youth justice system

Victoria's youth justice system is composed of a community supervision system and a detention system.

The detention system consists of two centres—Parkville Youth Justice Precinct and Malmsbury Youth Justice Precinct. Parkville 'accommodates:

- 10–14-year-old males (remanded or sentenced)
- 15–18-year-old young men (remanded or sentenced)
- 10–17-year-old females (remanded or sentenced)
- 18–21-year-old women sentenced to a Youth Justice Centre Order by the Magistrates', County and Supreme Courts'.[300]

Malmsbury 'accommodates young men aged 15–20 years when remanded or sentenced to a Youth Justice Centre Order in a mixture of low and high security residential units.'[301]

On an average day in 2018–19 there were 191 young people held in youth justice detention in Victoria.[302] A further 766 were subject to community-based orders.[303]

Community supervision means the supervision of children and young people who are on community-based orders including probation, Youth Supervision Orders, Youth Attendance Orders and parole orders. This supervision is undertaken by youth justice units staffed by youth justice workers who support the children and young people to comply with their orders, along with providing referrals to other parts of the social services system, including health, education, employment and housing.

Aboriginal young people are significantly over-represented in Victoria's criminal justice system. Ms Hansen reported that '[o]n an average day in 2018–19 in Victoria, Aboriginal young people were 11 times as likely to be under youth justice supervision than non-Aboriginal young people'.[304]

Young people in the youth justice system experience high rates of mental illness. This has been acknowledged by the Victorian Government in the master planning of the new youth justice centre currently being built at Cherry Creek, west of Werribee, which was intended to have a 12-bed mental health unit.[305] The 2019 youth justice survey reported that of the 185 young people under youth justice custodial supervision on 31 December 2019, 68 per cent presented with mental health issues.[306] The Youth Parole Board reported that 'around two out of three young people on parole will present with mental health issues'.[307]

Ms McCammon told the Commission that 367 (45 per cent) of young people in custody between July 2019 and May 2020 had a mental health 'diagnosis recorded, including a substance use-related disorder'.[308] These numbers reflect the short sentences and high churn associated with the youth justice system.

For example, the Victorian Auditor-General in 2018 described that:

> In 2017–18, 961 young people received a total of 1332 sentences and 460 young people received 777 remand orders. Between 1 November 2017 and 31 January 2018, young people on remand spent an average of 25 days and young people sentenced spent an average of 58 days in youth detention.[309]

Between July 2019 and May 2020, the top four diagnoses among young people under youth justice supervision in Victoria (excluding substance use-related diagnoses) were:

- reaction to stress and adjustment disorders (including post-traumatic stress disorder, acute stress reaction and adjustment disorder)
- attention deficit hyperactivity disorder and other hyperkinetic (frenetic energy or activity) 'disorders'
- depressive 'disorders'
- schizophrenia, schizotypal and delusional 'disorders'.[310]

The over-representation of young people living with mental illness in the youth justice system is not unique to Victoria.[311] The 2016 *Review of the Youth Justice System in England and Wales* found that more than a third of young people in the youth justice system in England and Wales have a 'diagnosed mental health disorder'.[312] This review recommended that:

> Health commissioners and providers in England and Wales should … rethink the way that mental health support is provided to children who are at risk and who currently do not get the access they need or deserve.[313]

Mental illness among young people in the justice system is correlated with experiences of neglect, trauma and abuse. For example, among young people in the American juvenile justice system, the vast majority have experienced trauma as a child and 90 per cent have experienced at least one traumatic event during their lifetime.[314] Dr Adam Deacon, Child and Adolescent Consultant Psychiatrist at Alfred Health, told the Commission in a personal capacity that a cycle of childhood trauma, mental illness and substance use is common among the youth justice cohort in Victoria. Dr Deacon observed that children in the Victorian youth justice system have often been neglected, abused and traumatised.[315] The impact of these experiences can include the onset of 'mood disorders' and 'anxiety disorders', as well as having a negative impact on neurological development, cognitive development and the capacity to regulate behaviour.[316] In turn, substance use to manage these psychological challenges is common. Dr Deacon concludes that '[e]xtensive drug use, particularly cannabis and methamphetamine, can contribute to the development of psychotic symptoms, and potentially enduring psychotic disorders such as schizophrenia.'[317]

These experiences may also contribute to cycles of recidivism among young people. Dr Claire Gaskin, Forensic Adolescent Psychiatrist at the University of New South Wales, referenced, in a personal capacity, the findings of a study of young people in youth justice custody in New South Wales:

> Another factor that increased recidivism was exposure to significant psychosocial issues when returning home—for example, if they had parents with mental illness, with substance use issues, or who are abusive. Additionally, homelessness and lack of support were key factors in determining the likelihood of recidivism.[318]

Young people in contact with the youth justice system often have difficulty obtaining access to mainstream youth mental health services. For example, the Youth Parole Board acknowledges the difficulties faced by young people in custody with significant mental health needs in getting parole because of the limited availability of community-based mental health services.[319]

Echoing the failure of mainstream services to support young people in contact with the youth justice system, Ms McCammon described the results of the 2018 Annual Survey of Young People in Youth Justice in Victoria, which showed that 'as of 31 December 2018, of the 361 children and young people on community orders who presented with mental health issues, only 144 were accessing mental health supports or services'.[320] Ms McCammon acknowledged that this limited access to services 'may be due to their challenging behavioural presentations resulting in access issues. That is, they may be turned away from mental health supports and services in the community because their behavioural presentations are often too challenging or complex.'[321]

Dr Cassar similarly noted that young people often have greater difficulty in obtaining access to forensic mental health services than adults, particularly those living in rural and regional areas:

> In regional areas, waitlists for forensic mental health services are long or offenders must travel to the city to engage appropriately qualified professionals. This is particularly true for young people under twenty five in Children and Youth/Adolescent Mental Health Service catchments, where there is even more restricted access to forensic mental health services.[322]

Professor Stuart Kinner, Head of the Justice Health Unit in the Centre for Health Equity at the Melbourne School of Population and Global Health, University of Melbourne, emphasised the significant health needs of young people in contact with the justice system who are living in the community:

> People who have contact with the criminal justice system but do not experience incarceration also typically have significant unmet health needs. For example, our work in Victoria has shown that the burden of mental health and substance use problems among young people under youth justice supervision is concentrated among those under community supervision—this is because only a minority of justice-involved young people are in detention at any one time.[323]

Gaps in service delivery are reflected in current funding arrangements. Orygen, the National Centre of Excellence in Youth Mental Health, told the Commission that while mental illness is evident long before a young person reaches custody, 'funding for mental health intervention is currently aimed toward the population of young people in custodial settings'.[324]

23.3.1 The state of Victoria's youth forensic mental health services

The following programs comprise the current suite of youth forensic mental health services in Victoria:

- Children's Court Mental Health Advice and Response Service, provided by the Orygen Specialist Program
- Community Forensic Youth Mental Health Service, operated by Alfred Health and the Orygen Specialist Program
- Youth Justice Mental Health Initiative, coordinated by Forensicare
- Custodial Forensic Youth Mental Health Service, provided by the Orygen Specialist Program (including a secure unit in the Orygen Inpatient Unit at Footscray Hospital).

Table 23.3: Existing youth forensic services

What is the service?	Who delivers the service?	Who is it for?	Where is it delivered?
Children's Court Mental Health Advice and Response Service	Orygen Specialist Program	Children and young people appearing before the Children's Court	Melbourne Children's Court
Community Forensic Youth Mental Health Service	Alfred Health and the Orygen Specialist Program	Children and young people engaged or at risk of becoming engaged with youth justice who are referred by child and youth mental health services and child and adolescent mental health services	North, West and Southern Metropolitan Regions of Melbourne
Youth Justice Mental Health Initiative	Coordinated by Forensicare, delivered by clinicians in child and youth mental health services and child and adolescent mental health services	Children and young people under the community-based supervision of Youth Justice	Child and youth mental health services and child and adolescent mental health services
Custodial Forensic Youth Mental Health Service	Orygen Specialist Program	Children and young people in custody	Youth justice centres (including the secure unit in the Orygen Inpatient Unit at Footscray Hospital)

In addition to these components, the new youth justice centre at Cherry Creek will provide bed-based mental health treatment, care and support to young men living with mental illness aged between 15 and 18 years.[325] This centre is expected to be open by 2022.[326]

The **Children's Court Mental Health Advice and Response Service** provides mental health assessments for young people appearing before the Children's Court.[327] The service may also advise the Children's Court if a young person's offending was affected by mental illness, as well as facilitate access to mental health support services. [328] The program is being trialled in the Melbourne Children's Court with a single clinician available. The Children's Court submitted to the Commission that there is a view for the service to be expanded across all Children's Courts in Victoria, but there is currently no timetable for its expansion.[329] This service is provided through the Orygen Specialist Program.

The **Community Forensic Youth Mental Health Service** started operating in mid-2019 and 'provides mental health support to youth who are experiencing mental illness and who are at risk of offending or have offended'.[330] Specifically, it is a consultation service that provides forensic expertise to child and adolescent mental health services and child and youth mental health services with 'complex clients presenting with forensic issues'.[331] The service currently provides assessments of 'young people presenting with problem behaviours, including interpersonal aggression and violence, threats, stalking, sexualised behaviour, arson, animal cruelty and other complex behaviour disturbance.'[332] The program currently does not provide case management and treatment.[333] The program is operated by Alfred Health in the Southern Metropolitan Region and Melbourne Health (Orygen Specialist Program) in the North West Metropolitan Region.[334]

The program was initially developed to support the 'missing middle' of youth justice consumers who may be excluded from community-based mental health services. Dr Deacon, the lead psychiatrist of the program operated by Alfred Health, stated that:

> Once police become involved or youth justice intervention has occurred, Child and Adolescent Mental Health Services (CAMHS) and Child and Youth Mental Health Services (CYMHS) may not consider the adolescent to be a suitable candidate for their service.[335]
>
> Likewise, many clinicians do not have the confidence, or do not perceive that it is within their clinical remit, to treat children and adolescents with complex needs that includes offending behaviour.[336]

Dr Paul Denborough, the Clinical Director of Alfred Child and Youth Mental Health Services and headspace at Alfred Health, in a personal capacity, described the impetus of the program as:

> The [Community Forensic Youth Mental Health Service] program was implemented to address the lack of forensic mental health services available for youth within Victoria. Forensicare provides support to all adults with mental health issues and there was no comparable support for youth experiencing similar mental health and juvenile justice issues.[337]

Dr Denborough told the Commission that beyond the assessment provided through the Forensic Youth Mental Health Service:

> No further treatment or follow up service is able to currently be provided. Forensic work generally requires specific expertise that generic mental health services struggle to manage. A treatment arm to the forensic youth services is critical and would match equivalent Forensicare adult services.[338]

Dr Denborough said the biggest impediment to the service is a lack of resources and staff members.[339] Dr Deacon reiterated this need for more resources:

> Ideally we would be better resourced with more expert staff and have the capability to provide a case management model akin to that provided at Forensicare with their community programs, including the Problem Behaviour Program.[340]

The **Youth Justice Mental Health Initiative**, coordinated through Forensicare, was established in 2010 and aims:

> to improve access of young people (those aged 18–24 years) to mental health services, and to support the capacity of youth justice staff and mental health staff to effectively meet the needs of young people with mental health issues.[341]

The program has six forensic clinicians, five of whom are based in child and youth mental health services or child and adolescent mental health services across Victoria.[342] The sixth clinician is based at Forensicare, providing direct services to Parkville, as well as coordinating the initiative overall and supervising the other five clinicians.[343] The initiative has four core functions. As described by Ms McCammon, these are to:

> - build the capacity of the youth justice program
> - provide mental health assessments in the community
> - facilitate referral pathways and advocate for appropriate service provision
> - engage mental health community support services and clinical mental health services before a young person's mental health concerns escalate.[344]

Dr Grigg advised the Commission that:

> In redesigning Victoria's mental health system, the Youth Justice Mental Health [Initiative] could be repositioned to take on a more active leadership role that better supports the capability of youth justice staff to understand and respond to the mental health needs of young people. … there is an opportunity to better embed forensic mental health youth expertise across youth mental health services.[345]

The Custodial Forensic Youth Mental Health Service is a specialist mental health service operated by Melbourne Health (Orygen Specialist Program) at Parkville and Malmsbury, which provides evidence-based specialist assessment and treatment for young people in detention. In November 2020 three secure beds opened at the Orygen Inpatient Unit at Footscray Hospital. These beds are for providing 'compulsory treatment for children and young people in custody'.[346]

An evaluation of the program is expected to be completed in early 2021.

Case study:

Custodial Forensic Youth Mental Health Service

The Custodial Forensic Youth Mental Health Service is a specialist mental health service located in both Parkville and Malmsbury Youth Justice Centres. It provides clinical mental health services for children and young people on remand or sentenced in the centres. It began in February 2019.

The service is operated by Royal Melbourne Hospital (Orygen Youth Health) and works closely with Correct Care Australasia, which provides the primary health service to the children and young people in detention. It is funded through the Department of Health, which manages the program in consultation with Justice Health.

Ms Emma Burke, a clinical psychologist at Royal Melbourne Hospital, said the service was designed to provide tertiary mental health care through a multidisciplinary team made up of medical staff, including a neuro-psychologist, psychiatric registrar and consultant psychiatrist, as well as other allied health clinicians (including psychiatric nurses, social workers, occupational therapists and psychologists).

> Prior to this service, young people in custody were provided with a mental health service that was primarily focused on a psychiatric response. The Custodial Forensic Youth Mental Health Service is an attempt to start to make specialist mental health services that young people require in custody more equitable to what young people receive from a community youth mental health service.

Ms Burke said the service provides assessment, case management and therapeutic work, as well as discharge planning at both detention centres. Young people in custody present with a range of complex mental health illnesses, as well as conditions that are difficult to diagnose.

> We often see young people in custody through this service who you wouldn't typically see get into a tertiary mental health service. This is particularly the case in the under 15 cohort who may present with a lot of things going wrong but nothing that you can easily diagnose, but they clearly need specialist input.

Ms Burke said young people can be discharged to other tertiary specialist mental health services, or services such as headspace or to GPs, but it is catchment-based, which can limit the type of care they receive and whether Orygen can provide continuity of care into the community.

> If the young people are in Orygen's catchment area, then we will refer them to other community teams. That's where we actually find that this works, when we can all liaise together. For example, when someone in the court role can communicate that someone is coming into custody, or when the custodial team can let the justice mental health workers know when someone is being discharged we can work together to provide care.

Source: RCVMHS, *Interview with Ms Emma Burke*, November 2020.

The Commission has heard that this service is not meeting demand, and that the effectiveness of service delivery is being compromised by the quality of youth justice centre facilities.

Mr Kelly stated that the program is currently not keeping up with demand and requires a significant increase in funding.[347] Orygen said the 'funding is not adequate to reach the demand of young people experiencing mental ill-health in custody'.[348]

The Commission has heard about the significant challenges in the way that specialist mental health services are delivered within youth justice custodial centres. They include:

- inadequate physical infrastructure (including inappropriate facilities to treat the children and young people)
- a youth justice workforce that is not equipped with the appropriate skills, experience or support to manage children and young people living with mental illness who are under their supervision
- unmet need for the services provided in custody—both primary and specialist mental health services
- barriers to information sharing both within custodial settings and at the points of transition into and out of custodial settings
- a lack of oversight, including the lack of clarity of the role of the Chief Psychiatrist in relation to safety and quality
- a lack of clarity about who commissions and manages the service.[349]

Dr James Belshaw, Consultant Psychiatrist for the Custodial Forensic Youth Mental Health Service, also told the Commission that inadequate physical infrastructure in youth justice centres was limiting the capacity for a trauma-informed approach to care. Dr Belshaw told the Commission that the current custodial sites are not 'fit for purpose, in terms of delivering effective mental health care'.[350] He described the areas allocated to interview people as 'the opposite of what a trauma-informed approach would dictate'.[351] The rooms are dimly lit, do not have dual exits and there are often windows whereby peers can observe and communicate with the young person being interviewed.[352] This limits the ability of staff to accurately assess young people and give a valid diagnosis as there are other confounding variables.[353] Dr Belshaw also observed that the lack of facilities such as sensory rooms limits the tools that can be recommended in management plans.[354] It is clear that custodial services in particular are facing difficulties in delivering a trauma-informed approach.

The lack of a trauma-informed approach is particularly concerning given the high rates of mental illness among young people in custody, the negative mental health impact of custody and the subsequent increased likelihood of recidivism. Dr Belshaw said that the Orygen team working within Parkville and Malmsbury:

> find that youth custody makes people with mental health issues, which is perhaps all of them, more unwell. And we often see that they're more likely to offend, especially the clients that we're working with. At the current time, our average client ... sadly and inevitably seems to return to custody within a number of months.[355]

Inadequate custodial mental health service provision has also been identified in reviews of the system. The 2017 *Youth Justice Review and Strategy: Meeting Needs and Reducing Offending* report identified issues affecting the Victorian youth justice system at the community and custodial levels and proposed reforms.[356] Although the mental health of young people engaged with youth justice is not a headline of this review, it was acknowledged as 'central'.[357]

The review found that '[o]nce in contact with Victoria's youth justice system, the life outcomes of young people are poor and there is no change in their offending patterns' and that 'Victoria has the most expensive youth justice system per capita, with little difference in outcomes'.[358] With specific reference to mental health services, the review highlighted:

- the informality of mental health referrals into the system
- the lack of a dedicated and secure adolescent mental health unit
- how ill-equipped custodial facilities were to deal with the mental health needs of young people, with the result that they may be inappropriately held in custody
- limited staff training in mental health.[359]

No fully functioning youth forensic service in Victoria

Victoria currently does not have a fully functioning, adequately resourced forensic youth mental health service that meets the needs of young people. Ms McCammon reported that there are currently 'gaps in mental health infrastructure that restrict the ability for children and young people involved with Youth Justice to have their needs met (secure and non-secure).'[360] Distinguished Professor Ogloff noted, referring to forensic outreach services, that any youth service is 'severely limited' with 'far fewer resources' than those devoted to adult services.[361] And, more directly, he concluded:

> we need a joined-up service system. It's one of the only elements I think the Royal Commission is looking at that simply doesn't exist. That is, we don't have a youth forensic mental health system, in Victoria.[362]

Dr Deacon described the 'disjointed' system currently facing children and young people:

> There are too many disjointed parts. Many children are repeatedly assessed. This is taxing, disrespectful and unhelpful to the child. There is often a lack of clear coordination of information sharing. The reports on the children are often invaluable, but not necessarily readily accessible.[363]

Dr Elkadi summarised the impact of an under-resourced and disconnected mental health system for young people:

> The trajectory into the criminal justice system is too often the cumulative result of a reactive and belated mental health system response to mental ill health in young people. The lack of systematic prevention, early identification and treatment interventions for young people is a key contributor to the decline of mental health in young people which over time manifests in serious mental illness, a cycle of offending and reoffending and inevitable contact with the criminal justice system.[364]

Orygen stated that '[t]here is immense scope for the improvement of the forensic system in order to better support and improve the mental health of young people who are justice-connected'.[365] Orygen provided the Commission with recommendations 'to better respond to the mental health needs of young people who are at risk of offending or who are in contact with the justice system'.[366]

Specifically, Orygen highlighted the need to:

> Develop and deliver a state-wide comprehensive forensic mental health service for young people both in custody and in the community. This should include: a focus on early intervention, integration of specialised mental health treatment with interventions that address offending behaviours; and Youth Forensic Clinical Specialists for youth justice clients (12–21 years).[367]

Box 23.5: Queensland youth forensic mental health system

The Queensland youth forensic mental health system has been presented to the Commission as 'the most comprehensive and effective program' of its kind in Australia.[368]

Queensland's Forensic Child and Youth Mental Health Service has two main components:

- the Brisbane Youth Detention in-service of the Mental Health Alcohol and Other Drugs Service, which operates in custodial settings
- the Child and Youth Forensic Outreach Service, which is delivered in the community.[369]

These two services feature multidisciplinary teams. Staff include child and adolescent forensic psychiatrists, psychiatry registrars, clinical nurses, psychologists, social workers, administrative officers and Aboriginal health workers.[370] Dr Denborough considers the community service 'a great success and a model which could be replicated within Victoria's mental health and justice systems.'[371] This service uses an 'individualised and multi-systemic approach to intervention'.[372] This means the treatment approach differs for each young person depending on their needs and circumstances. This may include a co-therapy arrangement with a primary service provider from the local child and youth and mental health service, providing a block of therapy for a specific period of time, or being the sole therapy provider.[373] The service operates across most of the state[374] and has the fulltime-equivalent staff of 30.[375]

The Commission was told that the most important component of this system is the integration of a mental health team into the youth justice system. As Dr Denborough described it, this 'allows for not only assessments to take place, but also for those individuals to receive initial treatment and further referrals into the mental health system as required'.[376]

The Commission has recommended that aspects of the Queensland system be adapted to the Victorian context and implemented in the youth forensic mental health system.

There is no statewide comprehensive forensic mental health service for young people in Victoria. That is, the equivalent of Forensicare does not exist in the youth system. However, there are some current programs that, if adequately resourced and connected, could form the basis of a well-functioning youth forensic mental health and wellbeing system. Dr Deacon noted that creating an integrated service model would be challenging:

> The major challenges that will be faced by the youth forensic mental health system over the next ten years will be in establishing an integrated service model and developing a workforce with sufficient skills and experience to work with children and adolescents with forensic backgrounds.[377]

Treatment for young people subject to an order under the CMIA

In 2014 the CMIA was amended to enable the Children's Court of Victoria to consider the defence of mental impairment. This followed a recommendation made by the Victorian Law Reform Commission.[378] If a young person's fitness to stand trial is raised the Court requests a psychological report from the Children's Court Clinic.[379] Of the 40 young people referred to the clinic since 2014, 23 have been found to be unfit, mentally impaired, or both.[380] 'Mental impairment' can mean the young person has mental illness, intellectual disability or another cognitive impairment such as a brain injury.[381] The Children's Court noted that most CMIA cases involve children and young people with intellectual disability, autism and attention deficit hyperactivity disorder.[382]

Despite guidance by the Victorian Law Reform Commission to adopt a 'specialised approach' to implementation,[383] the Children's Court of Victoria reported that 'the CMIA legislative framework was extended to the Children's Court without the facilities, programs and services intended by the [Victorian Law Reform Commission] to underpin an effective response for these vulnerable children'.[384] The Commission heard that this is having an impact on the effectiveness of the CMIA process. Her Honour Judge Amanda Chambers, the former President of the Children's Court, noted that she presided over almost all the CMIA matters that came before the Children's Court and, in her view:

> the process under the Act is lengthy and even where a child is ultimately placed on a supervision order, the supports and supervision available in the community to address the problematic behaviour are generally those that would otherwise be available, for instance under the NDIS.[385]

The Victorian Law Reform Commission originally recommended creating a framework for operating the CMIA in the Children's Court but only once a dedicated youth forensic facility was established. Despite the fact the CMIA is currently operating in the Children's Court, no dedicated youth forensic facility has been established.

The urgent need for a youth forensic facility has been highlighted in subsequent reviews of the youth justice system. The 2017 *Youth Justice Review and Strategy* found that 'young people under CMIA orders are not best placed for rehabilitation in youth justice custodial centres; they should be housed in environments that cater to their health needs first'.[386] The review recommended that the responsible department:

> immediately cease to house all young people on a CMIA order in youth justice facilities, and commence a process to determine appropriate alternate accommodation for young people currently on those orders in Youth Justice care.[387]

The 2018 *Inquiry into Youth Justice Centres in Victoria* also recommended establishing a youth forensic mental health precinct.[388] To date, these recommendations have not been acted on.

The Commission heard that this continues to be a priority concern for the sector. Dr Grigg advised:

> The establishment of an appropriate model of care for children and young people under the age of 18 who are under the CMIA should be a priority. The model of care is particularly complex for this group, as the number of people in this group is small, their needs (gender, developmental, educational, criminogenic and mental health) are diverse, and there is a need to safeguard vulnerable children and young people. Currently the only custodial setting available is a Youth Justice correctional facility which does not meet the treatment or therapeutic needs of the child or young person.[389]

Ms McCammon reported that:

> three young people have been detained in Parkville Youth Justice Precinct in the last five years pursuant to a Custodial Supervision Order following a finding of being unfit to stand trial or not guilty by reason of mental impairment.[390]

When a child is placed on a Non-Custodial Supervision Order, there is no coordinated approach for how the child is to receive rehabilitation and care, as required by the CMIA. It falls to the Chief Psychiatrist to negotiate with the relevant community-based services to ensure the young person receives treatment, care and support.[391]

The Commission notes that the failure of the government to provide the appropriate facilities, programs and services to support implementation of the CMIA demonstrates that the human rights of young people with mental impairment are still not being met.[392]

Dr Grigg further stated that:

> Services should be provided within a mental health setting that supports recovery and ensures children and young people have access to the same range and quality of services as their non-CMIA peers living with mental ill health and those in the adult forensic system under CMIA.[393]

There are at least three significant issues in the operation of the CMIA for young people. These include:

- the CMIA process is lengthy[394] and is not achieving good outcomes for young people[395]
- young people subject to a Custodial Supervision Order are placed in a youth justice custodial centre[396]
- young people subject to a Non-Custodial Supervision Order do not receive mental health treatment through an established care pathway.[397]

23.3.2 Establishing a statewide youth forensic mental health service

The Commission recommends expanding existing youth forensic mental health programs across the 13 Infant, Child and Youth Area Mental Health and Wellbeing Services to provide an integrated statewide model and to ensure consistency in treatment, care and support to children and young people in contact with, or at risk of coming into contact with, the youth justice system.

This suite of programs described below will provide Victoria with a statewide comprehensive forensic mental health service for young people both in custody and in the community.

Given that Orygen is currently delivering the bulk of the programs that will need to be subsumed through establishing this service and has the attributes of a statewide service, including strong and established links to academia, it is well positioned to run part or all of this new service. This service will play the equivalent role of Forensicare in the adult system by providing and coordinating service delivery and contributing to research. This service should be run in formal partnership with Forensicare.

This specialist Youth Forensic Mental Health Service will operate in community, inpatient and custodial settings.

In community settings, this includes young people living with mental illness who are:

- at risk of coming in contact with the youth justice system (through referrals from schools, police, parents and social support services)
- under the supervision of youth justice in the community (including those on parole orders, supervised bail and other community-based orders)
- appearing before the Criminal Division of the Children's Court
- subject to a Non-Custodial Supervision Order under the CMIA.

In inpatient settings, this includes young people living with mental illness who are:

- at risk of coming in contact with the youth justice system (through referrals from schools, police, parents and social support services)
- under the supervision of youth justice in the community (including those on parole orders, supervised bail and other community-based orders).

In custodial settings, this includes young people living with mental illness who are:

- under the supervision of youth justice in youth justice centres (including those serving sentences of detention and on remand)
- subject to a Custodial Supervision Order under the CMIA.

Required programs within a statewide youth forensic mental health service

To 'develop and deliver a state-wide comprehensive forensic mental health service for young people both in custody and in the community',[398] the following reforms are required.

The **Community Forensic Youth Mental Health Service** will be expanded to meet current demand. The expanded service will provide assessments, treatment and case management as required. Any young person aged up to 25 years old can be referred to this program. The implementation of this expanded remit will require close consultation with Forensicare to ensure there is no duplication in service delivery for young people aged 18–25 years.

The **Custodial Forensic Youth Mental Health Service** will be expanded to meet current demand. This expansion will require significant collaboration with youth justice to ensure a trauma-informed approach to care is facilitated by youth justice staff and supported by appropriate infrastructure. This expanded service will be available to all young people in youth justice custody.

A **youth forensic clinical specialist program** will be created to build forensic capability within Infant, Child and Youth Area Mental Health and Wellbeing Services. Such a program will be modelled on the forensic clinical specialist program in the adult system and should build on the existing base of the Youth Justice Mental Health Initiative. Implementation of this recommendation should consider how this new service will sit alongside the referral component of the Youth Justice Mental Health Initiative.

There will be at least one forensic clinical specialist in each of the 13 Infant, Child and Youth Area Mental Health and Wellbeing Services. The precise workforce requirements should be based on robust demand projections completed during implementation of this recommendation. Any young person with a forensic history, or those at risk of coming into contact with the justice system, aged up to 25 years old can be referred to this program.

Similar to the adult service, youth forensic clinical specialists will:

- work closely with the Infant, Child and Youth Area Mental Health and Wellbeing Service clinical manager, consultant psychiatrists, psychiatric registrars and other members of the multidisciplinary teams to ensure procedures to reduce risk in clinical settings are closely followed
- proactively identify and refer eligible high-risk, complex or severely unwell young people to the Youth Forensic Mental Health Service
- develop and deliver professional development, education and training activities
- establish and maintain referral pathways to enable young people with mental illness to access other necessary supports (such as general health, housing, employment, education/training and family services)
- evaluate clinical practices and systems against research evidence, identifying areas for improvement
- develop and/or review treatment and crisis plans.

As part of establishing the Youth Forensic Mental Health Service, the Commission recommends that the service leads two changes relating to the operation of the CMIA for young people. First, **creating appropriate accommodation options for young people subject to a Custodial Supervision Order**, noting that the small number of young people subject to these orders means an individually tailored solution could be provided. And second, **developing a care pathway for young people subject to a Non-Custodial Supervision Order**.

Echoing the recommendation made in Chapter 13: *Supporting the mental health and wellbeing of young people,* the Commission recommends that **all child and youth services are available until a person is 26 years old**. The expansion of this age bracket will also apply in the forensic mental health and wellbeing system, to both those in custody and under community supervision. At this point, or where considered appropriate in consultation with the young person, their families and carers, people will transition to receiving care through Adult and Older Adult Area Mental Health and Wellbeing Services.

This requires the **creation of a Youth Forensic Mental Health Service in adult prisons**. It is proposed that Forensicare be funded to operate this service alongside the adult specialist mental health services that it already provides. In the first instance, this service should be provided at the following locations:

- Melbourne Assessment Prison (Acute Assessment Unit)
- Dame Phyllis Frost Centre (Marrmak Unit)
- Ravenhall Correctional Centre (Ballerrt Yeram-boo-ee Forensic Mental Health Service).

Pending a two-year evaluation of the service by the Department of Justice and Community Safety, in partnership with the Department of Health, this function could be expanded to other prison locations.

Supporting elements for the service

In developing this recommendation to establish a statewide specialist Youth Forensic Mental Health Service, the Commission proposes four supporting elements that must be considered in its implementation—a consistent model of care, supporting principles, workforce development and careful demand projections.

A consistent model of care will underpin these services. The Commission recommends that the development of the model of care be informed by the model created for the existing custodial and community services.[399] The core attributes of this model are that services will:

- be culturally and gender safe and sensitive
- promote a focus on early intervention
- provide person-centred care and continuity of care that will reduce the need for consumers to repeat their stories and go through unnecessary transition points
- deliver trauma-informed, recovery-focused treatment, care and support
- deliver age and developmentally appropriate treatment, care and support through a multidisciplinary team
- improve accessibility and effectiveness of the redesigned Infant, Child and Youth Area Mental Health and Wellbeing Services
- establish clear pathways for referral, admission and discharge.[400]

The Youth Forensic Mental Health Service will be underpinned by the *National Statement of Principles for Forensic Mental Health.*[401] The first 11 principles are of particular relevance and have been adapted to form the principles for establishing and operating the statewide specialist Youth Forensic Mental Health Service. These are set out in Box 23.6.

Box 23.6: Principles of Victoria's statewide specialist Youth Forensic Mental Health Service

Principle 1: Equivalence. Young people living with mental illness who are under the supervision of youth justice, whether in the community or a custodial setting, will have the same access to treatment, care and support that has equivalent availability and quality to that which is available to the general population.

Further, young people living with mental illness who are under the supervision of youth justice have equivalence in relation to the legal rights and protection enjoyed by the general population as it relates to their treatment, care and support.

Principle 2: Safe and secure treatment. Treatment, care and support will be provided to young people living with mental illness under the supervision of youth justice in an environment that is appropriate and compatible with their needs while also considering any need of the community for safety.

Principle 3: Responsibilities of the health and justice systems. Providing mental health treatment, care and support for young people is the joint responsibility of the health and justice systems (including police, youth justice and court systems) and will be addressed in partnership. There will be a focus on communication between these systems.

Principle 4: Access and early intervention. A young person, whether on remand, serving a sentence of detention or in police custody, will have timely referral and access to mental health treatment, care and support when appropriate.

Principle 5: Comprehensive forensic mental health services. The Youth Forensic Mental Health Service will be a specialist mental health service providing integrated inpatient services, custodial mental health services, court liaison services and community mental health services in a coordinated clinical and administrative stream. The service will have strong links and partnerships with the redesigned infant, child and youth mental health and wellbeing system, the adult forensic mental health and wellbeing system and with consumer and carer organisations. The service will provide evidence-based, multidisciplinary, continuous care, consistent with those of the redesigned child and youth mental and wellbeing health system. The service will also engage social support services, including providing intervention relating to homelessness, alcohol and substance use.

Principle 6: Integration and linkages. Integration of the above elements of the service will minimise barriers to young people living with mental illness receiving treatment, care and support in the most clinically appropriate setting. There will also be close integration with custodial services and parole bodies.

Principle 7: Ethical standards. The rights of young people living with mental illness subject to supervision under youth justice to be respected for their individual human worth, dignity and privacy is not given up by any circumstance, regardless of the person's history of offending or their status as a forensic mental health client or a young offender. The person's capacity or right to consent is not given up as a result of their history of offending or alleged criminal behaviour.

Principle 8: Staff: knowledge, attitudes and skills. The service's workforce will require a high degree of professionalism and strong clinical leadership. Appropriate training and support will be required to maintain a highly skilled workforce.

Principle 9: Individualised care. The service will meet the changing needs of each person, considering their biological, psychological, social, cultural and spiritual context.

Principle 10: Quality and effectiveness. The service will have in place a quality improvement process that, through performance outcomes, identifies opportunities for improvement in the way services are delivered and includes action to address identified deficiencies. This improvement process will involve carers and consumers.

Principle 11: Transparency and accountability. The service will be subject to processes of accreditation against national standards for mainstream services. It will also be subject to external and peer review. The National Standards for Mental Health Services provide appropriate benchmarks for forensic mental health services.

Given the size of this reform, the workforce requirements are significant. The Commission recommends that the new youth forensic service includes a training and research function to support workforce development. Orygen is well placed to fulfil this function. Chapter 33: *A sustainable workforce for the future*, provides more information on building the capability required across the mental health and wellbeing system.

The specific level of demand for the new service has not been determined. The Commission recommends that during the implementation process a rigorous demand modelling process be undertaken. This should be based on population projections and from data from youth justice, Victoria Police, the Children's Court of Victoria and Infant, Child and Youth Area Mental Health and Wellbeing Services.

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2 *Witness Statement of Peta McCammon*, 13 August 2020, para. 13.

3 *Witness Statement of Peta McCammon*, para. 13.

4 Sentencing Advisory Council, Victoria's Imprisonment Rates, <www.sentencingcouncil.vic.gov.au/statistics/sentencing-trends/victoria-imprisonment-rates>, [accessed 10 November 2020].

5 Sentencing Advisory Council, Victoria's Indigenous Imprisonment Rates, <www.sentencingcouncil.vic.gov.au/statistics/sentencing-trends/victoria-indigenous-imprisonment-rate>, [accessed 16 November 2020].

6 Andrew Leigh, *The Second Convict Age: Explaining the Return of Mass Imprisonment in Australia*, 2020, p. 15.

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9 Corrections Victoria, *Monthly Time Series Prisoner and Offender Data*, Table 1—Number of Prisoners by Gender and Warrant Status —End of Month July, 1998 to November 2020.

10 Corrections Victoria, Offender Profile—Community Correctional Services (CCS), 2019, p. 1.

11 Corrections Victoria, Offender Profile—Community Correctional Services (CCS), p. 1.

12 Corrections Victoria, Offender Profile—Community Correctional Services (CCS), p. 1.

13 Corrections Victoria, *Monthly Time Series Prisoner and Offender Data*, Table 4—End of Month Offender Numbers by Offender Type and Gender.

14 Royal Commission into Victoria's Mental Health System, *Interim Report*, 2019, p. 49; Australian Institute of Health and Welfare, *The Health of Australia's Prisoners, Supplementary Tables—States and Territories*, 2019, Tables s169 and s193.

15 James Ogloff, Good Mental Health Care in Prisons Must Begin and End in the Community, *The Conversation*, 24 April 2015, p. 1.

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19 *Witness Statement of Dr Emma Cassar*, para. 68.

20 *Witness Statement of Dr Emma Cassar*, para. 68.

21 *Witness Statement of Dr Emma Cassar*, para. 70.

22 *Witness Statement of Dr Emma Cassar*, para. 70.

23 *Witness Statement of Dr Emma Cassar*, para. 70.

24 Victorian Auditor-General's Office, *Managing Community Correction Orders*, 2017, p. 26.

25 *Witness Statement of Peta McCammon*, para. 290; Victoria Legal Aid, *Correspondence to the RCVMHS: CSP.0001.0001.0151, Paving the Roads to Recovery: Building a Better System for People Experiencing Mental Health Issues in Victoria*, May 2020, pp. 51–52; Victorian Auditor-General's Office, *Managing Community Correction Orders*, p. 27.

26 Victorian Auditor-General's Office, *Managing Community Correction Orders*, p. 27.

27 *Witness Statement of Dr Emma Cassar*, para. 95.

28 Victorian Auditor-General's Office, *Managing Community Correction Orders*, p. 27.

29 Victorian Auditor-General's Office, *Managing Community Correction Orders*, p. 24.

30 Victorian Auditor-General's Office, *Managing Community Correction Orders*, p. 24.

31 Magistrates' Court of Victoria, *Submission to the RCVMHS: SUB.3000.0001.0672*, 2019, pp. 19–20.

32 Sentencing Advisory Council, Victoria's Indigenous Imprisonment Rates.

33 Victorian Aboriginal Legal Service, *Submission to the RCVMHS: SUB.0002.0030.0226*, 2019, p. 33.

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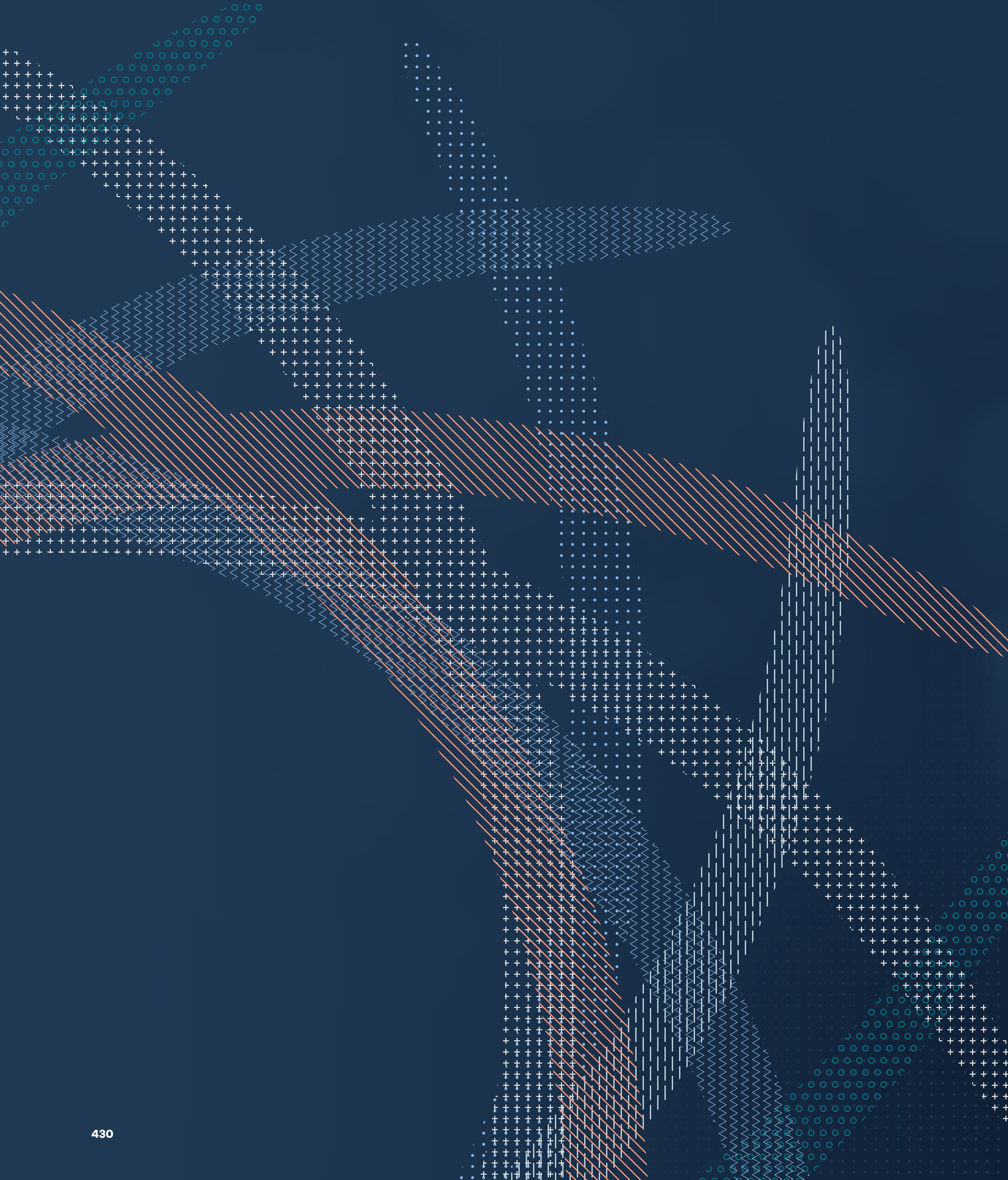


Chapter 24

Supporting the mental health and wellbeing of people in rural and regional Victoria

Recommendation 39:

Supporting the mental health and wellbeing of people in rural and regional Victoria

The Royal Commission recommends that the Victorian Government:

1. in addition to ensuring rural and regional communities receive the benefits of the Royal Commission's recommended responsive and integrated mental health and wellbeing system:
   a. provide additional resources to enable mental health and wellbeing services operating in regional Victoria to deliver services to small or geographically isolated rural communities; and
   b. by the end of 2022, trial two new digital service delivery initiatives in rural and regional areas that meet the needs of local communities.

Recommendation 40:

Providing incentives for the mental health and wellbeing workforce in rural and regional areas

The Royal Commission recommends that the Victorian Government:

1. address mental health and wellbeing workforce supply needs in rural and regional areas and establish an incentive scheme to:
    - **a.** attract mental health and wellbeing workers to rural and regional mental health and wellbeing services; and
    - **b.** retain mental health and wellbeing workers in such services.

24.1 Responsive and accessible services in rural and regional Victoria

The Commission's recommendations present a vision for a future mental health and wellbeing system that adapts and responds to the needs of all Victorians. This includes a more equitable, high-performing system for people living in rural and regional Victoria.

In its interim report, the Commission stated that wherever possible, people living in these communities should be able to obtain mental health services close to home, and close to their families and loved ones.[1] Regardless of where they live, all Victorians have the right to access mental health treatment, care and support that is responsive to their needs and context.

The new integrated mental health and wellbeing system is designed to respond to the changing composition, needs and choices of rural and regional Victorian populations.

Victorians in rural and regional communities will be able to use a diverse range of face-to-face treatment, care and support. To complement in-person services, digitally enabled mental health and wellbeing services—including digital interventions and services offered through telehealth—will offer consumers, families, carers and supporters service options across the state.

In the future system, Regional Mental Health and Wellbeing Boards will have a critical leadership role in providing rural communities with mental health and wellbeing services. Area Mental Health and Wellbeing Services based in regional centres will have more responsibility for providing inreach services—that is, the delivery of services to people in their own communities—to more geographically isolated or smaller rural communities.

The collective strength and wisdom of rural and regional communities will be harnessed to shape service delivery, partnerships and operating models that work for local communities and their mental health and wellbeing needs.

While the future integrated mental health and wellbeing system is designed to respond to the needs of all communities, the challenges that rural and regional services face will require tailored action. At the Commission's Maryborough hearing on mental health and wellbeing in rural communities, Dr Ravi Bhat, Divisional Clinical Director, Goulburn Valley Area Mental Health Service, Goulburn Valley Health, emphasised this, saying '[o]ne of the things I think we all have to appreciate is that the problems that mental health services face are hugely amplified in rural areas.'[2]

The future system must redress disparities in service access and mental health outcomes that rural and regional communities face, compared with their metropolitan counterparts. This will require:

- a structured, coordinated and appropriately resourced approach to providing services with the right capability to support the needs of people in these communities
- using digital service delivery and innovation to their full potential in rural and regional settings
- responding to workforce availability and distribution in rural and regional Victoria by introducing strategies to attract, develop and retain mental health and wellbeing frontline workers.

24.2 Diverse and growing rural and regional communities

Victoria's rural and regional communities vary in geography, community demographics and experiences of mental health and service delivery. As outlined in Chapter 1: *The reform landscape,* the rural population in Victoria is growing, and people living in rural and regional communities already require additional, and more accessible, mental health and wellbeing services.[3]

Census data indicates a trend over the past decade towards people moving from capital cities to regional areas.[4] Anecdotal evidence in relation to the impacts of the COVID-19 pandemic suggests that more people from metropolitan regions are interested in moving to rural and regional areas for a better quality of life.[5]

As the population grows, there is likely to be increased demand for mental health and wellbeing services, particularly in regional centres. This presents both challenges and opportunities for communities and mental health and wellbeing services, which will greatly affect the design and planning of these services.

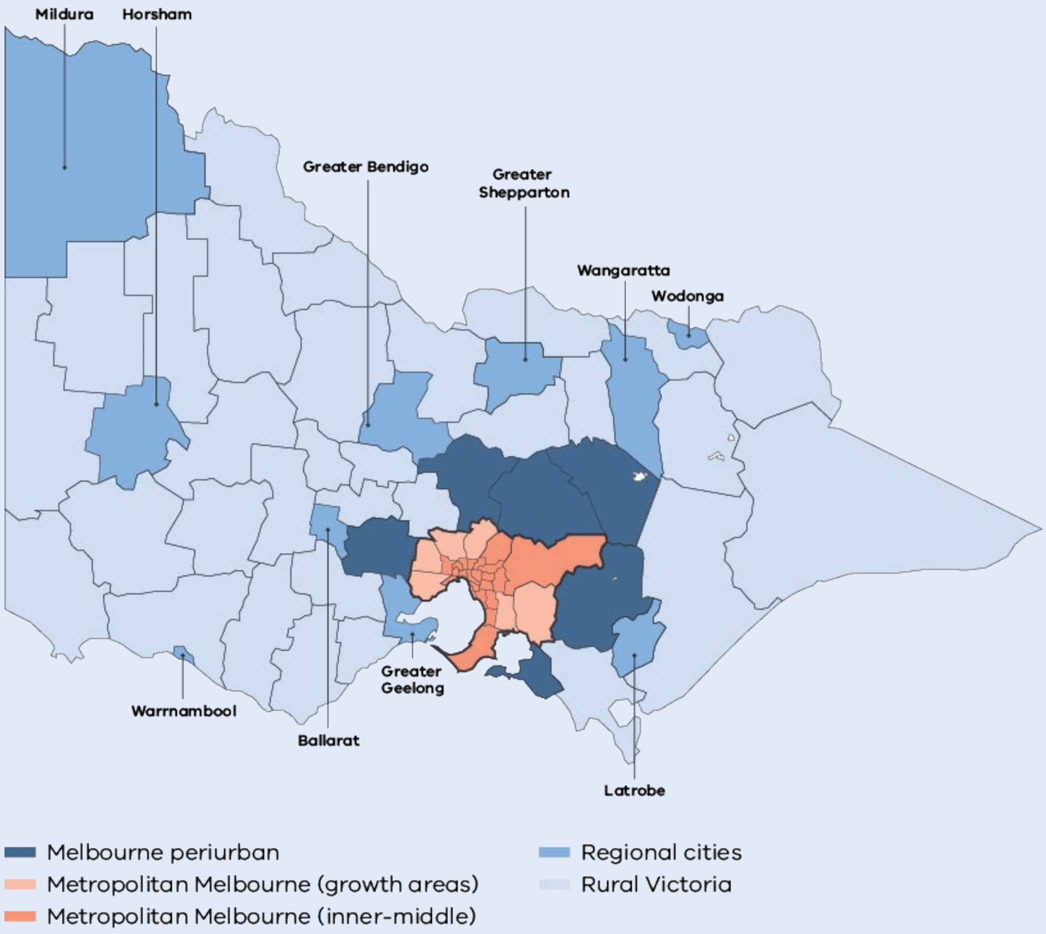
There is considerable diversity in the background and experiences of rural and regional communities. Measures of remoteness are often used as an indicator of whether a person can reach necessary supports and services.[6] However, experiences differ between large regional centres, smaller country towns and dispersed rural farming communities. People's experiences of living in large regional centres may be more similar to those of people living in metropolitan cities, while communities on the outskirts of Melbourne may have more in common with smaller regional towns.

Associate Professor Steven Moylan, Clinical Director for Mental Health, Drug and Alcohol Services at Barwon Health, observed that this diversity can occur within a single region, with an impact on the range of services that are required:

> we have an interesting spread of kind of inner urban plus very rural population needs, and I think that speaks a little bit to the need for localised variation in service delivery.[7]

The Commission recognises this diversity and acknowledges that each community has its own identity and culture. For the purposes of this report, however, the term 'rural and regional' is used to refer generally to all areas in Victoria outside metropolitan Melbourne (refer to Figure 24.1).[8]

Figure 24.1: Metropolitan, regional and rural areas of Victoria



Source: Regional Development Victoria, Regional Descriptions, <www.rdv.vic.gov.au/information-portal/more-information/region-descriptions-and-geography-structure>, [accessed 25 November 2020].

Notes: Metropolitan Melbourne (inner-Middle) areas include 25 local government areas in and surrounding Melbourne, including Greater Dandenong, the Mornington Peninsula and the Yarra Ranges. Metropolitan Melbourne (growth areas) include six local government areas (Cardinia, Casey, Hume, Melton, Whittlesea and Wyndham).

Melbourne periurban areas surround Metropolitan Melbourne and interface with rural or bush areas – they are neither urban nor rural in the conventional sense. There are six periurban areas in Victoria (Bass Coast, Baw Baw, Mansfield, Mitchell, Moorabool and Murrindindi).

Regional cities refer to the 10 regional city local government areas of Ballarat, Greater Bendigo, Greater Geelong, Greater Shepparton, Horsham, Latrobe, Mildura, Wangaratta, Warrnambool and Wodonga. The remaining 38 local government areas, including six alpine resort areas, are referred to as rural local government areas.

The circumstances and needs of Victorians living in rural and regional locations are diverse, but common experiences affect the mental health and wellbeing of people living in these communities. For example, many communities have experienced profound and devastating natural disasters from which they have, at times, struggled to recover.

The Commission has heard about the commitment of rural and regional towns to community participation and leadership, to overcome the impact of such events through involvement in volunteering, local events, sporting clubs or community groups. These traumatic experiences have provided opportunities for people to come together, but can erode the sense of hope for the future.

As discussed in Chapter 15: *Responding to trauma*, people exposed to repeated traumatic events or prolonged adversity are at increased risk of developing mental illness.[9] This includes people who are commonly exposed to traumatic events or stories of traumatic events. However, protective factors such as social connection increase the likelihood of recovery from trauma.[10]

Nationally, research suggests that more people are moving from cities to regional areas than from regional areas to cities.[11] Between 2011 and 2016, regional Victoria was the third-most-popular destination (behind regional Queensland and regional New South Wales) for those leaving interstate cities of Sydney, Brisbane, Darwin and Canberra.[12]

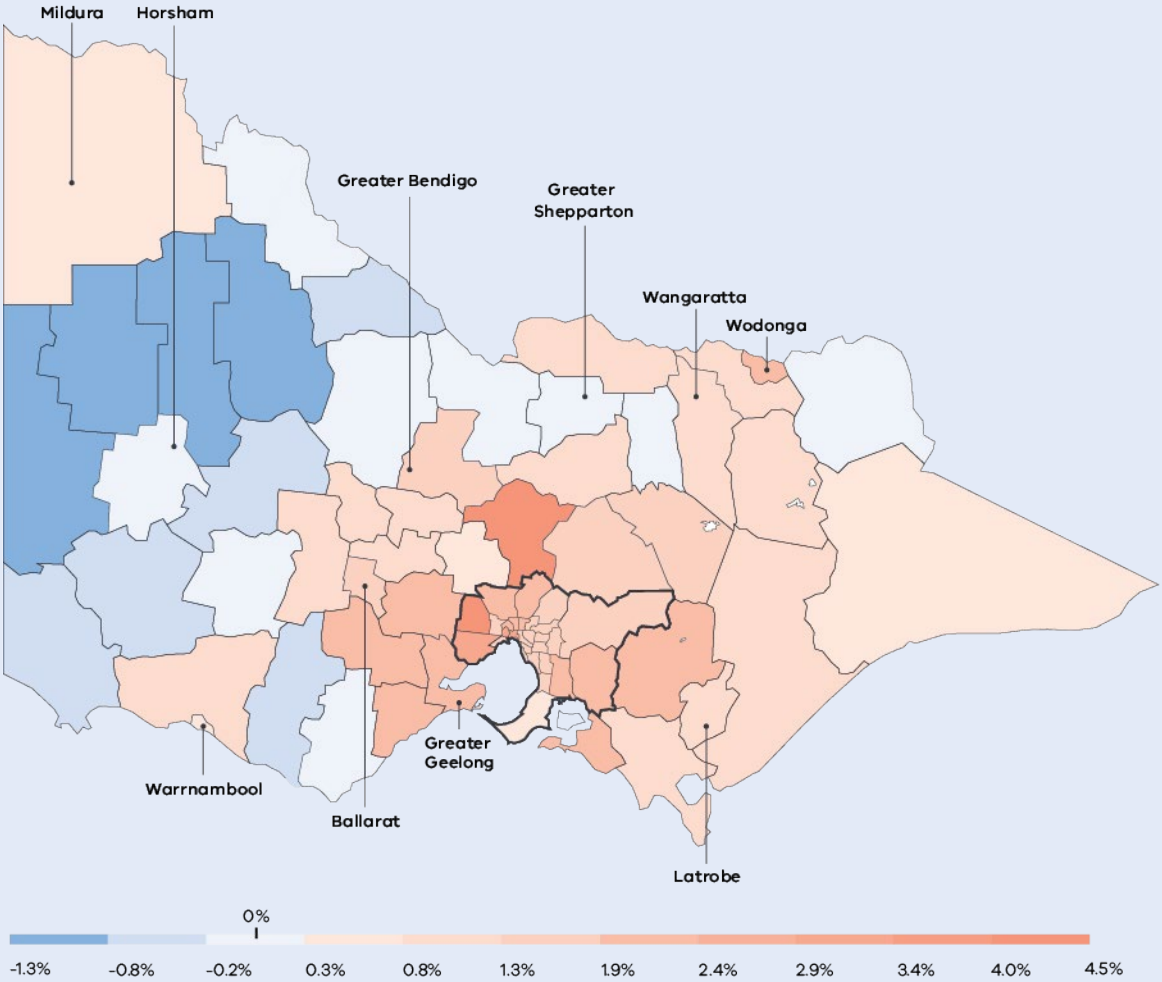
While the population of rural and regional Victoria is forecast to increase from 1.6 million in 2018 to 2.4 million in 2056, there is variation in projected population growth across the state.[13] The largest areas of growth in regional Victoria are expected to occur in major regional cities and regional areas that are close to Melbourne. These areas have the largest numbers of recent apartment construction and projected extra dwellings.[14]

As illustrated in Figure 24.2, the regional and rural local government areas with the highest projected growth rates between 2018 and 2036 include Mitchell, Golden Plains, Greater Geelong and Wodonga.[15] A number of periurban areas—including Moorabool, Baw Baw and Surf Coast—are also expected to grow above the Victorian average growth rate over this period.[16]

In contrast, the size of many rural communities is expected to decline due to population ageing, overseas migrants' preferences for urban areas, and younger people moving to metropolitan areas.[17] This includes the local government areas of Glenelg, Southern Grampians, Buloke, West Wimmera, Gannawarra, Swan Hill, Northern Grampians, Corangamite and Yarriambiack.[18] While the growing populations in regional centres will place increasing demand on mental health and wellbeing services, declining rural populations will require improved inreach service support to maintain equitable access to a diverse range of services.

These population projections do not take into account any potential changes in light of the COVID-19 pandemic. While migration to and from rural and regional areas has varied, evidence suggests the increased acceptability of flexible and working-from-home arrangements may contribute to more regional migration from metropolitan Melbourne.[19]

Figure 24.2: Forecast population growth rate (compound annual growth rate) by local government area, Victoria, 30 June 2018 to 30 June 2036



Source: Department of Environment, Land, Water and Planning, *Victoria in Future 2019*.

Notes: Annual growth represented in this figure is compound annual growth. Compound annual growth is the smoothed annual change over the specified period (as if the growth had happened steadily each year over that time period).

Demand for rural and regional properties is expected to increase,[20] accompanied by calls for government to invest in regional areas to capitalise on 'post pandemic migration'.[21] This will present both opportunities and challenges for rural and regional mental health and wellbeing services. While there will probably be more opportunities to attract new workforces moving into regional Victoria, such migration patterns are likely to favour regional centres. Migration patterns will therefore largely reflect the previous projections of higher regional population growth and decreasing population growth in smaller, more remote rural towns. This will mean larger regional services will need to play a more active role in supporting smaller rural communities.

24.3 Mental health and wellbeing needs in rural and regional communities

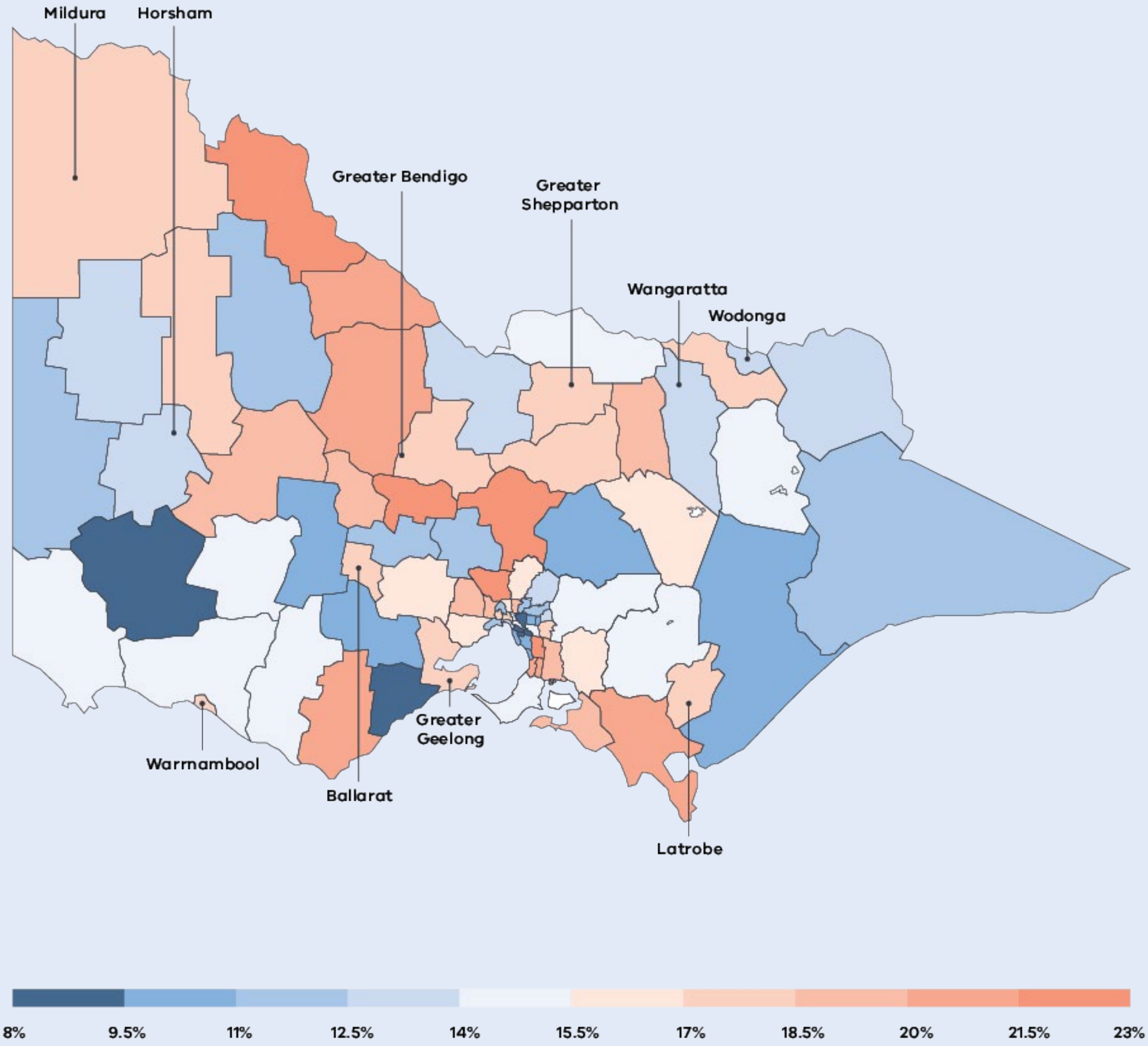
There are many social, environmental, cultural and physical factors that influence whether people experience poor or good mental health, and how they seek and receive treatment, care and support. The Commission's interim report found that people in rural and regional Victoria face particular challenges that affect their mental health and wellbeing needs, and their ability to access appropriate services and supports.[22]

24.3.1 Prevalence of psychological distress

Victorian Population Health Survey data indicates that there are varied levels of psychological distress in rural and regional Victoria. As illustrated in Figure 24.3, while many areas in rural and regional Victoria report lower levels than the average Australian rate, most of the local government areas with the highest levels of psychological distress are in rural or regional Victoria (including Mitchell, Mount Alexander and South Gippsland). In 2017, Swan Hill had one of the greatest proportions of adults with high to very high levels of psychological distress, at 23.3 per cent.[23] In contrast, Southern Grampians had one of the lowest, at 8.0 per cent.[24]

There is also a higher prevalence of anxiety and depression in adults in rural and regional areas compared with metropolitan areas, as illustrated in Figure 24.4.

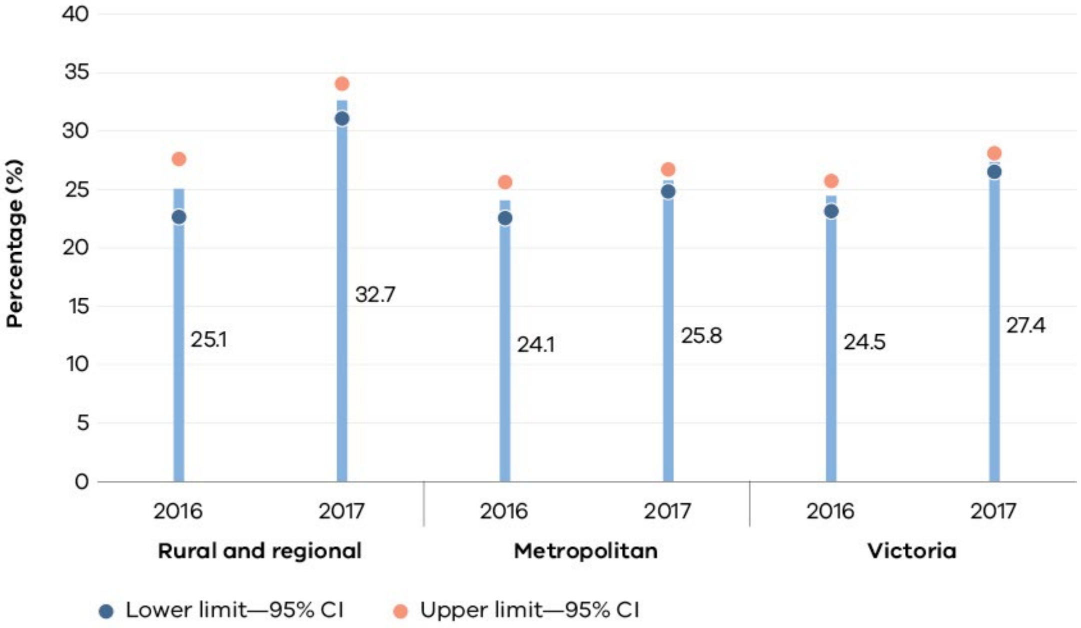
Figure 24.3: Proportion of adult population with high or very high levels of psychological distress, Victoria, 2017



Source: Department of Health and Human Services, *Victorian Population Health Survey 2017.*

Notes: Psychological distress is measured using the Kessler-10 psychological distress scale. People with a score of 22 or greater are defined as having high or very high psychological distress.

Figure 24.4: Proportion of adults ever diagnosed with depression or anxiety, by metropolitan and rural and regional Victoria, 2016 and 2017



Sources: Department of Health and Human Services. Victorian Population Health Survey 2016; Victorian Agency for Health Information. Mental Health and Wellbeing—Victorian Population Health Survey 2017 (preliminary draft and unpublished). For more information, refer to <www2.health.vic.gov.au/public-health/population-health-systems/health-status-of-victorians/survey-data-and-reports/victorian-population-health-survey>.

Notes: Proportion represented in the graph is 'ever diagnosed' with anxiety or depression.

Data is age standardised to the 2011 Victorian population.

Upper/lower limits are the 95 per cent confidence interval upper and lower limits.

As discussed in section 24.2, there is great community diversity in rural and regional Victoria. Some groups of people in these communities experience high incidences of trauma and psychological distress.

Many Aboriginal people call rural and regional Victoria home.[25] Census data from 2011 shows that approximately 54 per cent of Aboriginal Victorians live in regional areas. The local government areas with the highest Aboriginal population included Shepparton, Mildura, Geelong, Bendigo, East Gippsland, Ballarat and Latrobe.[26]

Aboriginal people can have a range of mental health and wellbeing needs, although there is a significant prevalence of trauma, which is both transgenerational and shared by communities.[27]

A number of rural and regional areas also have significant populations of people from migrant or refugee communities recently arrived in Australia. In 2014, the Victorian Auditor-General reported that there was little reliable data on migration and settlement of refugees and asylum seekers within Victoria. However, at least 10 per cent of the population of Greater Shepparton, Swan Hill and Greater Geelong have backgrounds with languages other than English.[28]

Research indicates that many recent arrivals to Australia may have pre- and post-migration trauma that requires support for effective recovery.[29] For example, refugee families have often been exposed to torture and traumatic pre-migration experiences.[30] Around half the migrant community arrives as children, and may never have known safety and security.[31]

Research also suggests that the physical and psychological stresses many refugees and asylum seekers experience in their countries of origin, during transition, and on arrival in the host country can lead to increased risks of poor mental health.[32] These stresses have variable effects across different refugee and asylum-seeker populations.[33] A 2017 survey study of refugees and asylum-seekers attending a refugee health service in Melbourne reported that 'mental health services in areas with high refugee and asylum-seeker populations need to understand the mental health problems of their local client base' in order to plan appropriate culturally sensitive treatment.[34]

Similarly, many people choose to retire to rural and regional locations, and earlier life trauma or other mental health and wellbeing needs can sometimes emerge later in life.[35]

Data from 2018 indicates that people aged 65 years and over comprise 13.8 per cent of the population of metropolitan Melbourne, but 19.9 per cent in other parts of the state.[36] In 2020, three of the five local government areas that were home to the most Department of Veteran Affairs pensioners and Treatment Card Holders in Victoria were outside metropolitan Melbourne—namely Greater Geelong, Greater Bendigo and Wodonga.[37]

Chapter 14: *Supporting the mental health and wellbeing of older people*, discusses research by the National Drug Research Institute that indicates that many older Australians (aged 65 years or older) drink more alcohol than the healthy recommended amount.[38] The research suggested that alcohol use could occur as a result of distress caused by loss or grief, chronic pain, loneliness or homelessness experienced by older people.[39] Older adults may also use drugs to combat chronic pain, to cope with the symptoms of depression or anxiety, to manage the distress of social isolation, or because they have a long-term substance use disorder for which they have not received appropriate treatment, care and support.[40]

24.3.2 Higher levels of self-harm and suicide

One of the most tragic costs of mental illness is the loss of human life, and rural and regional Victorians are disproportionately affected by suicide and self-harm. While the prevalence of psychological distress is comparable to that of people living in metropolitan areas,[41] the rates of suicide and self-harm are higher among people living in rural and regional Victoria:

- the rate of self-harm-related emergency department presentations between 2013–14 and 2017–18 was about 30 per cent higher in rural and regional areas than in metropolitan areas[42]
- data from the Coroners Court of Victoria indicates that between 2009 and 2018, the annual suicide rate was about 40 per cent higher in rural and regional Victoria than in metropolitan Melbourne[43]
- the rate of suicide among men aged 35–54 years, who lived in rural and regional Victoria, was about 60 per cent higher than in Melbourne between 2009 and 2018.[44]

Headspace states that people in close proximity to suicide, particularly young people—whether by geography, relationship or social connection, or shared experiences—are more at risk of suicide themselves.[45] This may increase the risk for people in small and isolated communities, and among young people. In 2009, concerns about a 'suicide culture' among young people in the Greater Geelong and Barwon South West regions of Victoria initiated a cross-agency, coordinated response to strengthen community suicide prevention.[46]

As emphasised in the Commission's interim report and elsewhere in this report, suicide does not always mean that mental illness is present.[47] Research into farmers who have died by suicide has suggested that farmers' familiarity with risk and pain, the distress of needing to euthanise animals during disaster, and high levels of pressure all contribute to suicide.[48]

One participant in a study exploring the effects of climate and environment on rural mental health explained that financial pressures of 'green drought' can impact farmers' mental health:

> it's a farming community ... there's water, it's green ... but some farmers have been incredibly depressed ... there's just not enough grass to feed the cows ... all the farmers were having to buy hay ... they'd have bills in the tens, if not, hundreds of thousands of dollars.[49]

Greater access to firearms may also be a risk factor. Farmers rely on firearms for tasks on their farms, and fear of firearm removal may stop them from seeking help for mental distress.[50]

The Commission has also heard that people's vulnerability to self-harm and suicidal ideation is increasing as a direct result of compounding traumatic events such as bushfires and COVID-19—this is especially the case for children and young people.[51]

Aboriginal communities from across rural and regional Victoria have shared with the Commission the devastating losses of members of their community to suicide.[52] Intergenerational trauma associated with the Stolen Generation, and loss of family, culture, place and connection all contribute to a suicide crisis for Aboriginal people and the communities they belong to.[53]

This was reflected in community consultations dedicated to mental health and wellbeing in regional areas of Victoria:

> Earlier [in 2020], the Victorian Coroner's office released a report in regards to Aboriginal suicides. Now [2018–2019] was the highest number of Aboriginal suicides in the history of the report. So far ... this calendar year, we're tracking to actually beat that with the number of Aboriginal suicides within Victoria. So [the] big thing for us is not the postvention focus ... it's how do we work with the Aboriginal community to address poor mental health and wellbeing ... and prevent that extreme action and extreme behaviour from occurring. Postvention support is all good and well for those who have left, but for the person who is actually suffering that trauma, it doesn't help, it's too late.[54]

Aboriginal people are around three times more likely to experience high or very high levels of psychological distress than non-Aboriginal Victorians.[55] Self-harm emergency department admissions for Aboriginal people are four times the rate of other Victorians.[56] The national suicide rate for Aboriginal people is estimated to be twice the rate of the general population,[57] and generally occurs at much younger ages.[58]

Aboriginal people should ideally receive social and emotional wellbeing services on country, so they remain connected to family, community and culture, thereby minimising retraumatisation.[59] However, many services lack the resources to provide culturally appropriate, place-based care.[60] This can add to the distress and trauma that Aboriginal people can experience.[61]

In the *Balit Murrup Aboriginal Social and Emotional Wellbeing Framework*, the Victorian Government identified the need to develop Aboriginal culturally informed approaches to treatment, care and support.[62] In its interim report, the Commission considered in some detail the challenges faced by Aboriginal communities, and recommended the expansion of social and emotional wellbeing teams in Aboriginal community-controlled health organisations.[63]

As discussed in Chapter 17: *Collaboration for suicide prevention and response*, the Commission understands that people from LGBTIQ+ communities may be at particular risk of suicidal behaviour. This includes substantially higher rates of suicidal thoughts and self-harm,[64] as well as 10 times higher rates of attempted suicide than that observed in the general population.[65]

A study examining the experience of student suicide for rural high schools in the Gippsland and Loddon Mallee regions of Victoria found that teachers and school counsellors were more likely to have experienced student suicide if they taught Aboriginal and/or LGBTIQ+ students.[66]

National research indicates that Aboriginal LGBTIQ+ Australians, LGBTIQ+ migrants and refugees, LGBTIQ+ young people and LGBTIQ+ people residing in rural and remote areas are likely to be at particularly high risk of suicide.[67]

Dr Louise Flynn, Manager, Support After Suicide, Jesuit Social Services, told the Commission that the insufficiency of services available for Victorians bereaved by suicide is particularly acute in rural and regional areas.[68]

24.3.3 Social determinants of poor mental health

The Commission understands there are many reasons why some rural and regional communities may experience higher rates of psychological distress, suicide or self-harm.

The Commission's interim report recognised that there is a considerable unmet need for mental health and wellbeing services in rural and regional Victoria, which affects people's ability to receive the right treatment, care and support when they most need it.[69] Research indicates that the prevalence of poor mental health, including depression, anxiety, substance use disorders and first-episode psychosis, is higher for young people in rural locations, partly because of barriers to accessing services.[70]

As discussed in Chapter 1: *The reform landscape*, mental health and wellbeing is shaped by the social, economic and physical environments in which people live.[71] For example, unemployment and job insecurity is linked with poor mental health,[72] as are other factors such as housing and access to resources, including water and food.[73]

Individuals, families and communities living in rural and regional Victoria can be disproportionately affected by social determinants of poor mental health. When coupled with a lack of services and supports, people's mental health and wellbeing can suffer.

Rural and regional communities face higher levels of socioeconomic disadvantage compared with metropolitan communities, which can negatively affect mental health and wellbeing. Demographic data indicate that eight of the 10 most disadvantaged local government areas in Victoria are in rural and regional areas.[74]

Many smaller rural towns provide low-cost housing, thereby attracting people who may be migrating due to financial or other stressors.[75] There are also people already living in rural and regional areas under considerable financial stress.[76] The combination of excessive distance from services and limited options for transport has a compounding negative impact on mental health and wellbeing.[77]

24.3.4 Extreme weather events and the impacts of climate change

Rural and regional communities are often affected by extreme weather events and the impacts of climate change.[78] They experience regular and severe natural disasters and weather conditions that occur much less in metropolitan areas, that may affect mental health and wellbeing.[79]

Regional Development Victoria reports that bushfires in Victoria have had devastating and wide-ranging impacts on regional areas of the state.

> Victoria's bushfires in December 2019 and January 2020 resulted in catastrophic impacts to rural and regional communities around the state. Towns in North East Victoria and East Gippsland suffered significant loss. More than 1.4 million hectares were burnt, affecting all aspects of life, including business and tourism, and causing flow-on effects for communities elsewhere in Victoria.[80]

The report highlights that rural and regional communities have struggled with the 'compounding challenges of bushfires, drought, economic transition and coronavirus'.[81] For example, it was identified in the Hume region that bushfires, followed closely by the COVID-19 pandemic, had major impacts on tourism and wine sectors.[82]

People living in rural and regional communities face unique mental health risk factors relating to natural disasters, such as bushfires and drought.[83]

South West Healthcare told the Commission:

> Rural areas often experience environmental issues, natural disasters, and other extreme weather conditions, which can impact upon the mental health experienced by the population.[84]

The Royal Commission into National Natural Disaster Arrangements found 'compelling evidence of the impacts of natural disasters on mental health'. It reported that natural disasters give rise to increased rates of stress, depression, anxiety, post-traumatic stress disorder, alcohol and substance abuse, aggression and violence, suicide and exacerbation of other underlying mental health problems.[85]

As part of the 2008 National Review of Drought Policy, the expert social panel on the social impacts of drought on Australian farm families and communities observed, 'extended dryness has a significant negative impact on the mental health of farm families and others within rural communities'.[86]

An editorial in the *International Journal for Mental Health Nursing* noted that the combination of drought and bushfires had 'a particularly devastating impact on rural agricultural-based communities':

> in addition to the impact experienced by other bushfire-affected individuals in Australia, rural communities have lost farms which represent years of family income, livestock, and buildings essential to run farms effectively. These losses were especially tragic for Australian rural farming communities as they have struggled through many years of severe drought prior to the onset of the bushfires. [87]

The Victorian Farmers Federation submitted:

> There can be many factors that lead to farmers encountering mental hardship; they include natural disasters, season failure, financial difficulty and relationship breakdowns.[88]

Dr Alison Kennedy, Research Fellow at Deakin University in the Faculty of Health and at the National Centre for Farmer Health, told the Commission, '[f]armers often have a strong connection to their land and can draw solace from that connection. Where that connection is threatened it can cause real psychological distress.'[89]

Research suggests that such disasters are associated with long-term mental health and wellbeing effects for both individuals and communities.[90] Ms Christine Morgan, CEO, National Mental Health Commission, told the Commission that successive national crises—such as the prolonged drought and recent catastrophic bushfires—can have cumulative mental health impacts.[91]

The cumulative impact of drought, fires, floods and now COVID-19 have significantly affected the mental health and wellbeing and strength of rural and regional communities.[92] Community members have described services being stretched to capacity prior to bushfires and COVID-19, and say that recent sudden increases in service demand have become unmanageable.[93]

A participant at the Commission's East Gippsland roundtable said that mental health and wellbeing supports were missing among other bushfire responses:

> These bushfires we've seen … had major impacts with [school] students and families with an increase in trauma, mental health presentations, increasing anxiety, depression, suicidal ideation … we've definitely seen an increase in complex cases for schools with mental health presentations … we've all seen the bushfire response, injection of funds and new services coming into the region. But … we've not really seen an increase in … extra assistance with mental health support [particularly for primary schools].[94]

Dr Sara Renwick-Lau, General Practitioner at the Mallacoota Medical Centre, giving evidence in a personal capacity, described how bushfires in the holiday town of Mallacoota affected mental health services, where demand already exceeded capacity for mental health services prior to the bushfires:

> Prior to the bushfire event [during the tourist town's busiest week of the year] there were no other visiting or resident mental healthcare providers in Mallacoota, including mental health social workers, relationship counselling services, child and youth counsellors and other counsellors.[95]
>
> the first thing that happened was everyone looked at each other and said 'We're not prepared, how do we deal with other people's distress'.[96]

Dr Renwick-Lau said there have been increased presentations of post-traumatic stress disorder and exacerbations of pre-existing mental illness resulting from the bushfires.[97] She estimated that 95 per cent of children present during the fire threat will develop symptoms and signs of post-traumatic stress disorder,[98] and that mental illness may emerge six to 12 months after the disaster event.[99] Another report on the 2009 Victorian bushfires indicated that five years after the fires, a proportion of the survivors were still experiencing significant mental illness at a rate higher than that of the general population.[100]

Dr Renwick-Lau warned:

> Failure to respond to the current and emerging mental health needs of the Mallacoota and Cann River communities following this major bushfire event will have long term implications on the town's ability to recover. The ramifications of poor mental health outcomes in these small isolated communities, are the degradation of personal and social lives and loss of productivity and ability to work and other social problems.[101]

Research examining wellbeing in drought-affected communities found that the impacts of drought can have traumatic effects on families and children. Wellbeing concerns in these communities include increases in financial stress, household and family tension, spousal stress, domestic violence and abuse, mental health problems (such as anxiety and depression), suicide and reduced help seeking behaviour.[102]

A teacher from one community noted that these can be triggered by small things, due to the build up of trauma from external events, including drought-related stresses:

> you know they might have had so much built up trauma related to external things that have happened with them, and it's just that one seemingly insignificant event that tips them over because of this built up vicarious trauma.[103]

Dr Renwick-Lau also noted that people seeking 'psychological care' prefer that it is with a familiar local service provider.[104] However, the Commission recognises that members of the mental health workforce and their families who live and work in these communities face similar events, losses and distress to those experienced by the people in their care.

Roundtable participants explained that staff need support as members of the community:

> But our staff work in the community, [living] in the community as well, they've been affected by drought, by fire, by COVID, too. So we have [a] number of counsellors that we have going out and seeing people in our communities, we actually need to look after them as well.[105]
>
> We had some of our own staff … who have lost their properties. They've lost everything and to look after those … staff members and they keep wanting to work. But you know, people are fragile and now we've got COVID on top of that, it's just adding another stress to the whole community, to the staff, and you wonder where this is all going to end to be honest.[106]

The COVID-19 pandemic has had a devastating impact on communities that rely on tourism (see Box 24.1). In addition, the Australian tourism industry has reportedly suffered around $2 billion in losses, with a further $4.5 billion in projected losses, as a result of bushfires in the 2019–20 season.[107] The Department of Jobs, Precincts and Regions reports that in 2018–19, tourism in Victoria was estimated to be worth $29.4 billion to the Victorian economy and generated approximately 263,300 jobs. However, the dual crises of bushfires and COVID-19 have had 'a devastating impact on the visitor economy', with total tourism expenditure in Victoria showing an 18 per cent decline in the year ending June 2020.[108]

Ms Sue Medson OAM, CEO, Gippsland Lakes Complete Health, described the community and individual trauma experienced and its effects:

> the effects of the drought followed by fire, followed by COVID restrictions, has had an enormous impact on [East Gippsland]. And it'll be ongoing until we're able to safely restore tourism, see rain on the pastures and have gone through at least one other fire season without a repeat of the devastation. And none of us can guarantee that. So they're the sort of trauma events that do trigger a lot of mental health aspects. But it's not just the tragedy, the trauma and the tourism that affects the mental health and people in East Gippsland. We were essentially already in trouble …[109]

Rural and regional participants have told the Commission that a rapid influx of funding, and external clinicians and services to the regions after a natural disaster can be overwhelming for an already traumatised community.

One participant at the Commission's East Gippsland roundtable explained how external services quickly converging can create confusion for people who are already overwhelmed:

> We have noted that there's been some frustration post the bushfires with an influx of new different service providers coming into some of these remote communities with very good intentions. But in the community kind of feeling like it can be a bit confusing about not knowing which service to access.[110]

Evidence put before the Commission has highlighted the importance of communities and community leaders in trauma-informed disaster recovery. Rural and regional service providers describe feeling displaced and minimised by incoming providers unfamiliar with their regions and communities.

Dr Rob Gordon, Clinical Psychologist, President of the Australasian Confederation of Psychoanalytic Psychotherapies and consultant to the Department of Health and Human Services and the Red Cross, giving evidence in a personal capacity, emphasised the need to support communities to lead recovery:

> There needs to be community organisation with a focus around the formation of community recovery committees, advocacy processes and social organisation so people can let their needs be known and communicated. Outreach programs and programs to help bring the community together should be adopted. Helping the community form their own 'community led recovery process' where community advocates communicate with government has enormous mental health payoffs because it gives people what makes them resilient—confidence, trust, optimism and security.[111]

The Commission has also heard that the state lacks a repository of knowledge gained and lessons learned from natural disasters to draw on when new disasters occur. Professor Alexander McFarlane AO, Professor of Psychiatry in the School of Medicine at the University of Adelaide, giving evidence in a personal capacity, told the Commission:

> one of the great tragedies is that people quickly lose knowledge about how to manage these tragic events ... The way to help individuals is to have a system that maintains knowledge within it in an organized way, which should then be imparted to clinicians and other health workers ... In this way, health workers at all levels in the system would be equipped to get the best results.[112]

The Victorian Bushfires Royal Commission, reporting on the Black Saturday fires of 2009 'urge[d] all involved in developing and implementing bushfire policy to look to the long term'[113] and to anticipate future events:

> This was one of Australia's worst natural disasters. It will be many years before its effects dim. Governments, fire and emergency services agencies and all individuals can learn valuable lessons from those days, so that we might reduce the risk of such destruction occurring again. It would be a mistake to treat Black Saturday as a 'one-off' event. With populations at the rural–urban interface growing and the impact of climate change, the risks associated with bushfire are likely to increase.[114]

The Bureau of Meteorology indicates that the rate of natural disasters, such as flood, drought, cyclones and bushfires, in Australia is increasing. It anticipates conditions that result in more time in drought, but more intense rainfall events, longer fire seasons and an increase in the number of dangerous fire weather days.[115] This has been reinforced by the Department of Environment, Land, Water and Planning, warning that harsher fire weather and longer fire seasons are also expected across the state.[116]

The Australian Psychological Society notes that 'assuming this trend continues there will be higher costs to community resilience with potential to impact on the mental health of Australians'.[117]

Associate Professor Moylan emphasised to the Commission how recent disasters have further revealed the fragility of a system in which people are unable to access services in regional areas:

> What I see is a system that was already broken … especially in the regional areas. And [with] the last disasters of the bushfires and the flood have actually shown how fragile the system actually is … [w]ith people essentially being traumatised and not being able to access the appropriate services all over.[118]

Box 24.1: The impacts of COVID-19 on health and wellbeing in rural and regional Victoria

Rural and regional communities have told the Commission that COVID-19 has had a deeply negative impact on mental health and wellbeing.

Community organisations that support the mental health and wellbeing of the community through shared activities, fundraising and social gatherings have not been able to operate.[119] These services support social contact, exercise and recreation for community members.[120] Sporting groups also provide health promotion and screening in an informal manner for their communities, but this extra safety net has not been in place since the onset of the pandemic.[121] Sporting groups and other similar community groups have lost funding associated with memberships, fundraising and other activities, which places them at financial risk in the future.[122]

Aboriginal communities describe the COVID-19 restrictions generally, and travel restrictions more broadly, as having a distressing effect on their people. Not being able to meet and gather—a practice that promotes healing and recovery for Aboriginal people—has meant that trauma from bushfires and the burning of sacred land remains painful and unaddressed. The inability to travel across borders in communities that extend across states has meant that many families and communities have been separated and isolated from one another. Aboriginal health workers who would ordinarily work across borders to care for their community members have not been able to do so.[123]

Similarly, in rural areas affected by the recent bushfires, there has been a delay in healing and recovery processes, which has compounded trauma within communities. Local events that would ordinarily provide a chance to connect, share experiences and regain a sense of belonging and stability have not happened.[124] Most mental health and community health providers describe a notable increase in demand for help during the COVID-19 pandemic, but services were already at capacity before COVID-19 struck.[125]

There has been a considerable increase in psychological and suicidal distress during the COVID-19 pandemic across age groups, which local providers have done their best to respond to within existing resources. Young people have become increasingly disadvantaged.[126] Older people who were already somewhat isolated before the pandemic have experienced an increase in their isolation. Some health providers continued to provide outreach services to these older people rather than use telehealth, which can be difficult to introduce in times of crisis.[127]

Financial and employment stress resulting from the pandemic has added to the pressure on rural and regional communities that experience high levels of psychological distress, domestic violence, and alcohol and drug use.[128]

Clinical and community support staff and volunteers describe high stress levels within their workforces, as they too have often experienced loss associated with prolonged drought and the recent bushfires.[129]

An important source of employment for rural and regional areas is tourism and hospitality, which has been unable to operate for most of 2020.[130] In turn, this has contributed to compounding disadvantage in rural and regional communities, felt most keenly by those who were already struggling.

Despite these challenges, the pandemic has given rise to some new and innovative ways of working, which have come from necessity and the goodwill of rural and regional people. Telehealth was expanded and largely well received when there was the infrastructure to support its use,[131] and some regional tertiary health providers trialled innovative methods of community-based care, and aimed to keep as many consumers out of hospital as possible.[132]

24.4 Access to mental health and wellbeing services in rural and regional areas

Victorians living in rural and regional areas can face additional challenges in receiving mental health and wellbeing treatment, care and support.

Chapter 5: *A responsive and integrated system*, introduced the Commission's vision of a mental health and wellbeing system that is strongly reoriented towards community-based treatment, care and support. As outlined in Chapter 6: *The pillars of the new service system—community-based mental health and wellbeing services*, this reorientation recognises the benefits of treatment, care and support for people in their own communities and close to their homes, families, carers and supporters.

The responsive and integrated system is designed to improve equity of access to mental health and wellbeing services in the future. People living in rural and regional Victoria face additional barriers to consistent access to service compared with those in metropolitan Melbourne.

The proportion of Victorians accessing Medicare-subsidised mental health services is lower in rural and regional communities than in metropolitan Melbourne, and there are also fewer average services per person in these areas (see section 24.4.3). This indicates that Victorians living in rural and regional areas can face great challenges in getting the mental health treatment, care and support they need.

24.4.1 Stigma can discourage help-seeking

In its interim report, the Commission found that mental health stigma can be felt acutely in rural and regional communities.[133] Many people in rural and regional Victoria have told the Commission that people are reluctant to seek help for fear of judgment or embarrassment, or fear that their circumstances may become public.[134]

At its hearing on rural mental health, Dr Kennedy told the Commission of 'a case in which one person who, despite wanting to seek assistance from a mental health professional, remained silent because he feared that seeking professional advice would lead to the loss of his business'.[135]

The Royal Flying Doctor Service said that stigma acts as a barrier to help seeking:

> In rural and remote communities, stigma, in particular, self-stigma, is a key barrier to progress. There [is] still [a] strong cultural desire for independence and an attitude that aligns asking for help with failure.[136]

Miss Jennifer Rowan, witness before the Commission, explained how stigma can prevent people from asking for help:

> The stigma associated with mental ill-health in rural towns is a massive barrier holding communities back. Young people and in particular men can find it challenging to go to their GP, let alone a mental health professional.[137]

In some communities, mental health workers of local services are well known to the people they support.[138] As noted above, some people prefer to receive 'psychological care' from a familiar local service provider.[139]

A number of community service providers within and outside of the mental health system noted that people in isolated communities were most likely to be open with people they have built up trust with. This means that people in a range of professional and social relationships—including agricultural organisations, financial counsellors, employment services, men's sheds, neighbourhood houses and sporting clubs—are confided in about mental health issues.[140] It was suggested to the Commission that there would be benefit in equipping a range of people working in local communities with the capacity to provide 'Mental Health First Aid' supports, and to be conduits for introducing people to appropriate professional supports and mental health and wellbeing services.[141]

However, proximity can often result in a perceived lack of anonymity or confidentiality when accessing services. Mr Terry Welch, CEO, Maryborough District Health Service, told the Commission:

> In regional towns, one of the challenges is that when a resident presents at the GP (which is the access point); they know the person who is at the reception desk. People are not likely to seek and engage with support in those circumstances.[142]

The Victorian Farmers Federation echoed this sentiment:

> Farmers often get a sense that by having a personal relationship with the GP, or small towns often knowing personal details of residents, that farmers may not visit the GP for fear their circumstances may be public or become gossip.[143]

Evidence indicates that farmers in small towns may also feel ashamed or embarrassed, or find it to hard reach out for help.[144]

Carer groups have also reported high levels of stigma and discrimination in rural and regional areas, leading to increased social isolation and loneliness. Loddon Mallee Mental Health Carers said this particularly affects people in rural towns:

> Small town syndrome (stigma) for carers who live in rural towns is very real; they suffer in silence and eventually become a shadow in their own community.[145]

This was echoed by a business that provides financial counselling and other supports to rural farmers:

> Small rural communities are very supportive. They're resourceful. They band together in emergencies in drought, or when they're organizing community events. But they can also be incredibly distant and closed off when it comes to business, family and personal matters … Hence, people are rarely asked if they're okay, why would you because everything looks fine … if people do enquire the rural culture and the family expectation is to say, well, we're fine, thank you. Or we're having a bit of a tough patch, but everything's under control, which is nowhere near the truth. And then when people can't hide it anymore, they just work harder. They withdraw from the community, so they don't get asked, or [say] that they're too busy to attend the events … by the time they come to [the] notice of friends, neighbours and community groups, they are often very unwell, or they have committed suicide … or are the victim of a farm accident, or vehicle accident with very suspicious circumstances.[146]

The Commission also heard that familiarity in small communities can sometimes mean people experience being 'labelled' as someone living with mental illness or experiencing psychological distress, which can affect their ability to receive other services. It may also result in people assuming a person intends to do themselves harm, even when that is not the case. One person told the Commission how police were called when they were close to a train line because of concerns for their safety, despite there being no risk.[147]

Some people from minority communities reported experiences of stigma from health providers.[148] In addition, specialist services for LGBTIQ+ people in rural and regional areas are limited, despite the evidence that this population is at greater risk of psychological distress, stigma and discrimination, including homophobia, bullying, violence, self-injury and suicide.[149]

A man from rural Victoria who participated in Beyond Blue research reflected on the importance of open and accepting service providers:

> When my GP made the referrals, it was important to her that she find me gay-friendly providers. Having bipolar disorder was/is unrelated to me being gay, but some of the pressures of life as a gay man mean that those stressors need to be examined and put into order to prevent life stresses from contributing to a situation where I could become unwell.[150]

24.4.2 Geography can create barriers

Geographical barriers, such as location of services, extended travel times, increased travel costs and the need to take time off work or other commitments to use mental health and wellbeing services, can contribute to limited help-seeking behaviours in rural and regional communities. Although modest compared to other states, there are many locations in Victoria that have large travel times to major regional centres.

Dr Bhat noted that people in more remote locations may not be able to afford to own or maintain a car, or to pay for petrol to travel long distances. He said this challenge is compounded by the fact that '[t]here is little or no public transport in some or many areas in Regional Victoria to access long distances.'[151]

Ms Emma King, CEO of the Victorian Council of Social Service, also advised that being able to travel to access services can be a significant issue for people experiencing poverty.[152] These factors limit the ability of consumers to use face-to-face services.

Even where a person can access services, families, carers and supporters face multiple challenges in having to deal with long distances, travel time and the added burden of a child, friend or family member being treated away from home.

Mr Welch explained to the Commission:

> We witness regularly, even for life saving treatments, many people will not go to treatment arranged for them because of the cost, for example, of travelling to Ballarat.[153]

For some people, work or caring responsibilities may present a barrier to leaving a town or farm to access mental health and wellbeing services.[154]

People living in rural and regional communities are often forced to make the difficult decision to either stay with their friends and family, and use more limited local services, or travel to get help. The Commission has been told of people being transferred far from their home in order to receive treatment, including people who have been transported long distances to mental health services.

As one carer explained to the Commission:

> The local hospital is not equipped for mental health admissions; my son was sent in a taxi from Shepparton to Kilmore by the hospital because they could not be admitted.[155]

The Commission has also been told about the lack of available transport to transfer people from local health services to regional hospitals. As Mr Welch explained to the Commission:

> There is no dedicated centralised transport service or specific vehicles for transfer of acutely mentally unwell patients. We have other centralised services (for example Adult Retrieval Victoria for medically unwell patients and [Paediatric, Neonatal and Perinatal Emergency Response] for pregnant mothers) but there is no such service for acutely mentally unwell patients.[156]

Dr Gerard Ingham, a General Practitioner working in Daylesford, said that regional clinicians have to rely on larger services to whom they are making inpatient referrals to determine where patients need to go, and to make the appropriate travel arrangements:

> the difficulty with the mental health process, is we have no oversight of bed capacity, bed availability, and I'm sure Bendigo Health are under extreme pressure and then we're contacting them escalating that pressure even further … With the medical process, with Adult Retrieval Victoria, they have oversight over the system: they know bed capacity, they know resource availability, so they support our clinicians with the care, at the same time arranging transportation and the location for where the patient will go.[157]

Barwon Health told the Commission that accessing out-of-area services can also create 'inefficiencies and risks through handover' between multiple service providers.[158] One participant in a community consultation explained the situation of a consumer who was discharged from a metropolitan hospital:

> We've had people released from hospital three hours away, selling their medication to afford transport home. By the time they get home, they're unwell and we're sending them back again.[159]

Rural and regional services often have no local inpatient beds for children and adolescents who are acutely unwell. They have to be admitted to inappropriate environments, such as emergency departments and paediatric wards, while they wait for an inpatient bed.[160] Inpatient beds for children and young people, if they can be secured, may involve hours of travel, and sometimes multiple ambulance transfers (due to ambulance boundary limitations).[161]

South West Healthcare told the Commission this was necessary for some young people in its catchment needing an inpatient admission:

> The closest adolescent beds to the [South West Healthcare Mental Health Service] catchment are located at the Royal Children's Hospital in Melbourne, which can be up to 500 kilometres away from where consumers live (requiring up to four ambulance transfers/handovers).[162]

Albury Wodonga Health also said this was the case in their catchment:

> When a child or adolescent who resides in the [Albury Wodonga Health] catchment region requires a specialist mental health admission, the current options are to transfer them to Box Hill, Victoria or Orange, New South Wales. The admission catchment for [Albury Wodonga Health North East Border Mental Health Service] extends out past Barham in the west, which is a 7-hour road trip to Box Hill via Albury (or 4-hour trip direct from Barham) or a 7-hour road trip to Orange.[163]

In Chapter 5: *A responsive and integrated system*, the Commission outlines evidence of significant challenges in accessing services—including insufficient capacity, high access thresholds and long waiting lists to get treatment, and inequitable variation in the choice, quality and affordability of services—and the impact these have on consumers, families, carers and supporters.

These challenges are felt most acutely in communities that are a long way from the specialist services they need, particularly for children. Ms Amelia Morris, a witness before the Commission, explained the sense of isolation she felt when having to leave her family and community supports in regional Victoria to access private inpatient care in Melbourne.

Personal story:

Amelia Morris

Amelia's mental health began to deteriorate when she was about 15 years old. Living in a regional area, it was difficult for Amelia to find the support she needed.

> the closest headspace centre was a 45-minute drive away, with no public transport, and it was only open between 9am and 5pm. My mum had to take time off work, pick me up from school, drive me to headspace, wait for my appointment to finish, drive me back to school and then drive herself back to work.

While Amelia sees value in headspace, there came a point where she needed more intensive support.

> While I believe headspace plays a positive role for many young people, it was insufficient to meet my needs. There was nothing for me in between primary care and the emergency department. As someone with more complex needs, I felt abandoned by the mental health system when I needed it most. I also feel that the services I have managed to access are not suitable for me as a young person.

Amelia was moved to an inpatient ward in Melbourne, away from her familiar supports and surroundings.

> I spent nearly three months in the psychiatric hospital in Melbourne. I turned 17 just after my arrival there. I was two hours away from my family and friends, who could only visit me on weekends because of school and work … I had restricted access to my mobile phone, meaning I was not always able to communicate with my support networks. I felt incredibly isolated from the people I loved.

Amelia would like to see better access for consumers in rural and regional areas.

> Access should also be improved for rural and regional communities, especially people within these communities with complex needs. Like me, some people may be forced to go to Melbourne and leave their support network to get help. This was a very isolating experience for me and I believe it impacted upon my recovery.

Amelia felt abandoned by the mental health system.

> when I asked for help, it felt like there was nothing there … It's so heartbreaking when you finally work up the courage to voice the horrible things that you're experiencing, but there's nothing there to help you.

Amelia reflected on the impact her mental health challenges and having to move out of her community had on her family.

> There needs to be more support for families. During the time I was in hospital, my sisters were 15 and 13. There was no support for them or for my parents. While not everyone wants their families involved, more support should be provided for families and carers.

Source: *Witness Statement of Amelia Morris,* 24 June 2019.

24.4.3 Services can be difficult to access and navigate

The current mental health system can be difficult to navigate for rural and regional consumers, families, carers and supporters, representing another barrier to seeking help.[164]

Ms Karyn Cook, Executive Director of Mental Health Services at South West Healthcare, Warrnambool Community Health, spoke about the lack of community-based support for those living in rural areas of Victoria:

> The further away from larger centres a consumer is, the less options they have for support in the community mental health and primary health sector. In short, it is more challenging for a rural person to have all their needs met in relation to the social determinants of health.[165]

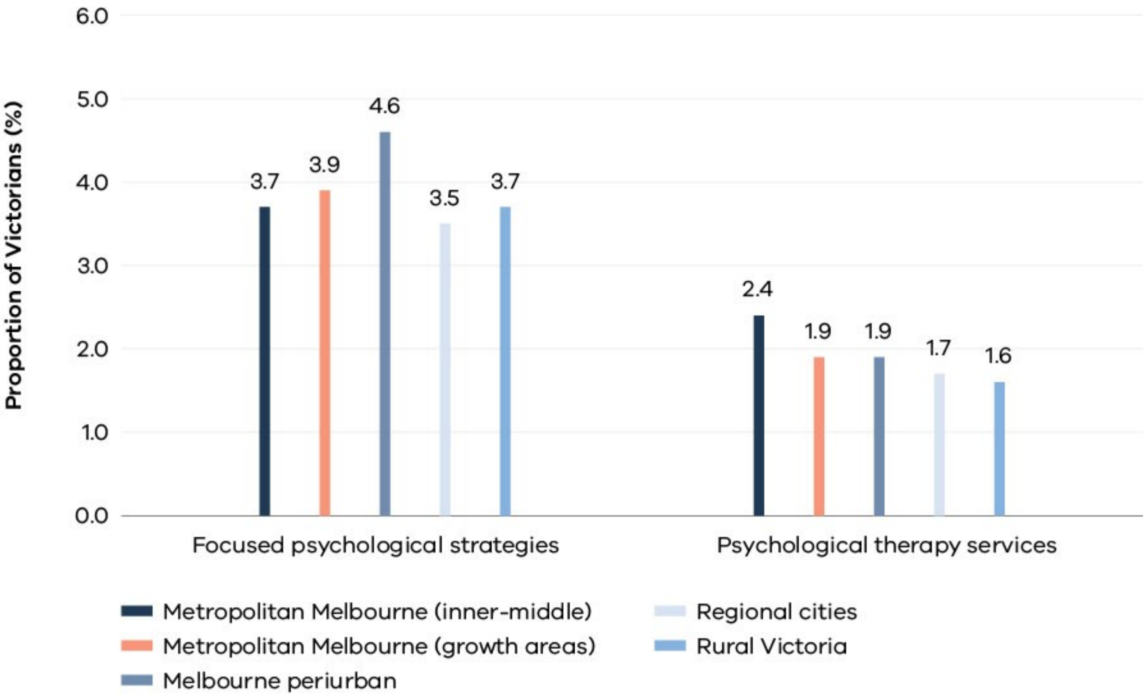
The Department of General Practice at the University of Melbourne stated that there is 'below optimal' access to general primary health services in rural and remote locations across the country:

> This results in patients [presenting] to emergency departments in tertiary hospitals for crisis or first aid mental health care as a result of not receiving proactive [preventive] care in the primary care setting.[166]

Workforce capacity is also an issue. In Victoria, workforce shortages for mental health professions are more pronounced in rural and regional areas.[167] The Commission's analysis indicates that the majority of mental health professionals work in major cities.[168] This limits people's access to expertise and opportunities for early support and intervention. Workforce shortages are discussed in more detail in section 24.6.

The accessibility of private mental health care in rural and regional areas is also limited. A range of mental health services are provided in the private sector and are eligible for financial subsidy through the Medicare Benefits Schedule. Analysis of service use in different residential locations has identified that a lower number of people per capita use Medicare Benefits Schedule services in rural and regional areas of Victoria.[169] As illustrated in Figure 24.5, the Commission's analysis indicates that for psychological therapies, roughly 2.4 per cent of people in inner metropolitan Melbourne areas received at least one session in a year, compared with 1.7 per cent in regional cities and 1.6 per cent in rural areas.[170]

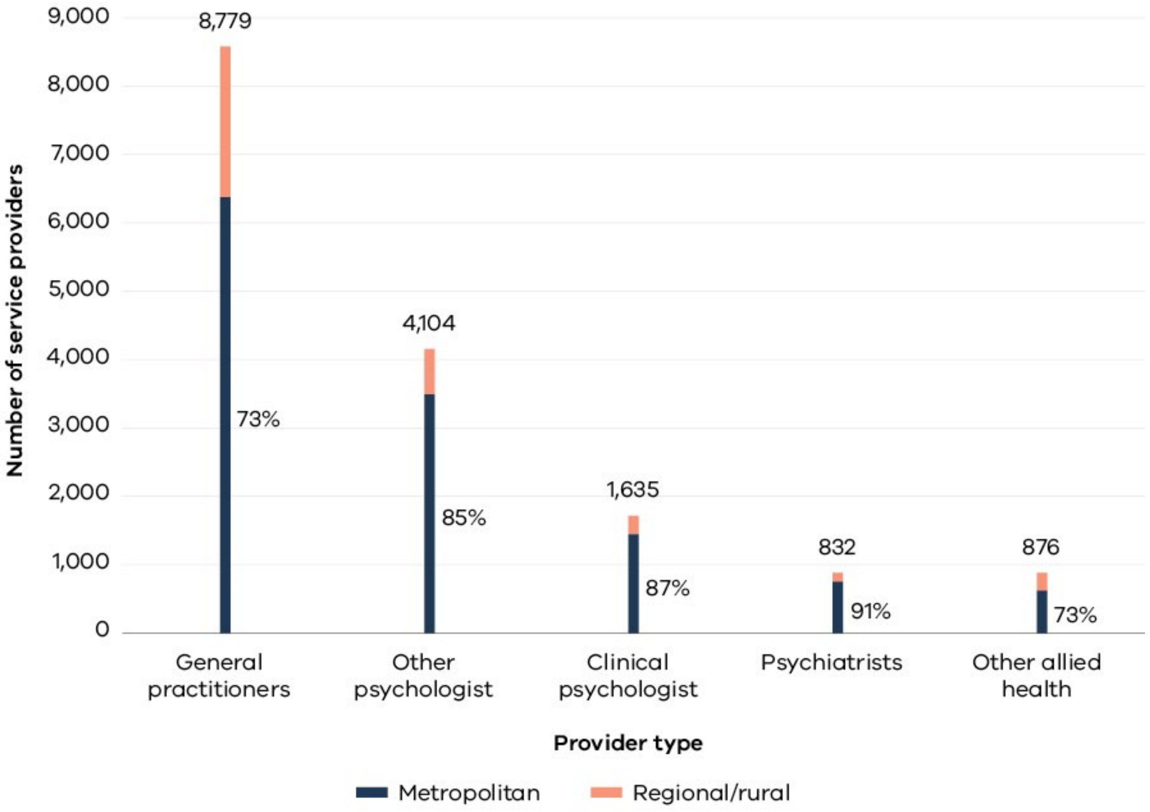
Figure 24.5: Proportion of people accessing focussed psychological strategies and psychological therapy services, by location, Victoria, 2017–18



Sources: Australian Government Services Australia, Medicare Benefits Schedule 2017–18; Australian Bureau of Statistics, Australian Demographic Statistics, June 2020, cat. no. 3101.0, Canberra .

In part, lower rates of access are driven by the predominantly metropolitan-based location of the mental health specialists who deliver the services (refer to Figure 24.6).[171]

Figure 24.6: Proportion of practitioners who provided Medicare-subsidised mental health services, by provider type and location, Victoria, 2017–18



Source: Australian Government Services Australia, Medicare Benefits Schedule 2017–18.

Note: The same practitioner may have provided services in metropolitan and regional/rural Victoria at some point in 2017–18.

The Commission has also been told there are limited numbers and choices of private mental health providers in rural and regional Victoria,[172] which is felt more keenly by communities in which it may be difficult to maintain privacy.[173]

One regional health service suggested that multiple points of entry are confusing, and make it difficult for people to understand where to get help.[174] As the Commission noted in its interim report, it has heard of the frustration and distress people have felt when facing barriers or delays in trying to identify the right mental health services for themselves or on behalf of someone else.[175]

Barwon Health told the Commission that the difficulty in navigating the system can cause consumers in its region to delay or choose not to access care, leading to poorer outcomes, or seeking help from the emergency system, which is often not appropriate for their needs.[176]

A regionally-based consultant psychiatrist said in relation to finding treatment, care and support for trauma, that:

> the idea of there being no wrong [door] is good in theory, but there are an awful lot of doors out there. And to ensure that [everyone] that's behind those doors is informed and aware of what needs to happen, I think is a fairly large ask.[177]

Smaller health and community organisations have reported a lack of effective communication processes between services, with regards to care and discharge plans.[178] Some consumers with mental health needs that merit early intervention actually access support from tertiary services, because of the limited points of access to the system, and therefore do not receive the most appropriate form of care.[179] One person at a community consultation in Ballarat told the Commission, '[s]ome people don't really need tertiary services but there is nowhere [else] to send them to.'[180]

24.4.4 Specialist expertise is not easily available

The Productivity Commission notes that a person's ability to access specialist mental health care is dramatically reduced outside major capital cities.[181] In a joint submission to the Royal Commission from five rural and regional area mental health services, service providers explained:

> Whilst there is a reasonable range of statewide specialist services within the Victorian mental health system, the vast majority of these are Melbourne based. As a result, these services, including Eating Disorder, Forensic, Personality Disorder, Neuropsychiatry and [Child and Youth Mental Health Services] inpatient beds, are often in high demand resulting in delayed access and a limited ability to provide early intervention. In addition, geographical distance further compounds access issues for patients and their family/carers living in rural and remote areas of Victoria.[182]

Within Victoria, there is an inequitable distribution of specialist expertise across the state, with specialist expertise concentrated in metropolitan Melbourne, including addiction specialists, child and adolescent psychiatrists, and clinical psychologists.[183] The vast majority of specialist mental health services, both inpatient and community-based, for people experiencing eating disorders and personality disorders, forensic patients, people needing neuropsychiatry, and children are based in Melbourne. They are in high demand, meaning it is even harder for consumers, families, carers and supporters living in distant parts of the state to access them.[184]

The Commission has heard from a range of consumers that needing to travel to Melbourne to use specialist services is a challenge:

> Victoria doesn't end at the Westgate Bridge.[185]
>
> I felt that the Melbourne psychiatrist was good, and we made some inroads. However, travel to and from these appointments was a whole day venture. I stopped seeing the Melbourne Psychiatrist because it was too inconvenient and too hard to be away from my work on the farm for that long.[186]
>
> Travelling over 400 kms at a time when you are vulnerable, away from the support of family and friends from an area that already has poor transport connections is not acceptable.[187]

There are a number of areas of specialist treatment that can be difficult to access in rural and regional locations.

The Commission was told there are few services or clinicians to provide support to people using alcohol or drugs in rural and regional communities,[188] despite the fact that these communities can have higher rates of alcohol and drug use.[189]

As discussed in Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction*, the relationship between mental illness and substance use or addiction is complex, and each can contribute to the other.[190] Substance use appears to be a factor that can increase the risk of a person experiencing poor mental health, or exacerbate the symptoms of mental illness.[191] Many people with substance use disorders also experience symptoms of mental illness.[192]

Despite recent investment, Victoria has insufficient residential rehabilitation beds for alcohol and drug treatment, particularly bed-based facilities for detoxification, withdrawal and rehabilitation. Hospitalisations related to alcohol in regional Victoria increased by approximately 80 per cent in the four years leading to 2016–17, and more than doubled over the same period for illicit substances.[193] The Victorian Alcohol and Drug Association advised there remains 'a dire need' to address underservicing, including in rural and regional Victoria.[194]

For those consumers receiving pharmacotherapy—the use of medication to assist in the treatment of opioid addiction—service gaps across rural and regional areas may limit access, as consumers have to travel long distances to receive treatment, such as daily dosing.[195]

Many rural and regional agencies said that the people and communities they represent have considerable experiences of past trauma.[196] However, specialist care and treatment for trauma can be limited in rural and regional areas. Dr John Cooper, Consultant Psychiatrist at Bendigo Health and Phoenix Australia (Centre for Post-traumatic Mental Health), highlighted that there are no inpatient trauma services for people aged under 18 in regional services, and they have to be sent to Melbourne to access treatment.[197]

Intergenerational trauma within Aboriginal communities can be communal and individual, and distressingly and tragically affects children and young people.[198] In Victoria (as at 30 June 2018), Aboriginal children were nearly 16 times more likely to be in out-of-home care than non-Aboriginal children, the highest ratio of all Australian states and territories.[199]

One roundtable participant explained how a lack of culturally appropriate services can add to people's trauma and distress:

> Not [being] able to receive such services in a culturally appropriate way also refers to the fact that if somebody can't go to a GP service, you know, that is specific for them in terms of an Aboriginal Health Service, they might try to receive a service in another part of the community, but that service may not be culturally appropriate for them. So that may add to the distress and to the trauma that people can experience. Things like bushfires destroying traditional lands and inability for people to gather is a huge issue.[200]

Another participant said that local regional mental health services ‘are not equipped to work with [culturally diverse] communities, lack competency and understanding of working with a cultural lens [or demonstrating] cultural sensitivities and trauma-based, trauma-informed … best practice’, and that access to appropriate support is constrained by the cost and availability of interpreters.[201]

Consumers can face a substantial fee gap to pay to see psychologists with advanced skills in assessing and treating consumers with complex needs.[202] Regional consumers with complex needs, such as those diagnosed with borderline personality disorder, may find it hard to access specialised and appropriate support.[203]

Rural and regional Victorians living with mental illness also tend to experience worse physical health than metropolitan consumers.[204] This is likely due to a lack of specialist services and practitioners who are able to help consumers with their physical health challenges, as part of a multidisciplinary service offering. Poor physical health can lead to worsening mental health outcomes, as well as poorer life outcomes.[205]

It can be difficult for GPs and small health services in rural and regional settings to access advice from specialists to help them make appropriate decisions. Associate Professor Moylan told the Commission that both GPs and consumers would benefit from more rapid input from specialists:

> it’s so challenging now to get specialist-based input and fast turnaround into things that the GPs, I think, feel a little bit under-prepared for some of these things and then feel uncertain about what to do … I think there’s been a functional disconnect and I think if we can really improve that for general practice I think we would find, in a capability building perspective, and a confidence building perspective, that for users accessing the system, they’ll find that, when I go to the GP I can get really good specialist-based mental healthcare, but also, very fast turnaround into a specialist system and come back to my GP who is the home of my care.[206]

One regional service leader made a ‘plaintive cry’ for specialist inreach support:

> [our generalist clinicians] foster relationships with specialist tertiary services in Melbourne. But if I had some specialists to compl[e]ment my generalists, I think that we could start approximating some of the outcomes [in other services]. And certainly, to get [specialists] to come up and spread [their] wisdom outside of Melbourne is always a worthwhile experience. But I think resourcing, training and relationships with the tertiary sector is probably the way that we get by.[207]

In its interim report, the Commission proposed an expansion of the Hospital Outreach Post-suicidal Engagement (HOPE) program (Box 24.2), which is an example of how a networked, inreach approach can support access to services in regional and rural areas.

Box 24.2: A networked approach to regional and local service provision

In its interim report, the Commission recommended the expansion of the Hospital Outreach Post-suicidal Engagement (HOPE) program to all regional area mental health services, to ensure availability throughout the state.

To achieve this, the Commission proposed a networked approach to enable people living in rural and regional areas to receive support. This approach included establishing a connected clinical outreach service in each subregional health service.

> Services delivering care at the sub-regional level often provide a range of more complex services than those delivered at the local level ... These providers bridge the gap between the range of lower-complexity services provided by smaller local rural healthcare providers and the larger regionally based health services.[208]

This networked regional approach facilitates strong collaboration and pathways between GPs, psychiatrists, psychologists and outpatient services, with regional services providing clinical and psychosocial support as required (for example, advisory and consultative support).

Services should have a focus on working with other health and social service providers to respond to local community needs. It is vital that, as part of their recruitment and training, outreach workers gain the ability to meaningfully interact with and support people in these areas. Services should be culturally sensitive and workers should possess an understanding of rural and farming life.

Source: Royal Commission into Victoria's Mental Health System, *Interim Report*, 2019, pp.445-458.

As illustrated in Figure 24.7, the Commission has heard from rural and regional consumers, families, carers and supporters, and the workforce about the challenges these communities face in accessing services.

24.4.5 Services for infants, children and young people are limited

According to regional communities consulted by the Commission, mental health services available for infants, children and young people are limited in rural and regional communities.[209] Many Victorian rural and regional providers reported that specialist mental health services including for children and young people are either absent, underfunded or over-extended.[210]

Dr Cooper said that regional services seeking to support children with complex conditions often have to be self-sufficient, relying on 'excellent and resilient generalist clinicians who are jacks of all trade' operating with limited resources.[211]

Some services described the loss of funding for programs such as perinatal and infant mental health,[212] a lack of access to mother and baby units,[213] an absence of services for primary-school-aged children,[214] or waiting lists of more than 12 months for autism assessment services.[215]

The Australian Education Union reported that a survey of teachers found high levels of frustration with a lack of services for children and young people, particularly in rural and regional schools:

> **Some respondents, particularly in rural areas, indicated that they virtually had no support while others said that the waiting periods for support undermined their usefulness and left the school to their own devices to meet urgent student needs.**[216]

Teachers also reported they were underprepared for managing the psychological and behavioural issues of students, and they had inadequate support when they did have to manage mental health issues.[217]

While most regional tertiary mental health services do deliver care to children and young people, these services are targeted to people with higher levels of need.[218] Therefore, services for less serious mental health concerns are typically being delivered by primary health providers (such as GPs or headspace), or through secondary providers, such as psychologists or psychiatrists.

Primary and secondary health services may be unable to meet demand and are at times fragmented, meaning children and young people are seeking services multiple times, and the flow of inpatients through child and adolescent mental health services may be disrupted.[219]

Rural and regional services report high levels of developmental delay, psychological distress including suicidal ideation, and illicit substance use among children and young people in their communities.[220]

People with neurodevelopmental disorders have higher rates of mental illness compared the general population.[221] Specialist services and clinicians who can diagnose neurodevelopmental disorders —such as autism spectrum disorder, attention deficit and hyperactivity disorder and sensory processing disorders[222]—are very difficult to access in rural and regional communities.[223] This means that children with neurodevelopmental challenges may not receive appropriate assessment, diagnosis and treatment, thereby delaying interventions and supports that could help both the child and their family manage their social, emotional and cognitive needs.

At the Commission's hearings in Maryborough, Dr Bhat said that historically child and adolescent mental health services were not as well planned as adult or older people's mental health services, which has resulted in barriers to access.[224]

Figure 24.7: Selection of quotes from consumers, families, carers and supporters and the mental health workforce in rural and regional Victoria.

Quotes from consumers, families, carers and supporters

People are vulnerable and then you add the complexity of them having to travel to get access to a service … this is removing people from an environment familiar to them and away from family and friends and what they know.[2]

It's frustrating when you're told you need an admission but there is nothing here for you.[3]

Well, I was brought up in a family of blokes who were blokes and didn't talk about that sort of stuff, which has been a big problem for a long, long time.[6]

[W]e didn't even have a hospital then, it had been washed away by the floods, so we had to go down to the major one … kilometres away.[5]

My son had a drug addiction but there were no carer or community services that could help me through this. There was no support and I got to a point where I was suicidal.[4]

I had a hard time getting in a psych ward when I was 10. By the time I was admitted it was in Box Hill, which was 3 hours' drive from our house so my dad could not come to visit me.[1]

Quotes from the workforce

> Our multidisciplinary team [comprises] two professions.[7]

> Some things work really well in rural and regional areas, but if they don't work well in metro areas the whole program gets cut.[8]

> We need boots on the ground to go to houses to help people in crisis.[9]

> It is difficult to do good work if we don't have enough people around and there isn't good infrastructure to support us.[10]

> [W]e know our clients. We see them in the street, see them in the supermarket. It's beneficial for us to know they are looked after.[11]

> Often there will be one really dedicated and overworked person and when they leave the service disappears.[12]

Sources: 1. RCVMHS, *Shepparton Community Consultation — May 2019;* 2. RCVMHS, *Seymour Community Consultation — May 2019;* 3. RCVMHS, *Bendigo Community Consultation — May 2019;* 4. RCVMHS, *Mildura Community Consultation — May 2019;* 5. *Evidence of Trevor Thomas,* 15 July 2019, p. 955; 6. *Evidence of Trevor Thomas,* p. 959; 7. RCVMHS, *Shepparton Community Consultation — May 2019;* 8. RCVMHS, *Bendigo Community Consultation — May 2019;* 9. RCVMHS, *Ballarat Community Consultation — April 2019;* 10. RCVMHS, *Geelong Community Consultation — April 2019;* 11. RCVMHS, *Mildura Community Consultation — May 2019;* 12. RCVMHS, *Shepparton Community Consultation — May 2019.*

Personal story:

Monique

Monique* has worked as a GP in regional Victoria for over 20 years. She combines private practice with work at headspace, where she specialises in youth mental health. Monique is also a parent and carer for her child who has experienced complex mental health challenges from early adolescence and into adulthood.

> The experience as a parent and carer is like being on a massive rollercoaster. The fact that all your love and support can't protect your child from mental health difficulties is pretty confronting for parents. The fear and distress and confusion that their difficulties might be our fault as parents was pretty challenging to deal with, let alone seeing the distress and pain our teenager was going through. Even as well-resourced parents, we were shocked by some of the interactions we and our teenager had whilst navigating [the system].

Accessing specialist help in regional Victoria can bring additional challenges. Monique's child received multiple diagnoses throughout adolescence and early adulthood.

> The various assessments, formulations and explanations we were given over many years completely missed an underlying neurodevelopmental disorder … This illustrates the importance of holistic, comprehensive, non-fragmented and 'over time' assessments.

Monique notes that where there is a lack of services in rural and regional settings, GPs often hold the responsibility for mental health treatment, care and support.

> GPs often provide a single thread of continuity for some of these young people in rural and regional settings. The [Medicare Benefits Scheme] does not reimburse us for our time or commitment to their care.

Monique's lived experience as a carer has shaped her professional pathway.

> I was … deeply ashamed of negative attitudes and internalised stigma that some of my medical peers and some other health professionals displayed—it was shocking to me that this was sometimes worse than in the wider community. This made me really driven to make a difference where I could.
>
> In my opinion, kindness, respect, collaborative decision making, clear patient centred explanations, advocacy and support make a huge difference and GPs are a vital cog in the system.

Source: 'Monique' (pseudonym), *Correspondence to the RCVMHS*, November 2020.

Note: *Name has been changed to protect privacy.

A respondent to a workforce survey of staff and volunteers across Victoria's mental health system held aspirations for more equitable access to specialist services for all communities:

> Providing support for rural and regional communities that is commensurate with metropolitan services is vitally important. All state-wide specialist services seem to be based in Melbourne, as are all centres of excellence. It would be great to see a progressive Mental Health Service that is accessible for all Victorians and improves the career prospects and pathways for staff in rural and regional settings, without having to move/travel to the capital.[225]

24.4.6 Digital technology could be better used to improve service access

One of the major benefits of digital technology is its ability to break down geographic barriers,[226] and as the Commission's interim report pointed out, this is particularly the case for people in rural and regional Victoria needing to access mental health services.[227] The potential for greater use of digital technology across the state is discussed in detail in Chapter 34: *Integrating digital technology*. This section focuses specifically on its importance and application in rural and regional settings.

The use of technologies such as video or phone conferencing (telehealth), and online mental health interventions can help by:

- reducing geographical barriers and travel for consumers and mental health workers
- making specialist supports available locally
- facilitating multidisciplinary care when workers are in multiple locations
- providing more options that support people's anonymity, reducing the risk of people experiencing stigma when they seek help, or being concerned that they will experience it
- expanding access to peer supports, helping to reduce feelings of isolation.

Many consumers have found telehealth services to be effective and convenient. Dr Paul Denborough, Clinical Director of Alfred Child and Youth Mental Health Service and headspace, Alfred Health, giving evidence in a personal capacity, told the Commission:

> We are already seeing a massive uptake of use of technology to see and help families via telehealth in the COVID-19 crisis and this has been very well received by families.[228]

Online digital services offer consumers more flexible and personalised services at a time and in a way that is convenient to them. Typically, they provide people with clinician-supported online cognitive behavioural therapy or similar therapeutic services. Around 40 per cent of the registered users of MindSpot—which delivers online mental health interventions—are from rural and regional areas,[229] as are around 30 per cent of users of THIS WAY UP, an online cognitive behavioural therapy program.[230]

But telehealth and other digital services are being underused to help people in rural and regional communities to access mental health services.[231] Despite increased uptake during 2020, digital technologies are still not being used to their full potential to benefit rural and regional communities.

Barwon Health advised that this was the case in its region:

> The use of telehealth and associated technologies has significant potential to improve access to mental health care, particularly to communities with limited local access to specialist services (e.g. regional and rural areas). At Barwon Health, there is untapped potential to utilise telehealth and other technologies to improve access to specialist services across the Barwon region and to support general practitioners in smaller population areas.[232]

Several barriers exist, including the capacity of service providers to deliver digital services; ageing devices and technology;[233] lack of funding and investment in information and communications technology (ICT) infrastructure;[234] inadequate workforce skills and capacity;[235] and lack of affordability of devices for consumers.[236]

Barriers for consumers and service users

The Commission was told that many people in rural and regional communities may struggle to use telehealth services or access digital mental health and wellbeing services. Some small rural towns and regional areas have poor internet connectivity, which can limit people's ability to use telehealth services and other digital tools that require internet data. People in rural and regional areas are less likely to have internet connectivity at home than people in metropolitan areas,[237] and even when they do have internet, it may be less reliable.[238] A business supporting rural and regional farmers told the Commission that lack of connectivity would inhibit online service delivery:

> the move to online [has] got its place. But what [we're] hearing all the time is, 'oh, it's online'. Most of our people don't have connectivity. That's why we set up the IT company … we [tried] to have a farmers meeting this morning … you know, four of them kept dropping out all the time. So how can you deliver services when you can't even get very basic … connectivity let alone a mobile phone service?[239]

Some rural and regional communities have high levels of socioeconomic disadvantage. Digital inclusion is lower for low-income households, those who are unemployed, Aboriginal people, people from culturally diverse backgrounds, and people with a disability.[240] Mr Shane Solomon, partner of Caligo Health, giving evidence in a personal capacity, cited study findings that identified 'a substantial digital divide between richer and poorer Australians', and noted that '[c]onsequently, the potential to take advantage of telehealth and related mobile apps is likely to require some investment in improving access to digital health resources for consumers of mental health services.'[241]

Associate Professor Moylan said Barwon Health has noticed that some consumers have struggled to use telehealth services due to a lack of technology and connectivity, and a lack of access to public libraries and other sources of Wi-Fi:

> In respect of the telehealth services that Barwon Health have able to provide, we noticed a digital divide between consumers who have the necessary technology (i.e. hardware, internet connection and data allowance) and those consumers who do not. The divide is further exaggerated by the fact that the lockdown measures prevent consumers from accessing community based services (i.e. public libraries, internet cafes etc.) which would be available in normal circumstances.[242]

The Commission also observes that, while libraries and other public facilities may provide internet connectivity, people may not be comfortable having personal conversations in proximity to others, nor should they have to. A lack of designated and private space can limit people's ability and willingness to use digital services.

Barriers for service providers

The Commission was told that public mental health services in rural and regional areas often lack the ICT infrastructure and equipment to offer their consumers state-of-the-art digital services. Mr Welch told the Commission that a lack of suitable ICT infrastructure is the predominant barrier to mental health services using telehealth and other digital technologies.[243]

In a joint submission by five rural and regional area mental health services, service providers argued that more funding is needed to support 'innovative approaches to service provision in which distance and cultural differences are a significant challenge', including 'infrastructure to address geographical distance' such as mobile devices (phones and computers for access to digital clinical information at the point of care) and telehealth.[244] Several other services also indicated that a lack of suitable devices, internet and technology limits their ability to offer people telehealth consultations and remote assessments.

As discussed in Chapter 34: *Integrating digital technology,* recent changes to the Medicare Benefits Schedule in response to the COVID-19 pandemic have expanded access to telehealth. Previously, telehealth had been funded through the Medicare Benefits Schedule for specific rural and regional areas in primary health care, and its availability in metropolitan areas was limited. During 2020, the then Department of Health and Human Services purchased additional call volumes for area mental health services in Victoria to support the switch to telehealth.[245]

The Productivity Commission noted how the expanded Medicare Benefits Schedule rebate has improved access to specialist services and supports. It recommended that the Commonwealth Government make the statewide rebate for mental health telehealth services permanent. If this recommendation is accepted, it is anticipated that the statewide rebate will greatly improve rural and regional communities' ability to seek out psychiatric and psychological services.

The Commission welcomes the announcement made subsequently by the Commonwealth Minister for Health, Greg Hunt, that 'for the long term, telehealth will become a permanent part of the Medicare system'.[246]

The Productivity Commission has also recommended that the Commonwealth establishes a new digital platform that includes clinician-supported online interventions. If adopted, these supports will help people living in rural and regional Victoria to use evidence-based digital interventions, either on their own or as part of their broader service supports.

Digital initiatives in mental health are promising, but old systems and infrastructure are preventing people from engaging with and benefiting from digital services in rural and regional Victoria. For these communities to take full advantage of digital technologies, they need state-of-the-art ICT infrastructure, connectivity and devices, as well as support to establish new innovative digital programs that meet the needs of their local people.

This will require:

- giving consumers better access to technology in safe and private environments, so they can use and benefit from telehealth and other digital services
- greater support and funding for rural and regional mental health and wellbeing service providers to build their digital capacity and digital service offerings
- support and partnerships to help rural and regional communities, consumers and service providers to establish, test and share digital interventions that increase consumer access to high-quality services, based on local needs and priorities.

The Commission notes that the Victorian Budget 2020–21 includes investment in technology to facilitate access to telehealth,[247] and to improve mobile coverage and broadband connectivity[248] in rural and regional Victoria.

24.5 Funding to reflect the cost of service delivery

The Commission has heard that Victorian and Commonwealth Government funding arrangements may not adequately cover the additional costs of delivering services in rural and regional areas, or allow for appropriately flexible models of treatment, care and support that reflect the needs of people living in these communities.[249] This has led to some disparities in how services are funded across the state.[250]

One person attending the Commission's consultations in Shepparton observed:

> There are huge funding disparities for mental health services—there are differences between metro and regional areas, and differences region to region. If your lottery of birth wasn't enough, what services you get is also a lottery.[251]

The *National Strategic Framework for Rural and Remote Health* states there are significantly higher costs involved in rural and remote healthcare delivery.[252] While the cost of providing health services increases with remoteness, the availability of existing infrastructure and workforce becomes more limited.[253] Assumptions that can generally be applied to the funding of metropolitan services—such as availability of an appropriately skilled workforce; consumers and provider proximity to services; adequate community and social infrastructure; and robust health care services including private options—do not necessarily hold in rural and regional locations.[254]

The Victorian Auditor-General's *Access to Mental Health Services* report found that current funding models do not take into account that rural and regional services may have inherently higher operating costs than metropolitan services.[255] Current funding models may not adequately account for:

- the vast geography of the catchment areas and additional costs of transport to meet the needs of people living in remote locations (such as practitioner travel times as a consequence of covering large geographical areas to reach a dispersed population group)[256]
- the impact on clinician time of delivering services to consumers in rural communities (for example, required staffing levels)
- the additional costs required to support staff wellbeing in dealing with the unique stressors associated with working in rural settings (such as increased travel).[257]

Dr Bhat told the Commission:

> Current funding arrangements for rural state-funded mental health services do not necessarily take into account the combination of travel times and dispersed population, which does not incentivise assertive community-based mental health treatment and care. Instead, care becomes focused on seeing people in clinics who may require people to travel long distances, medications, and monitoring and risk management.[258]

In its submission, Ballarat Health Services explained the problem with existing funding models:

> funding models disadvantage regional, rural and remote mental health services as the funding does not take into consideration the social, economic and geographical challenges inherent in these catchments.[259]

Area mental health services have reiterated to the Commission the funding issues identified by the Victorian Auditor-General. As a consequence, they advised that funding models are inappropriate in rural and regional areas, because they do not encourage community outreach or home visits. Instead, service provision is focused on people attending clinics, meaning they may be required to travel long distances.[260]

In addition, costs are higher for services with low-volume demand due to population size. South West Healthcare explained:

> Due to the large geography covered by rural services, together with small population numbers and lower bed numbers, rural services struggle to leverage economies of scale when it comes to making the most efficient use of funding.[261]

Latrobe Regional Hospital said that funding reform is needed 'to address the rural and regional context of service delivery and support innovation to provide access to those hard to reach populations who are not receiving service'.[262]

The Rural Health Standing Committee observes that the combination of limited resources and high administrative burdens could endanger services in rural locations:

> Rural and remote services are unlikely to enjoy the same economies of scale as metropolitan-based services, and many small rural facilities experience a significant administrative burden on their limited resources due to multiple accreditation, accountability and reporting requirements … When these factors combine, small rural health facilities and service providers can find it harder to maintain their viability, and may struggle to continue providing the services their communities need.[263]

The Commission considers that more deliberate planning, design and resourcing of mental health and wellbeing services is needed to keep pace with the population changes and growing needs of rural and regional populations. Larger regional services will need to be more active in supporting rural communities.

As stated in Chapter 1: *The reform landscape*, agencies should work together to create a system that respects the experience and needs of individuals, and ensures that consumers, families, carers and supporters are more easily able to access and receive services.

24.6 Workforce shortages

Workforce shortages in rural and regional communities can negatively affect consumer access to responsive, integrated and person-centred mental health and wellbeing services.[264]

As noted above, workforce shortages for mental health professions are more pronounced in rural and regional areas of Victoria.[265] Service directors and practitioners have told the Commission that rural and regional Victoria struggles to attract psychiatrists, psychologists, GPs, nurses and other community mental health workers.[266] As a consequence, services experience staff shortages that can increase the workloads of existing staff, leaving them at times challenged to provide the level of care they would like.[267]

Area mental health services report that staff shortages result in understaffed mental health units, inexperienced staff, crisis-driven care, and an inability of services to reach or meet the needs of their target consumer populations.[268]

Consumers, families, service providers and communities have said that limited workforce availability has had a negative effect on the mental health and wellbeing of the rural and regional communities across Victoria.[269]

Dr Lynne Coulson Barr OAM, Victoria's former Mental Health Complaints Commissioner, said that workforce shortages in rural areas ‘create risks for consumers’, particularly where extended vacancies force the high use of poorly trained agency staff.[270] Dr Barr said that Complaints Commission investigations have identified shortcomings in the induction and training of new staff and agency staff to ensure they understand the Mental Health Act, and have sufficient access to skill development in key areas of practice, such as trauma informed care.[271]

24.6.1 Nature of workforce shortages

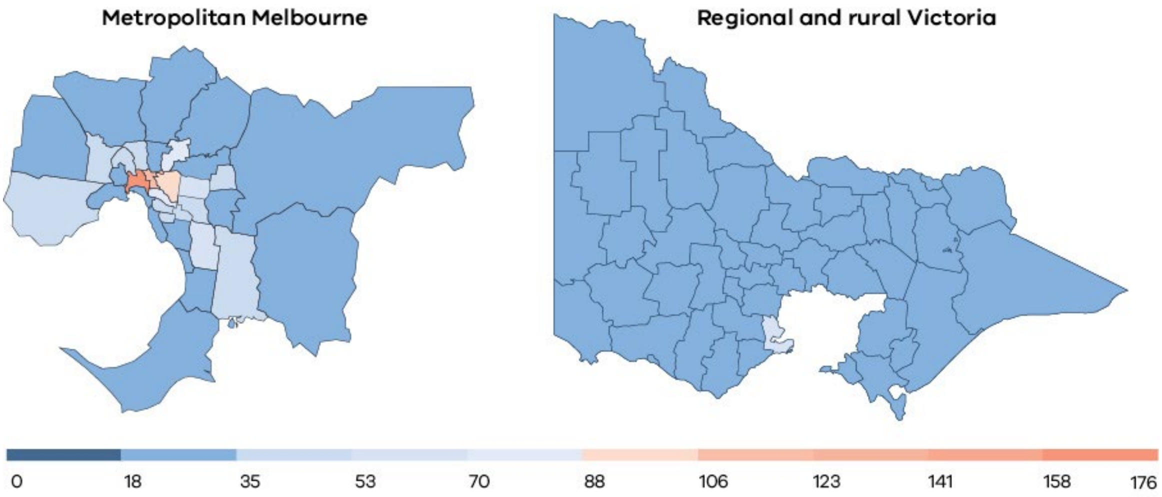
Workforce shortages are evident across primary, secondary and tertiary services, and private practice, including GPs, psychiatrists and medical staff, mental health nurses, psychologists, allied health professionals, social workers and peer support staff.[272]

Nationally, the number of mental health professionals registered with the Australian Health Practitioner Regulation Agency is significantly less per capita across rural and regional areas than in metropolitan locations.[273] In Victoria, most registered professionals working in mental health—including psychiatrists, psychologists, GPs, nurses and occupational therapists—are concentrated in metropolitan Melbourne, as indicated in Figure 24.8.

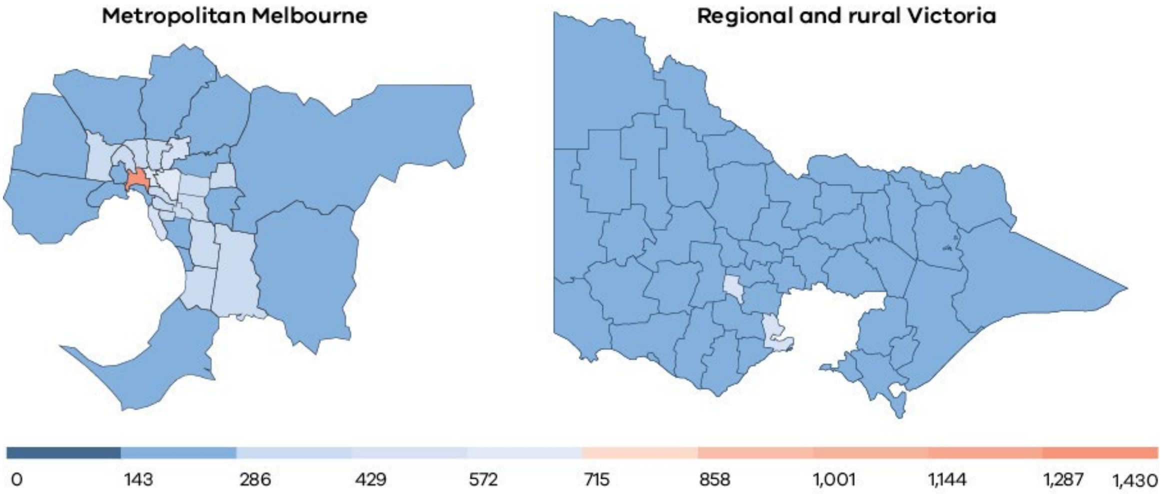
Albury Wodonga Health reported that its catchment has very few private psychiatrists and psychologists, which means the area mental health service is a one-stop shop for primary care right through to acute psychiatric and tertiary care. The service is aiming to build a team of what it considers ‘rural clinicians’—mental health clinicians who understand and have a skill set to work in rural communities, and partner with rural agencies and consumers to deliver the best possible care.[274]

Figure 24.8: Number of psychiatrists, psychologists, GPs, nurses and occupational therapists, by local government area, Victoria, 2019

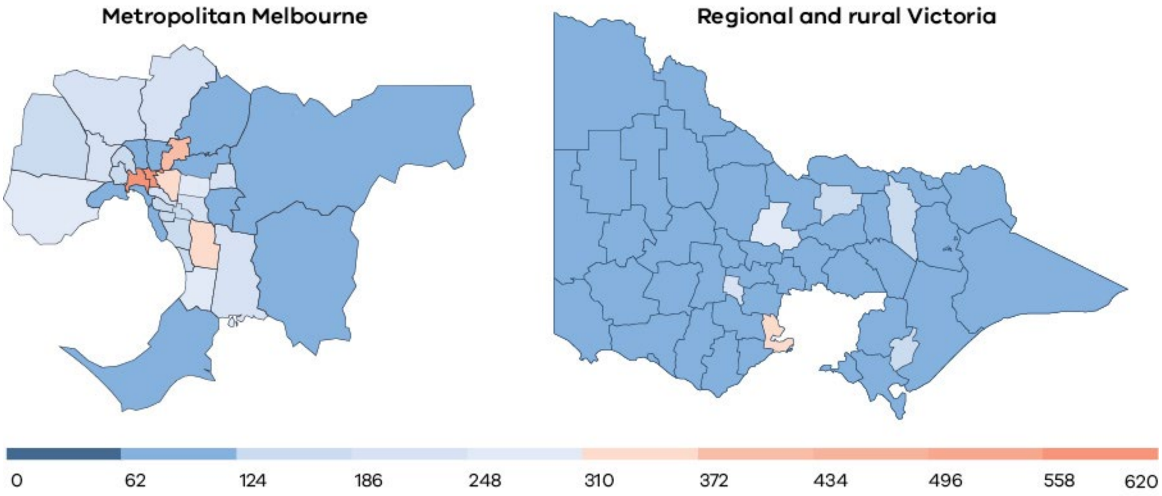
A. Psychiatrists



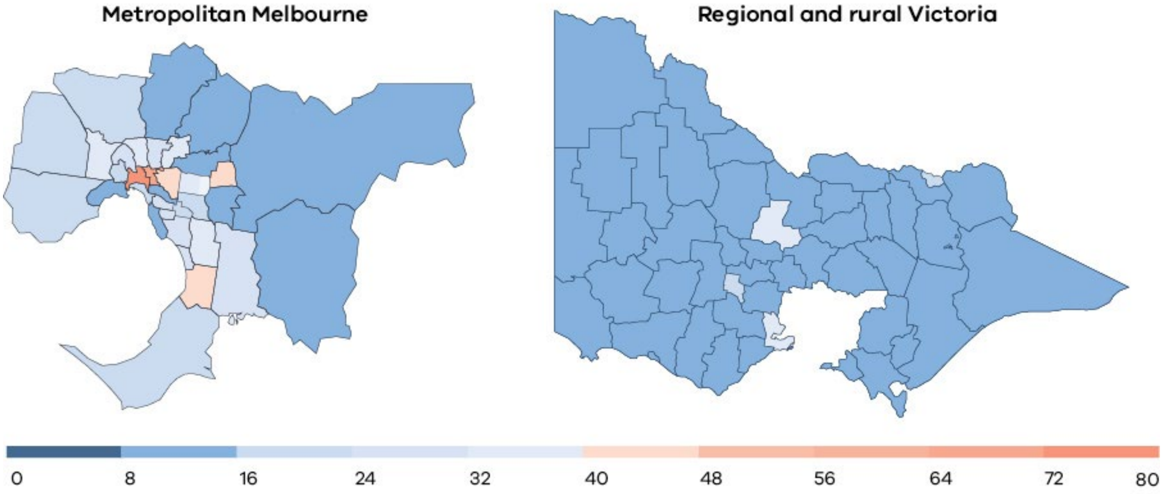
B. Psychologists



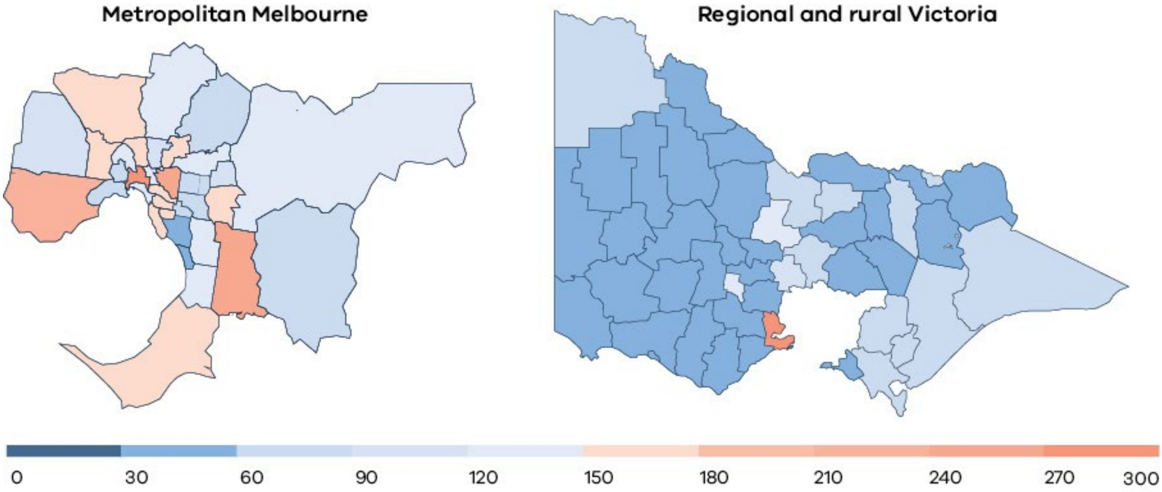
C. Mental health nurses



D. Occupational therapists



E. General practitioners



Source: Commission analysis of Australian Government Department of Health, Health Workforce Data, <hwd.health.gov.au/datatool.html>, [accessed 10 December 2020].

Note: Only includes practitioners working in Victoria in registered professions.

Recruitment of specialist mental health clinicians takes place within a limited and competitive workforce market.[275] Non-government organisations often need to compete with area mental health services to recruit staff, but may be unable to offer competitive wages. This limits their ability to attract highly trained clinicians equipped to provide complex care.[276] Short-term funding cycles causing job insecurity may contribute to challenges with retaining staff in rural and regional areas, particularly in non-government organisations and community-based services.[277]

Rural and regional community members report a desire for workers who are sensitive and respectful of the local culture and history.[278] However, there is a shortage of culturally trained mental health practitioners—for example, a lack of specialised, culturally trained Aboriginal workers.[279] The Commission's interim report recommended actions to grow and develop Aboriginal social and emotional wellbeing teams.[280]

The Royal Flying Doctor Service said the local rural mental health workforce needs to grow and diversify to meet the needs of rural communities. The service used telehealth and 'drive-in/drive-out' models to mitigate workforce shortages in some regions. But it highlighted that more roles such as outreach workers, community connectors and health coaches were needed to assist in addressing local community needs, as well as 'extending the scope of practice of existing trusted rural health professionals' such as community nurses, GPs and Aboriginal health workers.[281]

It has been reported to the Commission that people from culturally diverse backgrounds, including people with traumatic pre-migration experiences, often cannot access appropriate mental health care or interpreters.[282] Health and community service providers report limited access to alcohol and other drug, and dual diagnosis specialist clinicians, which results in increased risk and vulnerability for consumers.[283]

24.6.2 Causes of workforce shortages

Many factors contribute to the shortage of mental health professionals in rural and regional locations. Geography is a particular barrier to attracting suitably skilled professionals to smaller, rural towns. Dr Bhat told the Commission that '[i]n rural areas recruitment is harder with fewer incentives for trained staff to move to regional towns.'[284]

One community member told the Commission:

> We struggle to attract qualified health professionals to our town. We are not metropolitan, we are not a regional centre. We don't have positions with high salaries for people rising in their profession or seeking a career path. We are too far from regional centres for young people or socially dynamic people to visit and return after their working day. We are limited in the profile of people who would find living in our town and providing services to our community attractive.[285]

Accommodation and employment opportunities can be limiting factors. Grampians Health said '[t]he constraints of funding can mean that positions are offered on a fractional basis, and this may not be enough to attract somebody to relocate to that area.' It suggested that financial and housing incentives would encourage staff to work in regional area mental health services.[286]

Family factors—such as housing, educational options for children, spousal employment opportunities and remoteness from family and friends—can be important in influencing professionals to consider rural and regional practice.[287] One systematic review noted that 'in rural settings it is often a whole family that is recruited to an area, not just an individual'. It found that support in securing housing and spousal employment may help attract and retain health workers.[288]

Social and personal satisfaction with rural lifestyle has been found to influence workforce retention over longer periods. People who are older, have school or family connections locally, or have established professional and community networks, are more likely to stay in their post longer, while 'a sense of social and personal isolation may contribute to the decision to leave a rural area'.[289]

Work pressures and safety make it hard to attract and retain skilled mental health professionals.[290] The rural and regional workforce also experiences limited support and networks.[291] Lack of access to supervision limits the capacity to train and employ more junior psychologists in small services in rural and regional areas.[292]

Ms Cook told the Commission about the difficulties rural services face:

> While we are trying to attract experienced skilled workers, there is currently a workforce shortage—especially in rural areas. Workers willing to live outside the metropolitan area will generally elect to go somewhere like Ballarat, which has a shorter commute to Melbourne. As a result, we primarily attract clinicians with less mental health clinical experience such as social work or [occupational therapy] graduates, junior nurses and provisional psychologists, who require high levels of training, supervision and support.[293]

Fewer opportunities for professional development and continuing education are also a disincentive. Travelling to larger regional cities or metropolitan areas for professional development and training can be both expensive and time consuming for professionals and service organisations.[294] The Commission has been told there are minimal incentives to support local training programs in rural and regional areas.

Grampians Health submitted to the Commission:

> Most learning opportunities for mental health professionals and allied health staff are Melbourne centric, which makes participation more challenging. There needs to be greater investment in learning opportunities in regional and rural centres.[295]

Dr Bhat told the Commission:

> Rural state-funded mental health services are not incentivised to develop and sustain local training programs. Even when they exist, they have little support for sub-speciality training such as that in Eating Disorders, Neuropsychiatry etc.[296]

24.6.3 Effects of workforce shortages

Mental health workers in rural and regional areas can be faced with managing high-risk situations with limited workplace support.[297] Smaller teams or limited resources can also result in high levels of pressure.[298] They may lack supports such as direct case supervision, clinical and/or professional practice supervision, multidisciplinary team oversight and support, medical oversight and clinical governance structures.[299]

A regional service provider said that mental health staff needed to have a diverse array of skills, because there is limited scope to refer people to other agencies or specialists.

> There are a lot more hurdles. There are a lot less outside support agencies to help the people that we work with. So we find that we're doing more and more and more. They say to be a social worker in the country means you have to be a jack of all trade[s] … Everybody has to be skilled in a number of different areas … because it's not so easy to refer them to somebody down the road who specializes in that area.[300]

Workplaces in rural and regional areas can be professionally isolating for some, with limited informal or peer support.[301] Dr Neil Coventry, Victoria's Chief Psychiatrist, told the Commission:

> providing a variety of clinical services … requires a critical mass of qualified clinicians for training, clinical supervision commensurate with level of experience, and service provision. Providing an appropriate level of discipline-specific, clinical supervision can be a particular challenge in rural and regional services …[302]

Workforce shortages impact the wellbeing of mental health staff, who may experience fatigue and burnout when they cannot offer the care that people need due to resource shortages.[303] One professional from a large area mental health service told the Commission:

> they're working with far more acutely unwell people than they have previously in 2020. They're holding a lot of people in the community. And I'm really proud of the work that the teams are doing to be able to hold people who previously may well have been admitted to an inpatient unit. But we're now at the point where that's not a feasible option …[304]

A lack of appropriately trained and available clinicians has increased the care burden on emergency workers, school communities, sporting clubs, volunteers and local councils.[305] One roundtable participant told the Commission that this places particularly heavy pressure on emergency service personnel who have minimal training to provide a mental health response.[306] There may also be added pressures on mental health workers in small rural towns, who are well known to the community and may feel obliged to meet expectations.[307]

Carers in rural and regional Victoria also report increased psychological distress and poor physical health associated with workforce shortages, lack of supports and a lack of respect for their rights.[308] Changes from previous carer support funding models to the current National Disability Insurance Scheme model have significantly disadvantaged some carers, who no longer have the same respite supports available.[309]

The Commission acknowledges the substantial pressures on the mental health workforce in rural and regional Victoria. However, it has also observed evidence of strong community connections, partnerships and goodwill, which could form the foundation of an improved and innovative future workforce. These connections mean that rural and regional residents are acutely aware of, and attuned to, the mental health and wellbeing of their community members.

While there is a critical need to attract and retain specialist mental health expertise, the Commission recognises great potential for a more diverse future workforce to play a role in health promotion and wellbeing support for rural and regional communities.

24.6.4 Workforce aspirations

In 2020, the Commission engaged ORIMA Research to conduct a survey that was open to all staff and volunteers who provide mental health treatment, care and support across Victoria. A total of 2,920 responses were received from people working in a variety of roles and settings across the state. Around 29 per cent of respondents provided services to people in regional Victoria.[310]

The survey included opportunities for individuals to share their aspirations for the system in the future. Staff shared their hopes for rural and regional communities, and the services that support them.[311]

Themes from regional-facing workforces included hopes that the communities they support will be afforded equal access to mental health treatment, care and support; and that regional and rural mental health services will have sufficient funding and resources to accommodate the differing challenges and needs of rural consumers and settings.

Staff wanted greater capacity to attend rural communities and provide home visits to farming communities, and access to the training and supports they need to work optimally in rural areas to meet needs of consumers. People in rural teams wanted to feel part of the broader state mental health service; for them, this would include partnerships between metropolitan, regional and rural services that provide access to training opportunities, peer and professional supports, and allow isolated staff to share experiences.

Personal story:

Jennifer Rowan

Jennifer Rowan is from the small rural town of Camperdown in Victoria's south-west. Living in a rural area, Jennifer has seen that it can be difficult for those in her community to access specialist mental health support.

> Living in a rural town, we have very limited health services and we experience long wait times for services. With a small number of psychologists in our area, they are inundated with work.

Although digitally enabled mental health services have a role to play, Jennifer emphasises that technology and online access don't necessarily make access easier in rural towns because not everyone has reliable access to the internet.

> It can also be difficult for us to use online services like eheadspace because of issues with internet access and connectivity. Having grown up in the area, I have seen how the gaps in the mental health system affect rural and regional communities.

Jennifer is passionate about mental health and is currently studying a Bachelor of Social Work. She is also a mental health first aid instructor with Mental Health First Aid Australia. Jennifer would like to see more opportunities for young people to enter the mental health field and sees this as a way of building more access to services in rural areas.

She also emphasised the lack of roles for professionals who deliver psychotherapeutic treatment, care and support:

> We have a lot of young people out here who are quite passionate about mental health and who want to become mental health professionals and work in the area, whether that be as a psychologist or social worker. However they find that after their studies if they want to return to the area there is unfortunately no funding for jobs.

In addition, more access to services and professionals would help to break down stigma and encourage people to reach out when they need support.

> I want our communities to get to a point where it is normal to talk about mental health and where we are all comfortable with it.

Source: *Witness Statement of Jennifer Rowan*, 22 April 2020.

> Living in a rural town, we have very limited health services and we experience long wait times for services. With a small number of psychologists in our area, they are inundated with work.
>
> Jennifer Rowan

24.7 The future system: building on the strengths and resilience of rural and regional communities

The Commission's vision is for a mental health and wellbeing system that adapts and responds to the needs of all Victorians. This includes supporting people in rural and regional Victoria with improved access to high-quality services.

Despite the barriers they face in accessing services, the strengths and resilience of rural and regional communities provide a solid foundation for building supports for mental health and wellbeing into the future.

The sense of community spirit and social connectedness in these communities can have a positive impact on the mental health and wellbeing of people.[312]

During community consultations, the Commission heard how volunteers had established local support groups to help each other through difficult times.[313]

Neighbourhood Houses[314] and Men's Sheds[315] have been described as safe and inclusive spaces that support wellbeing and social connection:

> One of the greatest preventative tools introduced is the development of Men's Sheds. These facilities have provided a great sense of belonging and camaraderie to a vulnerable sector of the community.[316]

Local services in rural and regional areas have said that place-based care is essential and achievable.[317] Many mental health service providers have found flexible and creative ways to use limited resources and deliver care.[318] Some tertiary providers are innovating and partnering with others to provide holistic, preventive treatment and care, based in the community.[319] Other initiatives embed mental health treatment, care and support in local primary health settings, such as GPs and dental services.[320]

Ms Medson said that Gippsland Lakes Complete Health has started training programs in drought-affected areas called The Accidental Counsellor 'to provide community members with some skills to listen to their friends and colleagues and make suggestions about seeking further help'.[321] Ms Medson also highlighted the value of community-initiated activities, such as 'bring a plate' dinners that provided social connection and support to people in Sarsfield who lost their homes to bushfires. She said that 'the initiative came from people within the community and that's what works best, not an organisation bringing in a solution'.[322]

This sentiment was shared by a person attending community consultations in Shepparton:

> Relationships and partnerships are the key to embedding service delivery. Community has a role to play. This conversation shouldn't just be about what services can do but what the community can do.[323]

A number of the Commission's recommendations aim to address the barriers faced by rural and regional communities in accessing services and supports. The future integrated mental health and wellbeing system is designed to respond to the specific needs of rural and regional communities in a variety of ways.

24.7.1 Building blocks in the Commission's recommendations

The new integrated mental health and wellbeing system will offer accessible, high-quality treatment, care and support to individuals living in rural and regional Victoria, along with their families, carers and supporters. As stated in Chapter 1: *The reform landscape,* localised community care will be a central feature of the future system. There are several ways in which this will be achieved. The Commission's reforms will support rural and regional communities to have better access to specialist and cohort-specific treatment, care and support closer to home. Overall, a more integrated, networked approach to service delivery will ensure better connections and continuity of care across primary, secondary and specialist mental health and wellbeing services.

Many reforms recommended by the Commission are designed to improve treatment, care and support for all Victorians across the state. A number will have particular benefits for rural and regional communities. Some of the most significant are summarised in Table 24.1.

Table 24.1: The Commission's recommendations with particular benefits for regional and rural communities

Relevant reforms	Benefits for regional and rural communities
Chapter 5: *A responsive and integrated system*	Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services will each tailor the services they deliver to the needs and context of their communities. New Regional Mental Health and Wellbeing Boards will assess the need for mental health and wellbeing services across their populations, and develop and publish plans—unique to each region—to support service providers to respond to their communities' needs.
Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect*	Funded 'community collectives' for mental health and wellbeing in each local government area will support local communities to promote social connection and inclusion and connect people to community initiatives that will support their wellbeing. More evidence-informed initiatives and programs will be available to all schools to support student's mental health and wellbeing. Schools in rural and regional areas will be given priority under new funding arrangements to select the most appropriate suite of initiatives for them.
Chapter 12: *Supporting perinatal, infant, child and family mental health and wellbeing*	One of the two new statewide subacute residential family admission centres will be located in regional Victoria. These centres will provide five-day admissions in an intensive therapeutic environment for families with a child aged 0–11 years who is experiencing major behavioural, emotional and relationship difficulties.
Chapter 14: *Supporting the mental health and wellbeing of older people*	Older people in regional and rural communities will receive more support from services located in regional centres through home visits, clinic visits and telehealth. Appropriate referral pathways and community supports will be based on each person's location and ease of access to services.

Relevant reforms	Benefits for regional and rural communities
Chapter 15: *Responding to trauma*	Regional and rural communities will benefit from mental health services trained in trauma-informed care. Mental health professionals working in these settings will receive additional training and support, including digital access to trauma specialist expertise, secondary consultation and peer workers.
Chapter 17: *Collaboration for suicide prevention and response*	The Commission recommends a range of steps to build on its interim report recommendation 3 on suicide prevention and response. Local communities will receive free, online evidence-informed 'community gatekeeper training' for Victorians to develop suicide awareness and prevention skills. A community grants program will support suicide prevention activities that are tailored and responsive to local needs. There will be a particular focus on enabling culturally safe 'community gatekeeper training' for Aboriginal people, and co-producing an aftercare service for LGBTIQ+ people following a suicide attempt. Rural and regional high-risk Victorian industries, such as farming, will receive support to invest in workplace suicide prevention and response programs.
Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress*	A new consumer-led agency, and the new Mental Health and Wellbeing Commission, will use digital capabilities and offer online resources, information and supports to consumers in regional and rural Victoria. The agency will have a virtual platform to ensure consumers living in rural and regional Victoria can find vital resources and supports in one place. It will be easier for people with lived experience of mental illness or psychological distress living across Victoria to: • have their perspectives and experiences heard • participate in developing and delivering mental health and wellbeing services • access resources and supports, including peer networks.
Chapter 19: *Valuing and supporting families, carers and supporters*	Families, carers and supporters who are more distant from services will feel more valued and supported in their roles. They will also have better access to appropriate information to help them care for their loved ones. New family and carer-led centres (with physical and online access) will provide tailored information about the supports, services and referral pathways available in their region. Young carers in rural and regional areas will receive targeted support through new co-designed programs, with consideration of diverse needs for Aboriginal communities, culturally diverse communities, and LGBTIQ+ communities.
Chapter 20: *Supporting Aboriginal social and emotional wellbeing*	Building on the interim report's recommendation 4 which supports Aboriginal social and emotional wellbeing, additional funding will be allocated to support culturally appropriate, family-oriented, therapeutic care. This includes a service for infants and children who require intensive social and emotional wellbeing supports.
Chapter 21: *Responding to the mental health and wellbeing needs of a diverse population*	People from diverse communities will be able to access better mental health information. Victorians in regional and rural communities, regardless of first or preferred language, hearing, literacy or neurocognitive ability, will have access to appropriate mental health information and means of communication. Digital technologies will support the delivery of accessible, confidential, timely and user-centric language service delivery for all communities. Local communities will receive support to navigate the mental health and wellbeing system.

Relevant reforms	Benefits for regional and rural communities
Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance use or addiction*	Emergency and crisis services suitable for mental health and alcohol and other drug treatment will be accessible in every region. In addition, all mental health and wellbeing services, including community-based services, will ensure that consumers in rural and regional communities living with mental illness and substance use or addiction can access integrated treatment, care and support. A new statewide specialist service will support education and training initiatives for a broad range of practitioners and clinicians, and provide secondary consultation to mental health and wellbeing and alcohol and other drug practitioners.

Collectively, the Commission's recommendations will deliver an integrated mental health and wellbeing system that responds to the needs of all Victorians, and will have particular benefits for communities that currently face barriers to access. In addition, the Commission recommends new approaches to funding, implementing digital reforms, and attracting workers to target the specific needs of rural and regional communities.

24.7.2 Funding regional services to support rural communities

The Commission's recommendations will achieve a networked approach to service delivery in rural and regional areas, supporting effective collaboration and coordination between services, and allocating funding that recognises the costs of delivering high-quality services in rural and regional areas.

In the future mental health and wellbeing system, services will function in a more integrated way. Promisingly, many models that support remote service delivery from regional and/or metropolitan centres already exist in health services. The Commission's recommendations are designed to support this networked approach, to ensure all Victorians can receive high-quality and innovative treatment, care and support.

Statewide services and Area Mental Health and Wellbeing Services will provide more inreach support (including primary and secondary consultation) and consultation–liaison support to Local Mental Health and Wellbeing Services. In rural and regional Victoria, this model will mean that Area Mental Health and Wellbeing Services located in regional centres, in conjunction with statewide services, will provide inreach support to more geographically isolated or small rural communities This includes providing services through small rural health services, community health services and bush nursing hospitals. Inreach support will be provided to rural and regional services via digital modes of service delivery, providing consumers with greater access and choice over the treatment, care and support they seek.

The Department of Health will also ensure that funding allocations capture the additional costs associated with:

- services located in regional centres providing inreach and primary consultation to rural communities face-to-face and through digital technologies
- adequate resourcing and sustainable ways of working for staff providing inreach support
- attracting and retaining visiting specialist professionals from metropolitan areas to provide sessional services to rural and regional communities

Building on these reforms, the Commission has also recommended a more regional approach to commissioning mental health and wellbeing services in Chapter 5: *A responsive and integrated system*. The establishment of eight Regional Mental Health and Wellbeing Boards will support funding decisions to occur close to communities, informed by the specific needs and preferences of individuals in each region, including in rural and regional communities.

The implementation of activity-based funding,[324] recommended in Chapter 28: *Commissioning for responsive services*, will help redress the inequitable distribution of resources by allocating funding based on each individual consumer's needs and preferences. Similarly, the implementation of more flexible funding approaches, including block funding[325] for smaller providers and capitation funding,[326] will support providers to respond to the unique needs of their communities.

The Department of Health will also recognise the additional costs of delivering services in rural and regional areas by providing additional funding for rural and regional services. One way this can be achieved is by providing additional funding, through a 'loading' or 'adjustment', to the activity-based funding price paid for consumers living in rural and regional areas.

The use of funding loadings, or top-up payments, is consistent with other approaches that recognise additional costs in activity-based funding models. For example, the Independent Hospital Pricing Authority acknowledges additional costs of regional and rural service provision in the national activity-based funding model by providing additional funding for services provided to people living in rural and regional areas.[327]

Similarly, the Department of Health recognises the additional costs of delivering other health services to Aboriginal people, by applying a 30 per cent loading to the price it pays to health services.[328]

These reforms will help ensure that people living in rural and regional areas can access the mental health and wellbeing services they need, when and where it would make the most difference to them. Rural and regional service providers will be encouraged to work together in partnership, with appropriate resources to respond to the unique needs and preferences of their communities.

24.7.3 Accelerated digital service delivery and innovation

Given the potential benefits of technologies to improve access to services, rural and regional communities need support to quickly adopt and grow digital service offerings.

In Chapter 34: *Integrating digital technology,* the Commission recommends creating a digitally-integrated mental health and wellbeing system. This includes new minimum digital service requirements for publicly funded mental health and wellbeing service providers; new funding and regulatory settings to support the adoption of new technologies; and support for consumers to increase their access to devices and data, and improve their digital literacy, where needed. The Commission believes that these statewide reforms will improve all consumers' access to digitally integrated services, regardless of where they live, and in line with their preferences.

All public mental health and wellbeing services need support to build their digital capacity, but challenges in accessing services and expertise in rural and regional Victoria mean that digital service delivery is particularly important in these communities. This need, coupled with the technological challenges and limitations identified, has led the Commission to conclude that the rollout of the proposed digital reforms should start in rural and regional Victoria.

The Department of Health should work with interim regional bodies (or Regional Mental Health and Wellbeing Boards once established) to select two trial sites for digital investment and innovation in rural and regional Victoria in the first two years of reform.

To do this, the department should:

- select the appropriate trial sites in line with the recommended criteria below
- provide selected sites with digital capability funding to support them to work with Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services to build digital capacity and innovation.

The Commission recommends that the department selects two trial sites that have the baseline capacity and resourcing to immediately begin implementing the proposed recommendations. Therefore, they should have:

- a reasonable level of ICT infrastructure already in place to deliver digital services
- staffing capacity and digital literacy skills to realise innovations quickly
- fairly well established Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services that can participate in the partnership.

In addition to the capability funding, the trial sites should be provided with support and funding to ensure they are properly resourced to deliver the reforms, without creating additional burden, and to support timely implementation. This may include funding for administrative staff, or in-kind support. The department should work with each trial site to determine the support required.

The Commission understands that people do not necessarily want digital technology to replace face-to-face care. Technology should augment and improve usage of services and supports, but it should not be the sole solution to the challenges that rural and regional communities face in accessing services and expertise.

Implementation approach in the two trial sites

Local Mental Health and Wellbeing Services, Area Mental Health and Wellbeing Services and community members are best placed to identify their specific service needs, the ICT infrastructure required to meet them, and to develop new digital services that deliver on these requirements. However, a coordinated approach needs to be taken to ensure that investment is optimised, and there is consistency in digital service offerings across the region, and the state more broadly.

Each trial site should work with their Local Mental Health and Wellbeing Service and Area Mental Health and Wellbeing Service, community members and consumers and academic leaders to determine priority areas for capability fund investment and innovation. Together, they should:

- complete a digital maturity assessment—with support from the Department of Health—to identify current digital service gaps, ICT infrastructure needs and areas for priority investment
- develop a comprehensive implementation plan that sets out digital opportunities, the planned investment and implementation pathway to realise these opportunities, and targets and metrics to track implementation progress and the service delivery outcomes. The plan should consider:
    - how to support regional centres to provide more inreach and primary consultation to rural communities
    - the needs of local communities (for example, bushfire trauma and recovery mental health programs) or diverse groups (such as rural and regional Aboriginal communities, LGBTIQ+ communities, and refugee and asylum seeker communities) that could be addressed through innovative digital programs.
- administer the digital capability funding to deliver the plan
- monitor progress of the plan, including regular updates to the department
- work with the department to evaluate the effectiveness of new digital innovations, with a view to extending promising innovations more widely across the state.

Urgent upgrades to digital infrastructure

Trial sites should ensure that investment prioritises upgrades to service providers' digital infrastructure, so they can implement the new digital service requirements outlined in Chapter 34: *Integrating digital technology*. This will also ensure that regional services have the foundational infrastructure needed to establish and deliver other innovative digital mental health and wellbeing services in the future.

The investment must also address the current connectivity or privacy challenges that some rural and regional Victorians experience when trying to use telehealth services. All Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services should have the technology and infrastructure necessary to offer telehealth and digital service facilities for consumers who wish to use them. This includes people who are unable or do not wish to do so at home, due to internet connectivity or privacy concerns. The facilities should be therapeutic and give people privacy. New digital support packages recommended in Chapter 34 will also help consumers to access digital services from home if they wish, where they do not have access to appropriate devices or data.

As stated in Chapter 34, the Department of Health should work closely with each trial site to ensure that new digital infrastructure, services and innovations align with minimum digital requirements, and there is a level of consistency in the products and offerings. This will ensure that consumers can access the same level of treatment, care and support, regardless of their location, and that investment is scalable.

The approach to the statewide rollout of Orygen's Moderated Online Social Therapy (MOST) digital program across all state-funded child and adolescent youth mental health services and headspace is one model that could be considered.[329]

Collaboration to deliver innovative digital delivery programs

The upgrades to service provider ICT infrastructure will support the delivery of digital service offerings. They also provide the opportunity to establish, test and grow digital innovation.

Trial sites should support service providers, consumers and innovators to design, develop and trial new digital programs and innovations designed to directly address the needs of the local community.

In Chapter 36: *Research, innovation and system learning*, the Commission recommends giving more support to Regional Mental Health and Wellbeing Boards and local services for innovation. Networks of clinical academic experts, innovators and lived experience experts will provide expertise, support and resources to develop and test new ideas, and translate promising approaches into practice. The Department of Health will be responsible for evaluating their effectiveness and enabling rapid uptake of effective approaches, so that they are widely available across Victoria, including to consumers in rural and regional areas.

24.7.4 Attracting and retaining mental health workers

There are many complex barriers to ensuring adequate supply of the mental health workforce across rural and regional areas of Victoria.[330] The Commission's recommended approach to workforce planning, as outlined in Chapter 33: *A sustainable workforce for the future,* will introduce measures to attract, support and retain workers where they are needed most. Having diverse professional expertise available to meet the needs of all Victorians, regardless of where they live, will be essential to realising the Commission's vision.[331]

As discussed in Chapter 33, the Victorian Government does not hold all the levers that influence workforce supply, distribution, retention or experience in rural and regional Victoria. To create sustainable workforce reforms, the Department of Health will need to work with many stakeholders to ensure the mental health and wellbeing system supports development of a sufficiently diverse and skilled workforce in rural and regional areas. Collaborative activities and targeted partnerships are needed with many parties including the Commonwealth Government, professional regulatory and representative bodies, and education and training providers, as well as services and other stakeholders across Victoria.

Regional Mental Health and Wellbeing Boards will help coordinate regional workforce planning to ensure a suitably diverse workforce that is reflective of the communities they serve. Workforce planning must consider population needs and how to distribute skills and expertise equitably across the region. Priority should be given to initiatives to attract, recruit and retain specialist capability in responding to consumers with the highest intensity support needs.

In Chapter 33, the Commission considers challenges of workforce supply and demand that persist, despite reform efforts at a state and national level over several decades. Many approaches have been tried to improve workforce distribution, and the Productivity Commission did not identify in its *Mental Health Inquiry Report* 'severe drawbacks' to the wide array of initiatives.[332] This suggests there is no clear solution, but that a range of different strategies can be beneficial.

It is the Commission's view that concrete, multifaceted and complementary incentives are necessary to attract and retain a mental health workforce with the capabilities and expertise to meet the needs of communities in rural and regional areas.

A new Mental Health Workforce Rural Incentive Scheme

Attracting and retaining healthcare workers in rural and regional areas is a longstanding challenge in Australia and internationally. A wide range of health workforce retention measures and incentives have been employed, ranging from coercive approaches—such as restricting the location of practice, or making a period of rural service a requirement of professional registration—through to rewards for extended periods of service in rural and regional communities.[333]

The World Health Organization has examined interventions that have been used around the world to reduce inequitable workforce distribution. It identified a diverse range of approaches that use workforce education, regulation, financial incentives, and personal and professional supports.[334]

Examples of evidence-based interventions include:

1. pre-vocational education interventions, such as: prioritising rural and regional students for tertiary places;[335] tertiary education and training located in rural and regional settings; [336] bursaries and scholarships;[337] rurally-oriented theoretical content of training curriculum;[338] clinical placement or rotations in a rural setting;[339] supported postgraduate pathways with flexible entry and exit points;[340] and bonding schemes (providing financial study support linked to agreement to work in rural settings)[341]
2. post-vocational education interventions, such as: training and research fellowship programs;[342] salary loadings, salary packaging or paying a 'rural allowance';[343]and specific retention bonuses based on length of stay[344]
3. personal and professional supports, such as: providing, clear supported career pathways;[345] supporting continuing professional development;[346] providing regular specialist outreach services;[347] providing periods of time-off relief (weekends/holidays/sabbaticals);[348] and addressing family and lifestyle issues (providing flexible working schedules, child-minding services, subsidised schooling, accommodation, or access to recreational facilities).[349]

While state and federal governments have trialled attraction and retention interventions across these domains, most programs have focused on leveraging regulatory requirements and financial incentives. For example, under the Commonwealth's *Stronger Rural Health Strategy*, newly arrived overseas-trained medical practitioners are required to work up to 10 years in under-served regional or rural communities for professional registration and eligibility to bill Medicare.[350]

International recruits account for a higher proportion of GPs in regional and remote Australia.[351] However, the Productivity Commission concluded that expansion of this type of intervention has substantial limitations:

> Expanding [international recruitment] much further is difficult because additional supervision and support is often needed to assist overseas-trained medical practitioners to align with Australian clinical practices and understand the local culture of the people they are there to help.[352]

Financial incentives can be an important component of effective schemes. Remuneration has been rated by some health professions as the most important intervention to motivate attraction and retention in those areas.[353] The Australian National Audit Office assessed such incentives as important to the viability of regional and remote health practice in Australia.[354]

The Productivity Commission concluded that offering higher levels of remuneration is likely to be an effective way to attract healthcare professionals to work outside metropolitan areas:

> State and Territory Governments also have a financial lever through their funding of positions for health workers in public sector providers ... the Productivity Commission has recommended an expansion of services to fill major gaps in available care, which would require public sector providers to hire more health professionals outside major cities. If the funding flows, it is likely that—with the existing incentives and other initiatives—the workforces would respond.[355]

A number of financial incentive programs have been successful. A New South Wales bonding scheme for postgraduate medical students showed an increase in the proportion of workers who remained working in rural areas.[356] Another Australian program increased retention rates of long-serving rural doctors by 86 per cent.[357]

The Commonwealth's Stronger Rural Health Strategy includes a range of incentives, targeted funding and bonding arrangements for doctors, nurses and allied health professionals in rural and remote communities across Australia.[358] The *Workforce Incentive Program* provides financial incentives to support general practices to engage the services of nurses, Aboriginal health practitioners and health workers, in addition to eligible allied health professionals.[359]

Other federal funding initiatives include the *Rural Health Outreach Fund*, to improve access to medical specialists, GPs, allied and other health professionals in rural, regional and remote areas of Australia. Delivery of mental health services is one of four priorities of the program, with funding distributed through state and territory agencies.[360]

Internationally, evaluations of the effectiveness of financial incentive programs are mixed. One systematic review indicated that the majority of programs were associated with increased uptake of rural jobs, but this was not universal.[361] Another found substantial evidence for the effectiveness of financial incentive programs for workforce attraction to rural areas, but more limited impact on long-term retention.[362] The Productivity Commission concluded that while there is little rigorous evaluation, payments in some programs are sufficiently large that 'it would be surprising if they did not have some impact'.[363]

Beyond financial incentives

The most effective incentive schemes take a multifaceted approach to both attraction and retention of practitioners over the long term, particularly for specialist practitioners. As one systematic review concluded, 'multidimensional programs appeared to be more successful than those relying on financial incentives alone'.[364]

In particular, the Productivity Commission reported 'evidence that health professionals are more likely to work in regional and remote locations if they did their training there, or had resided there prior to training elsewhere'.[365]

In 2018–19, the Commonwealth Government invested $95.4 million over four years to set up the Murray–Darling Medical Schools Network, as part of the 'train in the regions, stay in the regions' program under the *Stronger Rural Health Strategy*.[366] The Network consists of five rurally based school programs in the Murray–Darling region of New South Wales and Victoria (including Monash University in Bendigo and Mildura, and the University of Melbourne in Shepparton). The first students commenced their training in 2019.[367] Since 2019, La Trobe University has been funded under the Rural Health Multidisciplinary Training Program 'to establish a new University Department of Rural Health to increase clinical training opportunities for nursing and allied health students in rural Victoria'.[368]

After initial training, strategies are needed to create conditions for, and access to, continued professional development. This could involve tailored mentoring and professional development activities. For example, in Queensland, a continuing professional development program for medical doctors (consisting of tailored continuing education workshops with subsidised travel and accommodation costs, locum support and/or locum rebates) had a positive impact on doctors' confidence in practising in rural and remote locations and the alleviation of professional isolation, as well as on their intention to remain working in rural and remote areas.[369]

One longitudinal study of the Dr DOC (Duty of Care) program that provides social and psychological support and practical interventions for rural GPs found that it helped to reduce intentions to leave rural practice, decrease work-related low morale and distress, and significantly improve doctors' perceived quality of work life, personal mental health and wellbeing.[370]

A retrospective review published in 2019 considered Australia's heavy reliance on overseas medical practitioners in rural communities, and noted the importance of planning and providing access to professional development and career supports in these localities:

> **Increasing the locally trained generalist rural workforce requires sustained policies, enrolling rural-origin students into medicine, providing ongoing rural training opportunities, promoting generalist medical careers and building sustainable rural working conditions.**[371]

The evidence indicates that 'bundled' incentive programs that package financial, accommodation, educational and family-related incentives together are most likely to be effective in retaining practitioners in rural and regional areas.[372] Combining financial incentives with personal and professional supports—such as accommodation costs, leave and improved working conditions—over the medium-long term appear to be most impactful.[373]

The Commonwealth Rural Health Outreach Fund comprises both targeted financial incentives and professional supports. Delivery of mental health services is one of four priorities of the program, with funding distributed through state and territory agencies.[374]

The Health Workforce Scholarship Program provides funding for postgraduate studies for health professionals (including doctors, nurses and allied health professionals) working in rural and remote areas. The program is delivered through state and territory rural workforce agencies.[375]

Professional and representative bodies made a range of proposals to the Commission about improving workforce attraction and retention, particularly in rural and regional areas (refer to Box 24.3). The Australian Psychological Society told the Commission that programs that provide incentives for mental health workers to live in rural and remote locations would address some access inequity issues.[376] It recommended 'developing a well-supported rural pipeline to support rural students through their psychology training'.[377]

Box 24.3: Examples of attraction and retention incentives proposed by professional and representative bodies

The Australian Services Union reported that members sought greater investment in job security and more attractive salaries for mental health workers.[378] The Health and Community Services Union submitted that workforce supply strategies must consider pay and conditions, and that specific financial incentives must be designed to attract mental health workers to rural and regional Victoria.[379]

The Royal College of General Practitioners suggested providing GPs with incentives, and access to ongoing and advanced mental health training and education, that mitigate the deterrents of financial cost and time away from practice.[380]

The Australian Nursing and Midwifery Federation (Victoria) called for funding of incentives to recruit mental health nurses, nurse practitioners and nurse navigators to rural and regional general practice and community-based programs, and for mental health–specific continuing professional development of nurses and midwives practicing in mental health in rural and regional areas.[381]

The Australian Psychological Society proposed the implementation of a rural pipeline approach 'that includes mandated places for rural students in psychology programs, funded rural placements, scholarships, supported rural internships and registrar opportunities'.[382] It also recommended 'Higher Education Contribution Scheme exemptions for rural and remote practice, implementing financial incentives for rural psychologists who work under Medicare'[383] and implementing incentive packages to attract psychologists to rural and remote schools.[384]

Multiple research reviews emphasise the need for meeting personal and family needs, as part of a 'bundled package' of incentives. One review of international literature concluded:

> As professional and personal needs change over time, other interventions are needed to support the remote practitioner, such as ensuring that financial incentives, including salary loadings or retention bonuses, are commensurate with the job. However, these are insufficient on their own and need to be part of a customised bundle of incentives that might include a retention bonus, continuing professional development opportunities, 'time out', psychological support and/or family support, such as educational cost support for children.[385]

The Commission recommends that the Department of Health develop a Mental Health Workforce Rural Incentive Scheme. The scheme design should take account of the future role of Regional Mental Health and Wellbeing Boards and be undertaken in consultation with the Commonwealth, relevant professional and workforce bodies, regulators, unions and industrial bodies, and other stakeholders.

The Mental Health Workforce Rural Incentive Scheme should focus on existing and emerging workforce supply gaps for clinical, therapeutic and specialised practitioners in rural and regional settings. It should initially target workers with advanced skills in working with people living with the highest intensity support needs as an urgent priority. On an ongoing basis, it should take both a strategic view and respond to local requirements. This must include the workforce needs of all publicly funded mental health and wellbeing services, including those operated by non-government organisations.

The department could consider the value of local training and career opportunities to attract motivated workers, and encourage their commitment to rural and regional settings. Attracting and developing people with skills in clinical and professional practice leadership will be important for providing supervision and support. Particular skills and expertise to be targeted in priority recruitment initiatives are discussed further in Chapter 33: *A sustainable workforce for the future*.

Mental health practitioners at all levels can play important leadership roles, working across disciplines and service functions, to foster cultures of continuous learning and development of professional practice and service delivery, both within and across services. The Mental Health Workforce Rural Incentive Scheme could seek to attract, develop and reward experienced professionals with the skills to lead interprofessional reflective practice and professional practice development activities.

Wherever possible, attraction initiatives should support professional and peer networks within and between services, or through close linkages to regional centres providing inreach supports to rural communities. Clustering positions could mitigate risks of professional isolation, and be a valuable step in developing a specialist mental health workforce in rural and regional settings. Combating professional isolation by reimbursing the cost of travel to training locations and meeting with peers, is a related component of many other state and federal schemes.[386]

In addition to providing professional pathways, the Victorian Government may wish to consider embedding the use of financial and professional incentives into the scheme.

These could include:

- salary loadings, with additional loading for length of stay
- accelerated career advancement opportunities
- access to additional continuing professional development leave, including the costs of travel to attend professional development programs
- access to research grants and projects focused on responding to local needs and priorities, offered in partnership with regional educational institutions
- access to specialist communities of practice and peer professional support networks.

Incentives should be designed to attract existing, highly experienced and highly trained mental health professionals to fill existing gaps in rural and regional areas, as well as suitable graduates. They should support pathways for more people to work in mental health and wellbeing services—both people already based in rural and regional areas (for example, those working in private practice), and others who may be thinking about moving there. These incentives might include training, professional development and career change supports.

Broader attraction and retention initiatives

The Mental Health Workforce Rural Incentive Scheme will complement a range of other workforce development measures recommended by the Commission to build the future workforce across the state, including in rural and regional areas. While the main focus should be on building and sustaining a workforce in rural and regional areas, additional measures to supplement this workforce should also be pursued by the Department of Health, in collaboration with Regional Mental Health and Wellbeing Boards and services.

As identified above, regional areas may continue to see increasing levels of post-COVID-19-pandemic migration from metropolitan Melbourne. This presents an opportunity to pursue community-level strategies to make rural regions a destination of choice.

The Grattan Institute estimates that about a quarter of jobs in the healthcare and social assistance industry are at risk as a result of the COVID-19 pandemic.[387] People in the hospitality industry will be affected the most.[388] The Grattan Institute advises that government policies in areas such as workforce participation can help create preconditions for sustained economic growth.[389]

There may be opportunities to access funding and short-term initiatives to build a more diverse mental health and wellbeing workforce, attracting people who are choosing to move to regional areas. This may include jobseekers with experience in people-facing industries who could be re-trained to undertake existing or new roles—such as wellbeing supports or other roles providing holistic care, and supporting people to access and navigate the system.

Workforce attraction strategies could include campaigns and initiatives designed to attract target workforces to a new lifestyle that fulfils people's growing needs for greater work–life balance and more connection with nature—that is, the desire for a 'tree or sea change'. The Department of Health should consider such initiatives in collaboration with Regional Mental Health and Wellbeing Boards and location-based campaign experts such as Visit Victoria.

In relation to its own recommendations for service expansion in its *Mental Health Inquiry Report*, the Productivity Commission observed that this 'would require public sector providers to hire more health professionals outside major cities. If [government stimulus funding] flows, it is likely that — with the existing incentives and other initiatives — the workforces would respond'.[390]

Research consistently indicates that health professionals who undertook their tertiary education and training in rural and regional locations, or lived there prior to training elsewhere, are more likely to work in rural and regional locations and remain there over the long term.[391]

The Commission considers that exploring opportunities to increase tertiary training locations in rural and regional Victoria, and prioritising students from rural and regional backgrounds for tertiary entry, are both evidence-based strategies to progressively grow workforce capacity and retention in these settings.[392] Early career rotations and rurally oriented educational curricula—such as those implemented in various jurisdictions for teachers, doctors and police—may also grow interest in rural and regional practice.[393]

In Chapter 33: *A sustainable workforce for the future*, the Commission observes that opportunities exist for national collaboration with the Commonwealth and professional bodies in relation to training approaches. The national Specialist Training Program provides vocational training for specialist registrars in settings outside metropolitan teaching hospitals, including regional, rural and remote, and private health services. The program 'aims to improve the quality of the future specialist workforce by providing registrars with exposure to a broader range of healthcare settings'.[394] The Specialist Training Program also 'aims to have a positive influence on future workforce distribution'.[395]

Partnerships between service providers and education institutions should also be actively encouraged to support rotations and placements in rural areas. A new research initiative between Barwon Health and Deakin University called Change to Improve Mental Health Centre of Excellence (CHIME) demonstrates how partnerships can support workforce retention and peer support, as well as support service improvement and innovation (Box 24.4)

The Commission also considers that Project Echo, a digitally enabled support network developed by Dr Ravi Bhat and colleagues and described in Chapter 7: *Integrated treatment, care and support in the community for adults and older adults* provides an exemplary model for how linkages between small rural hospitals and larger regional centres can support regionally based training. It also enables collaborative learning and peer support to people working in professionally isolated contexts.

> It's a highly structured way of learning, and everyone learns, everyone teaches, and that's the motto of the program. So, if you layered a clinical service degree with an educational model, you are much more likely to get synergies ... for capacity building, for fine-tuning the service so that at least people then don't have to travel all the way from, say, Broadford or Wallan to Shepparton, they could go to Kilmore or the nearest smaller rural hospital and have that linkage.[396]

Dr Bhat said the model proves it is possible to provide an environment and training programs in rural settings that are attractive to clinicians such as psychiatrists.[397]

These are currently isolated examples, and the Commission considers there would be great benefit in replicating this kind of approach in a systematic way, to support more widespread collaboration between services across the state.

Box 24.4: Change to Improve Mental Health Centre of Excellence (CHIME)

As described in Chapter 36: *Research, innovation and system learning*, Barwon Health has established a research partnership with Deakin University called CHIME (Change to Improve Mental Health Centre of Excellence) that uses the deep community connections of both organisations to improve access, services and outcomes for rural and regional consumers and carers in the Barwon area.

Initial areas of research for CHIME include better understanding risk factors for poor mental health for youth in the region, and evaluation of mental health telehealth services in response to the COVID-19 pandemic. Barwon Health plans to work with IMPACT (Deakin's Institute for Mental and Physical Health and Clinical Translation) to expand opportunities for consumers and carers across the region to participate in mental health clinical trials and enhance the Barwon community's access to world-leading treatment, care and support.

Associate Professor Steven Moylan, Clinical Director for the Mental Health, Drugs and Alcohol Services at Barwon Health explained:

> Our ultimate goal is to develop a service system that helps consumers feel better … the partnership will ensure consumers and carers across the Barwon area are able to both shape and access evidence-based and contemporary treatment and care. It will drive transformation in mental health services in regional Victoria.

A key goal of the CHIME partnership is to create opportunities for people working in service settings across the region to engage in research and evidence-based policy and practice. These opportunities are intended to enhance attraction and retention of clinicians and clinician-researchers into rural and regional service settings. Barwon Health anticipates that this will also enable more rapid implementation of best evidence-based practice across the region's health providers.

First steps to achieve this include the development of a flexible program of clinical research fellowships and research higher-degree scholarships for clinicians. CHIME will provide opportunities for clinicians at Barwon Health to undertake research or research training at Masters and PhD levels, while maintaining clinical experience and service delivery in rural and regional settings.

Source: RCVMHS, Informal discussions with Barwon Health; Barwon Health, CHIME (Change to Improve Mental Health Centre of Excellence), <www.barwonhealth.org.au/research/our-research/item/chime-change-to-improve-mental-health-centre-of-excellence>, [accessed 15 December 2020].

Dedicated resources could be provided to implement retraining and other pathway support programs to attract people to new mental health and wellbeing workforce roles. Such initiatives—developed through partnerships with Regional Mental Health and Wellbeing Boards, Working for Victoria, Local Mental Health and Wellbeing Services, Area Mental Health and Wellbeing Services and local education providers—should focus on new roles and existing workforce shortages. Priorities could include wellbeing support roles and, where required, clerical staff to relieve administration pressures for people engaged in delivering treatment, care and support.

It is the Commission's view that stronger partnerships with private providers could increase specialist supports Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services in rural and regional Victoria. The Commission understands there may be capacity in some specialist private psychology and psychiatric practices in metropolitan areas that, enabled through telehealth, could be used to increase sessional inreach support to rural and regional services.[398]

Regional Mental Health and Wellbeing Boards could trial incentives that encourage specialist private practitioners based in metropolitan areas to deliver inreach face-to-face and telehealth psychology and psychiatric services to rural and regional consumers of Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services.

In collaboration with the Collaborative Centre for Mental Health and Wellbeing, Regional Mental Health and Wellbeing Boards, Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services could use digital technology to create support networks for Mental Health Workforce Rural Incentive Scheme participants. Drawing on models such as Project Echo, online networks can be used to provide access to specialist communities of practice and peer professional support networks for participants in the scheme, and to help develop specialist capabilities in smaller service settings.

Workforce wellbeing and professional practice initiatives should be a strong focus of attraction and retention strategies. These supports are critical to sustain a workforce, including volunteers, in rural and regional settings. The expansion of senior educator positions across lived experience, clinical and allied health professions should strengthen regionally based training and professional development across services, as well as providing local, tailored programs to meet community needs.

Together, these targeted measures—new approaches to funding rural and regionally based Local Mental Health and Wellbeing Services and Area Mental Health and Wellbeing Services, using the full potential of digital technology, and building a supported and sustainable workforce—will ensure Victorians in rural and regional communities can more fully enjoy the benefits of the Commission's reforms; that is, they can access high-quality services in an integrated and responsive mental health and wellbeing system.

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Chapter 25

Addressing stigma and discrimination

Recommendation 41:
Addressing stigma and discrimination

The Royal Commission recommends that the Victorian Government:

1. fund and support the Mental Health and Wellbeing Commission (refer to recommendation 44) to work with a network of partners, including research organisations, to lead the design and delivery of anti-stigma programs that:
    a. continue on a long-term basis; and
    b. aim to reduce the impact of stigma in a range of settings including, but not limited to, healthcare settings, workplaces and schools.
2. design and deliver an anti-stigma grants program to:
    a. support community-led organisations and community members to deliver projects that challenge stigma in Victorian settings and communities; and
    b. focus, as an immediate priority, on communities and social groups at increased risk of stigma.
3. conduct a comprehensive evaluation of anti-stigma efforts to:
    a. develop evidence about effective ways to address mental health stigma across Victoria; and
    b. inform the design and delivery of anti-stigma programs.
4. support and establish mechanisms to:
    a. address systemic issues of mental health discrimination;
    b. enhance individual access to legal protection from mental health discrimination; and
    c. enable one or two independent legal services with a demonstrated connection or ability to connect with people with lived experience of mental illness or psychological distress to initiate legal claims, including test cases relating to systemic mental health discrimination.

25.1 Our shared responsibility to end stigma and discrimination

The Commission's reforms are guided by a desire to enhance the lives of people with lived experience of mental illness. Having the opportunity to fully and meaningfully participate in public life, free from discrimination, stigma or exclusion, is fundamental to mental health and wellbeing, and is a basic human right.[1] However, as highlighted in the interim report,[2] stigma, discrimination and prejudice remain pervasive and harmful influences on the lives of people living with mental illness or psychological distress and on the lives of families, carers and supporters.

As a community, we have struggled to understand or be compassionate about lived experience of mental illness, and the varying ways people experience mental health or psychological distress. This has meant that people with lived experience of mental illness have been excluded from society. Experiences of stigma and discrimination deprive people of their dignity and constrain opportunities to fully participate in society.[3]

Stigma and discrimination reinforce harmful perceptions that mental illness and psychological distress are not valid and cannot be managed.[4] Stigma and discrimination act as barriers to seeking mental health services and can adversely affect treatment, care and support provided.

Stigma causes people to avoid socialising with, employing or working with, renting to, living near, or providing services to, people with lived experience of mental illness or psychological distress.[5] In some circumstances, this behaviour amounts to discrimination. The impacts of social exclusion adversely affect people's mental and physical health, financial security, job security and social relationships.[6] As such, stigma and discrimination are both determinants and outcomes of mental illness and psychological distress.[7]

Confronting stigma and discrimination in the community is crucial to creating the basic conditions for the attainment of good mental health and wellbeing. Tackling stigma and discrimination, respecting the dignity of every person and ensuring equality, are collective responsibilities. Individuals, families, communities, schools, workplaces, service providers and government all have a role to play.

Fundamentally, people with lived experience must be given the resources and opportunities to take the lead in these efforts. Governments, services providers, workplaces and the general community have much to learn from the insights and experiences of people with lived experience and must be prepared to act on the advice of their leadership.

As detailed later in this chapter, stigma and discrimination are complex and pervasive, occurring and manifesting in a range of ways. While actions to address stigma and discrimination at an individual and community level are critical, the Commission recognises that broader structural reform is needed to address entrenched stigma and to end discrimination.

The Commission's vision for the future mental health and wellbeing system is designed to effect this structural change. In addition to the recommendations outlined in this chapter, the Commission anticipates that other recommendations included in the report that will support anti-stigma and anti-discrimination efforts are:

- the establishment of the Collaborative Centre for Mental Health and Wellbeing. As outlined in the interim report, the Collaborative Centre will play a key role in helping to demystify perceptions that perpetuate the stigma and discrimination that people living with mental illness continue to experience[8]
- developing system-wide roles for consumers, including key roles across the mental health and wellbeing system, and developing and supporting their leadership capabilities (refer to recommendation 28)
- facilitating the leadership of people with lived experience in decision-making processes about mental health policies and programs, by requiring that the Mental Health and Wellbeing Commission has at least one Commissioner with lived experience of mental illness or psychological distress, and one Commissioner with lived experience as a family member or carer (refer to recommendation 44)
- the establishment of a consumer-led agency to create opportunities to better understand the diverse, rich and powerful experiences of consumers (refer to recommendation 29)
- a focus on immediately reducing the use of seclusion, restraint and compulsory treatment (refer to recommendation 54 and 55), and increasing access to non-legal advocacy services and legal representation for people who are subject to, or at risk of, compulsory treatment (refer to recommendation 56)
- the development of a Victorian Mental Health and Wellbeing Workforce Capability Framework, in collaboration with people with lived experience, to support learning and professional development activities across the whole mental health and wellbeing workforce (refer to recommendation 58).

25.2 Defining stigma and discrimination

In this chapter, except for sections that discuss stigma and discrimination in general terms:

- **'stigma'** relates to the stigma associated with mental ill-health, unless otherwise specified
- **'discrimination'** relates to the discrimination associated with mental illness, unless otherwise specified.

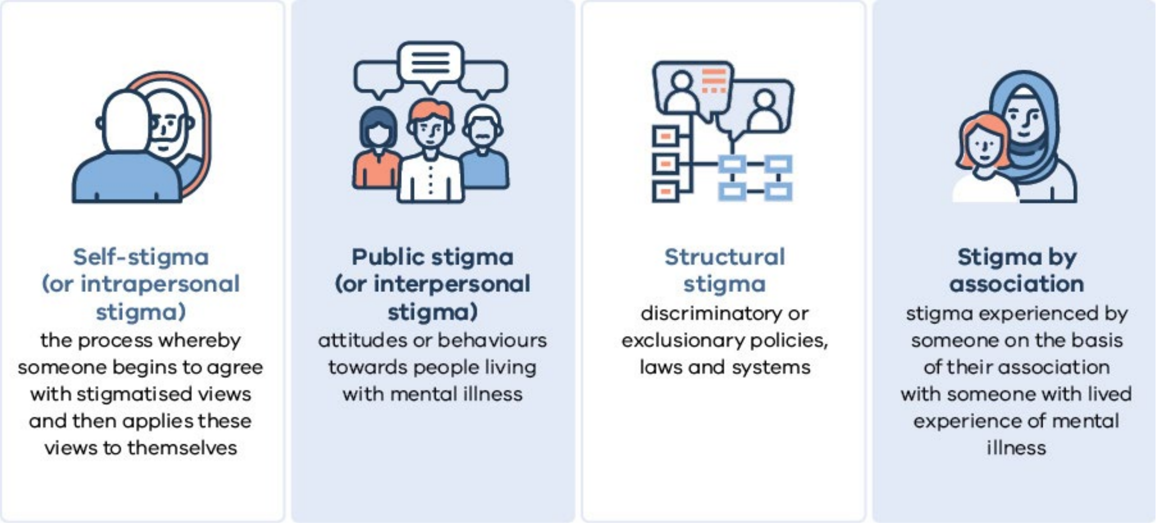
25.2.1 Defining stigma

The World Health Organization defines stigma as a 'mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society'.[9] In his foundational discussion of stigma, Erving Goffman described stigma as an 'attribute that is deeply discrediting' and that reduces the bearer 'from a whole and usual person to a tainted, discounted one'.[10] Stigma has also been described as the process of labelling differences, linking those labels to negative stereotypes, and shaming and 'othering' or devaluing individuals based on these stereotypes, which results in status loss and discrimination.[11]

Stigma is therefore a fundamentally social process—different characteristics or traits are not inherently negative; 'rather, through a complex social process, they become defined and treated as such'.[12] This process leads to social exclusion.[13]

As outlined in Figure 25.1, stigma occurs in four main ways. These different forms of stigma are interdependent and mutually reinforcing.[14]

Figure 25.1: Stigma occurs at four main levels



Self-stigma (or intrapersonal stigma)
the process whereby someone begins to agree with stigmatised views and then applies these views to themselves

Public stigma (or interpersonal stigma)
attitudes or behaviours towards people living with mental illness

Structural stigma
discriminatory or exclusionary policies, laws and systems

Stigma by association
stigma experienced by someone on the basis of their association with someone with lived experience of mental illness

Source: *Witness Statement of Dr Chris Groot*, 4 September 2019; *Witness Statement of Dr Michelle Blanchard*, 27 June 2019.

25.2.2 Defining discrimination

There are many definitions of discrimination, and the distinction between stigma and discrimination is not always clear. One view is that stigma relates to 'the attitudes or beliefs held by a person, whereas discrimination is behaviour or perceived behaviour'.[15] Another view is that the two concepts are interchangeable. One witness relayed to the Commission their perception that the impacts of stigma are often minimised, and that sometimes stigma is viewed as acceptable in a way that discrimination is not:

> As a cultural phenomenon, our society almost accepts stigma as being acceptable, but considers that discrimination is problematic and illegal. Society does not seem to consider that a consequence of stigmatising a cross-section of our community can lead to unlawful discrimination. A language change by governments and the media is necessary to change this stigma, as is calling out this negative behaviour as discrimination.[16]

At its most basic, discrimination refers to the prejudicial treatment of people based on their individual or collective characteristics. What makes a behaviour an instance of discrimination is not the mere presence of differential treatment, but rather, differential treatment that is worse for the people concerned than if they were treated in the same way as the broader population.[17] Discrimination results in an individual being excluded from participating in many aspects of society.[18] Discrimination is also sometimes described or understood as a manifestation of structural stigma (for further details, refer to section 25.2.3).

As one person told the Commission:

> Discrimination is real—you are treated as a second-class citizen if you have a diagnosis, and it's disgusting. This is done by services and the government.[19]

Box 25.1: *Equal Opportunity Act 2010* (Vic)

In Victoria, the *Equal Opportunity Act 2010* makes it unlawful to discriminate on the basis of 'disability' (which is defined to include a 'mental or psychological disease or disorder')[20] in certain settings, including health care, employment and schools. This can be through 'direct discrimination', such as when someone is treated unfavourably because of a personal characteristic like mental illness.[21] This kind of discrimination can involve a refusal to treat someone, provide them access to services or admit them to a school, because they have a mental health diagnosis.

The law also protects against 'indirect discrimination', where an unreasonable requirement, condition or practice disadvantages a person or group of people, based on a characteristic.[22]

Anti-discrimination law in Victoria goes beyond protecting individuals or groups, to providing a positive duty for organisations to eliminate discrimination.[23] This requires organisations such as schools, education providers and workplaces to eliminate discrimination as far as possible.[24]

The positive duty arises in response to discrimination occurring at an individual level, as well as structural or systemic levels.[25] Structural or systemic discrimination 'describes patterns or practices of discrimination that are the result of interrelated policies, practices and attitudes that are entrenched in organisations or in broader society'.[26] For people with lived experience, this can manifest in fewer workforce and leadership opportunities.

The Commission notes, however, that the *Equal Opportunity Act 2010* does not provide the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) with powers to enforce this duty.[27]

25.2.3 Structural stigma and systemic discrimination

Although stigma and discrimination are perhaps most readily considered as interpersonal, isolated experiences, it is clear that stigma and discrimination against people with lived experience of mental illness or psychological distress is entrenched and also occurs at a structural or systemic level.

Structural stigma refers to the 'societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing for stigmatised populations'.[28] As the Commission acknowledged in its interim report, the low priority given to mental health funding is a structural manifestation of the stigma associated with mental illness.[29]

Systemic discrimination 'describes patterns or practices of discrimination that are the result of interrelated policies, practices and attitudes that are entrenched in organisations or in broader society.'[30] People with lived experience face systemic discrimination in Victoria. Systemic discrimination is manifested in, for example, people with lived experience having poorer physical health and healthcare than other citizens.[31] The Victorian Mental Illness Awareness Council points to local evidence that their 'members who are labelled with SPMI [serious and persistent mental illness] are likely to die 30 years younger than the rest of the Australian community'.[32] The Commission has heard that the pervasiveness of systemic discrimination is compounded by the fact that this often renders it 'hidden'[33]—that is, those in society who are not directly impacted by it, are often 'blind' to it.[34]

25.2.4 Drivers of stigma and discrimination

In order to design and target interventions to prevent and address stigma and discrimination, it is critical to understand what 'drives' or causes stigma and discrimination to occur in the first place.

Stigma and discrimination are social processes that reflect and reinforce power imbalances across society between those with lived experience and those without. As Professor James Livingston, stigma researcher at Saint Mary's University in Canada notes:

> stigma reveals more about society than it does about individuals who carry stigmatized characteristics or persons who harbour negative beliefs about others. It sheds light on who in society has access to the power and privilege necessary to define rules and apply sanctions for violating them—those who do, become the beneficiaries of stigma; those who do not, become its subjects. In turn, the subjects of stigma are redirected on a path where their identities are engulfed, their relationships transformed, and the direction of their lives shifted because they have been marked by a stereotyped attribute.[35]

In her foreword to the *Like Minds, Like Mine National Plan 2003–2005,* Ms Mary O'Hagan MNZM, Manager of Mental Wellbeing at Te Hiringa Hauora, New Zealand, described the underlying reason for discrimination against people with lived experience of mental illness:

> People often say [discrimination] starts with fear, ignorance, misunderstanding, pity or malice. But these are just some of the clothes discrimination wears. Take off all the clothes and we are left with one thing; the devaluing of madness and the entwined assumptions that mad people are full of nonsense and incompetence.[36]

25.3 People with lived experience are stigmatised

There is longstanding ignorance about mental illness and the stigma that is experienced by people with lived experience of mental illness or psychological distress.[37] Historically, people with lived experience of mental illness or psychological distress were stigmatised and discriminated against in many ways,[38] including through institutionalisation, where people were locked away from their communities, often in brutal and inhumane conditions.[39] Despite decades of deinstitutionalisation, deeply held prejudices towards people with lived experience of mental illness or psychological distress and unfavourable treatment remain widespread.

In its *Mental Health Inquiry Report*, the Productivity Commission found that in Australia, most people with lived experience 'report experiencing stigma, although the degree, nature and experience of stigma varies by type of mental illness, age, gender and cultural background'.[40] In particular, people diagnosed with what was termed 'severe' mental illness are subject to high levels of stigma.[41]

Many witnesses with lived experience of mental illness or psychological distress relayed their experiences of stigma to the Royal Commission. It is clear that stigmatising attitudes and beliefs about mental illness are wide ranging.[42] They include beliefs that mental illness is a sign of personal weakness and 'not a real medical illness', and beliefs that people living with mental illness are dangerous and unpredictable.[43]

One witness reported experiencing the stigmatising—and false—narrative of 'you're weak'.[44] She also spoke of deeply rooted assumptions about people being incapable of making their own decisions once they had received a mental health diagnosis.[45]

Language used in relation to mental illness can perpetuate and reinforce stigma.[46] For example, diagnostic labels can affect the way people are perceived and treated, particularly by mental health practitioners.[47] There remains widespread perceptions that people diagnosed with borderline personality disorder are difficult and manipulative.[48] In a submission to the Commission, one consumer conveyed the following:

> The reason I resisted [dialectical behaviour therapy] is because it is associated with a Borderline Personality Disorder diagnosis. People diagnosed with BPD can experience a lot of stigma and discrimination within mental health services. For example, they're often unfairly characterised as being manipulative. I'm aware of this having spoken to clients I work with, so was resistant to the label being applied to me.[49]

Ms Janet Meagher AM, an advocate for people with lived experience, and former Mental Health Commissioner for the National Mental Health Commission, shared her own experiences of stigma and discrimination with the Commission:

> Many people who experience mental health issues are labelled impersonally as, 'a patient', 'a client' or 'the consumer' or have a diagnosis that represents only what is seen as their 'sick' or 'broken' parts. People see them not so much as a person, but more so as a diagnosis (e.g. 'a depressive', 'a schizo', a 'crazy one' … etc. etc.) and frequently as inherently dangerous and not to be trusted. This can lead to people being fearful or afraid when they come across people with mental health issues. I have experienced this fear first hand after people have become aware of my mental health status.[50]

One insidious and harmful aspect of stigma is that stigmatising attitudes held by the community can be internalised by people experiencing mental illness. That is, people with lived experience can adopt the prejudicial views held by others. Ms Erandathie Jayakody, witness, explained the burden and constant effort required to call out and reject stigmatising attitudes and discriminatory behaviour (refer to Box 25.2).

Box 25.2: The effect of prejudice, stigma and discrimination

'I have worked in the lived experience work-space for the past eight years, and you would be surprised by the things I hear. For example, "this is a very complex role. It is not suitable for someone with a lived experience", "people with a lived experience should be given part-time jobs not full-time jobs", "peer workers have high turnover rates" and "peer workers become unwell".

Such views are not acceptable. They come from the fundamental belief that people with lived experience are weak, incompetent and somehow "lesser" than other workers because of their mental health challenges.

Yet, people actually do not think twice before making such comments. These statements often go unchallenged in meetings. That is how blind we as a society are to overt stigma and discrimination. Those kinds of comments reinforce the sentiment that "people with mental health challenges are incompetent and are incapable and are weak". By not challenging these statements we continue to perpetuate that narrative. This narrative is incorrect …

> I have worked hard to reject the prejudice. But I am exposed to it all the time. Society tends to see people with mental conditions in a one-dimensional way, that is, it only sees the mental health condition (or probably more accurately, society's perception of mental health conditions). In a recent discussion about workforces a colleague said "personally I think people with a lived experience should be given part-time jobs not full-time jobs". I thought "oh wow, how could you hold that view?" and then immediately after I thought to myself, "oh yes, I did take a bit of sick leave last year". I am amazed how quickly I revert back to that 16 year old self where I think, "I'm weak". It is so quick. That is the effect of the prejudice, discrimination and stigma—that people with lived experience accept the prejudice as truth. I then have to pull myself up again, and reject the prejudice, which is exhausting. So much energy is spent doing a good job and managing a health condition and then on top of that you have to constantly challenge these prejudices with little support and not let it get to you.
>
> There is no understanding about how damaging these seemingly "insignificant" comments can be. It undermines a person's capabilities to work and limits their ability to reach their full potential. People begin to doubt themselves and it erodes their self-confidence. Not only is it a loss of opportunity and loss of potential at an individual level, but it is a loss for the organisation, the mental health sector and the community.'[51]

25.4 People with lived experience face widespread discrimination

Many people with lived experience of mental illness or psychological distress reported experiences of discriminatory behaviour, which, in some cases, left them socially and economically excluded from society.

The Victorian Equal Opportunity and Human Rights Commission (VEOHRC) is an independent organisation with responsibilities under Victoria's anti-discrimination and human rights laws. A core function of VEOHRC's role is resolving individual complaints of discrimination under the *Equal Opportunity Act 2010* which includes protections for people with 'mental health issues'.

Disability discrimination accounts for the largest number of enquiries and complaints that VEOHRC receives each year,[41] with mental health discrimination being a significant portion of these (refer to Table 25.1).[52] Between 1 July 2013 and 31 December 2019, 2,212 people made complaints to VEOHRC about discrimination based on disability. Of those, 472 people (21 per cent) made complaints of discrimination based on mental health.

Table 25.1: Number of disability complaints received by the Victorian Equal Opportunity and Human Rights Commission, by mental health status, Victoria, 2013 to 2019

Area	Number of disability complaints	Number of disability complaints–mental health	Proportion of mental health disability complaints
Employment	674	235	35%
Goods and services	1,005	163	15%
Accommodation	262	29	11%
Education	247	44	18%
Sport	19	1	5%
Clubs	4	0	0%
Local government	1	0	0%
Total	**2,212**	**472**	**21%**

Source: Victorian Equal Opportunity and Human Rights Commission, Resolve database, 24 March 2020.

Note: Collection period is 1 July 2013 to 31 December 2019.

Education complaints are generally made in the context of tertiary education. They typically concern students who experience difficulty completing course requirements because of their mental health, but 'are refused extensions or additional time to complete examinations'.[53] VEOHRC also received complaints by prospective students with a pre-existing 'mental health issue' who were denied access to a course or degree.[54]

Personal story:

Ruth

Ruth* is a peer researcher and consumer advocate living in Melbourne. Ruth grew up in a regional city in Victoria and is now in their mid-20s.

Ruth first experienced severe anxiety and depression at around 16 years old. At 19, they were diagnosed with an eating disorder, borderline personality disorder and were experiencing complex trauma. Ruth has a psychosocial disability and has been receiving support via the National Disability Insurance Scheme. On many occasions, however, Ruth has felt dismissed by mental health services as not meeting the eligibility criteria and has been declined mental health services in times of crisis.

> Services would say 'you're not early intervention, we can't help you', or 'you're not complex enough'. A lot of [Crisis Assessment and Treatment] teams just won't help me at all. And I've had a lot of hospital admissions, where they don't support me at all, and then just discharge me, only to still be in crisis.

Ruth has had some good experiences with services, for example at a Youth Prevention and Recovery Centre (YPARC) and the 12 months they spent at a youth residential rehabilitation program in Melbourne.

Ruth has felt discriminated against many times because of their mental health, including from people close to them, the media, and also from hospitals and mental health services. When Ruth was in the first semester of a course at a TAFE, it declined their requests for flexible learning options.

> I was in hospital for my mental health and was missing a lot of class and so I had to get special consideration, but they weren't really able to do much to help me. They're kind of like, oh well, you need to do this, it's a 'hurdle assessment', you need to do this assessment to continue the course. And they just weren't at all flexible. So I had to drop out of that course.

Due to the nature of Ruth's disability, it was difficult for them to complete practical assessments. However, Ruth said that the TAFE refused to reschedule, despite knowing about their disability. Ruth tried to negotiate flexible learning options and requested disability support through the student support services; however, they felt the TAFE lacked compassion or understanding about disability or mental health.

> So now I just feel like there is too much trauma associated with it to go back. I don't feel like I could handle a TAFE course, because of where I'm at, and because of what TAFE was like with supporting people like me.

Ruth did not finish the first semester of TAFE, and has tried to complete other education courses, including at university. Ruth describes being impacted so greatly by their experience at TAFE, that they have not subsequently been able to complete any tertiary education or certificates. As Ruth said, 'I dropped out of university another two times because of my mental health.' This has had a negative impact on Ruth's confidence and their mental health has deteriorated.

Ruth struggled to secure any full-time or ongoing employment, and was limited to casual work arrangements, a few hours a week, while remaining on the disability support pension. More recently, Ruth has gained additional casual work as a peer researcher and consumer representative. Ruth hopes for a future mental health system that is more responsive and caring for people experiencing psychological distress, particularly when in crisis.

> **I'm really passionate about ensuring safe and effective mental health care, and I'm starting to work in the lived experience workforce, and I'm really excited and passionate about that.**

Source: RCVMHS, *Interview with 'Ruth' (pseudonym),* November 2020.

Note: *Name has been changed to protect privacy.

This reflects what has been documented by the Victorian Mental Illness Awareness Council, which provides non-legal advocacy for people with lived experience:

> At universities, multiple VMIAC members have raised how there is a failure to make reasonable adjustments, and that these are often based on stigmatising statements and attitudes. For example, members who have gone through a mental or emotional crisis are often not given flexible learning options to re-engage with their university degrees. We also hear how young people are told that they should reconsider university, either by the universities themselves, or by clinicians involved in their care, because they are not considered competent or well enough to do so.[55]

In relation to 'the provision of goods and services, the most common complaints relate to income protection insurance'.[56] VEOHRC also commonly receives complaints about people with lived experience of mental illness or psychological distress being refused entry into public venues, often where the person seeking entry is in a state of distress.[57] Accommodation complaints typically relate to the denial of a rental property after 'an applicant has volunteered information about their disability', or revealed that they receive the disability support pension.[58] Complaints are also made about eviction, where a person is unable to pay rent because of their 'mental health issue'.[59]

In its submission to the Commission, VEOHRC emphasised that there 'is likely significant under-reporting of discrimination against people with mental illness'.[60] VEOHRC highlighted that complaints figures, when taken as a proportion of the Victorian population, are quite different from the proportion of the Victorian population experiencing mental illness:

> Given that one in five Australians experienced a mental or behavioural condition in 2017–18, there is likely significant under-reporting of discrimination against people with mental illness for a range of reasons.[61]

This observation has been made at the national level, with the Productivity Commission also concluding that 'it is likely that the number of people experiencing discrimination on the basis of mental illness greatly exceeds the number of complaints made'.[62]

National surveys of people with lived experience indicate a higher incidence of discrimination than is reflected in the number of complaints made to VEOHRC. For example, the *2010 Survey of High Impact Psychosis* study found that 37.9 per cent of respondents 'had experienced stigma or discrimination because of their experience of a psychotic disorder in the past year'.[63]

More recently, SANE's 2020 *National Stigma Report Card* found that, based on the *Our Turn to Speak* survey, Australians with 'complex mental health issues are commonly subject to pervasive, unrelenting, and impactful stigma and discrimination.'[64] Of those surveyed and who answered questions for the relevant life domain, in relation to the preceding 12 months:

- 95.6 per cent indicated they had experienced stigma and discrimination in relationships
- 60 per cent reported 'frequent' or 'very frequent' experiences of stigma and discrimination in health care
- more than 50 per cent reported 'frequent' or 'very frequent' experiences of stigma and discrimination in employment.[65]

25.5 Stigma and discrimination have profound impacts on people's lives

Stigma and discrimination undermine the dignity and wellbeing of people with lived experience of mental illness or psychological distress and unfairly limit their full participation in society. For people diagnosed with complex mental health issues, stigma and discrimination often pervade all aspects of life, including relationships, employment, healthcare services, mental health treatment, care and support services, housing, social media, welfare and social services, education and financial and insurance services.[66]

This has mental health and wellbeing consequences for people with lived experience. Stigma 'erodes confidence, damages self esteem and contributes to an overwhelming sense of isolation and fear'.[67] Stigma and discrimination can create or exacerbate mental illness and present barriers to accessing treatment and recovery.[68] People who are affected by stigma are more likely to withdraw from pursuing opportunities in the various domains of life.[69] For example, research indicates racism is associated with poor social and emotional wellbeing in Aboriginal young people, including anxiety, depression and suicide risk.[70]

Stigma and discrimination create and compound issues in other parts of people's lives. It has been found that 'experiencing discrimination can cause stress and anxiety and increase the risk of mental health issues, as well as lead to other forms of social disadvantage, such as unemployment, poor education and social isolation, and an increased risk of physical illness'.[71]

Stigma and discrimination are barriers to meaningful social and economic participation. Stigma and discrimination can reduce opportunities to make or maintain friendships, have intimate relationships, gain employment, be granted flexible work arrangements and receive adequate health care.[72]

The Commission has heard that social exclusion of this kind is very damaging for people's mental health, contributing to stress and depression, along with poor physical health.[73] It diminishes people's chances to lead successful and fulfilling lives through a lack of personal relationships that can be drawn on for practical, material and moral support to achieve aspirations. This consequence is described further in Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect*.

Ms Kristen Hilton, VEOHRC Commissioner, described the harm caused by stigma and discrimination:

> There is strong stigma associated with having [a] mental health condition. This stigma can lead to a misconception that mental health conditions are caused by a weakness of character, rather than an illness, or that people with mental health conditions are dangerous. This can cause shame, a reluctance to disclose a diagnosis and the perception that a person should be able to manage their condition on their own. … Stigma leads to discrimination and marginalisation, which can, in turn, affect peoples' economic, social and housing security, as well as their general health and wellbeing.[74]

This exclusion and disadvantage is compounded when more than one form of discrimination and stigma affects a person. For example, people living with mental illness and substance use or addiction often endure 'double-stigma' or 'double-discrimination' in their daily lives.

As outlined in Chapter 22: *Integrated approach to treatment, care and support for people living with mental illness and substance abuse or addiction*, exposure to this dual form of prejudice can make it especially difficult for people to participate in society and receive proper treatment, care and support in the mental health system. People living with mental illness and substance use or addiction are also frequently blamed for their circumstances, with prevailing sentiment in the community being that addiction is 'self-induced'.[75] Such a reaction dismisses and diminishes the hardships that may have led to a person's use of or addiction to alcohol or other drugs. As Mr Patrick Lawrence, CEO of First Step, explains:

> There can be judgment directed to people who appear to not be investing any energy into their life and making improvements. The strategy I often employ is to have direct discussions with people which tends to challenge stigma. I often explain that many of the people that may be stigmatised are likely to have been neglected or abused when they were children. Our society does not tolerate the abuse or neglect of children and has a visceral reaction to this. However, the people who are most in need of the support of organisations like First Step are these abused children who are now 'grown up'.[76]

There remains a lack of comprehensive and current data on the nature, extent and impacts of stigma and discrimination experienced by people living with mental illness or psychological distress in different domains of life. While research has been conducted to understand mental health stigma, it is not comprehensive. As highlighted in SANE's 2020 *National Report Card*, 'few Australian research or practice initiatives have specifically targeted stigma and discrimination for people with complex mental health issues'.[77] Consequently, the impacts of mental health stigma and discrimination remain poorly understood.

25.5.1 Experiences of consumers seeking mental health treatment, care and support

Many people shared with the Commission their experiences of stigma and discrimination within healthcare settings, including mental health settings. Consumers spoke of being ignored, judged, dismissed,[78] undermined and not believed,[79] particularly in relation to their personal history and treatment needs[80]—and often during periods of crisis.

There are many consequences that arise from this stigma and discrimination. Research indicates that stigma within healthcare settings is a deterrent to seeking care.[81] People described being dehumanised and devalued by health professionals, being excluded from decisions about care, being threatened with coercive treatment, and being spoken to in a demeaning manner.[82] These experiences often reflect a lower quality of care,[83] breaches of consumer human rights,[84] and poorer health outcomes:[85]

> These mental health services render me and my actions as non-compos mentis. I can sign a contract. I can run a business. I can have a family. But I am considered incapable of making decisions about my treatment, and I am strapped to a bed.[86]

Figure 25.2: Experiences of consumers seeking mental health treatment, care and support

> I have experienced so much shame and stigma calling mental health triage helplines and attending emergency rooms, that I now have a fear of using these services unless I have already harmed myself. In my experience, services are incredibly hard to gain access to, and fall short of meeting my needs when I am experiencing emotional distress.
>
> I have had too many experiences of calling triage for support and being made to feel ashamed or like I was just seeking attention. I have only ever called triage when I was in genuine distress and this distress was often increased when I was made to feel ashamed by the person on the other end of the phone for reaching out for support. I now choose not to reach out to triage services to seek support myself ...[1]

> I was patronised and blamed for my experiences. For example, when I disclosed the dark space I was in, the therapist rebutted 'well, with an attitude like that ...'. As a result of this, I didn't get the help I needed and ended up getting worse[2]

> The clinical system lacks the basic human needs—when you enter the clinical system you lose your right to make decisions, but you also don't get the basic things people need for healing. You can't talk to anyone. There are no activities that are interesting or healing—a therapy dog once a week is not an 'activity'. You enter with the clothes you are wearing and often stay in those clothes during the whole admission. You don't get to make choices about food, your toothpaste or shampoos.[3]

> When I asked for a female doctor, because I had women's health issues that I wanted to discuss, that was refused. They said that my case was 'too complex' for anyone else to take over. I asked to be shifted to another hospital to be under a female treating team, but they refused. As a result, my physical health was ignored.[4]

> Sometimes you have to ring triple zero just to get services to arrive. Police arrive, and then often you're treated worse than perpetrators in the justice system.[5]

Sources: 1. *Witness Statement of Rachel Bateman (pseudonym)*, 16 June 2020, paras. 20–21; 2. Victoria Legal Aid, *Your Story Your Say, Story #26*; 3. Victoria Legal Aid, *'Your story your say: Consumers' priority issues and solutions for the Royal Commission into Victoria's Mental Health System'*, 2020; 4. Victoria Legal Aid, *'Your story your say: Consumers' priority issues and solutions for the Royal Commission into Victoria's Mental Health System'*, 2020; 5. *RCVMHS, Preston Community Consultation — May 2019.*

The effect of these misconceptions was described in the evidence of Dr Chris Groot, Lecturer at the Melbourne School of Psychological Sciences, University of Melbourne:

> there is a common perception in mental health workers that people labelled with [borderline personality disorder] are manipulative and may not actually be at risk of suicide when they present as such to crisis services; however, they are 45 times more likely to die by suicide than people in the general population.[87]

Stigma and discrimination can also result in 'diagnostic overshadowing', where health professionals incorrectly attribute physical symptoms to mental illness, leading to delays in access to crucial physical health treatment.[88] This is in part reflected by evidence that people labelled with severe and persistent mental illness are likely to die 30 years younger than the rest of the Australian community.[89]

Associate Professor Dan Siskind, Clinical Academic Psychiatrist at the Princess Alexandra Hospital and academic at the University of Queensland, pointed to the discrepancies in diagnosis and treatment for cancer, noting:

> people with schizophrenia are no more or less likely to develop cancer, but are much more likely to die of it; they are less likely to be investigated for cancer and, even if they are investigated for cancer, they are less likely to get evidence-based care.[90]

People with comorbidities told the Commission they did not receive coordinated care due to stigma and discrimination. Victoria Legal Aid's *Your Story, Your Say* project shared the views of Imogen Gandolfo:

> The clinical system doesn't address physical health—despite being in a hospital, mental health units don't care for people's physical health issues. Your access to medication that is not for mental health is very limited to non-existent. It's a lengthy process, and unlikely to happen, that you will get your regular medications without an authority from another doctor.[91]

One person with lived experience of mental illness or psychological distress described being denied access to medication for their physical health issues:

> In many of my admissions, I couldn't access my medications for my physical health issues. I was denied my insulin for over a day, which resulted in an emergency department admission. There was no justification for being denied my medication. This resulted from a lack of communication between staff and a lack of understanding of my physical health needs. The physical health of many people in psychiatric wards often deteriorates.[92]

The Commission also heard that consumers' concerns regarding side effects of medication were not always heard. One participant in Victoria Legal Aid's *Your Story, Your Say* project said:

> I was forcibly medicated for 6 months. I was prescribed aripiprazole, which was meant to have the fewest side effects. There were plenty of harmful effects on me and I had a formal letter from my specialist telling the treating team they had got it wrong. Some of the side effects included severe chest pain and breathing issues, chronic fatigue, loss of concentration, loss of motivation, loss of eyesight and hair falling out as well as developing depression. I increased three dress sizes as a result of the increased appetite for food that went totally against my normally strict autoimmune diet. For all of this I saw no benefits from the medication. I wasn't ever given a say nor was I respected when I complained about the extensive side effects. It was coercive and draconian.[93]

In the *Our Turn to Speak* survey, on average, 63 per cent of participants said they expected to experience future discrimination in health care—for example, by being unfairly denied care when seeking help for physical health problems.[94]

Figure 25.2 provides first-hand accounts of stigma and discrimination that consumers encountered in healthcare settings.

25.5.2 Discrimination against lived experience workers

Lived experience workers (workers with lived experience of mental illness or psychological distress or workers with lived experience as a family member, carer or supporter) in the mental health system can also encounter stigma and discrimination. Witnesses described encountering negative beliefs about the capabilities of lived experience workers, hearing people living with mental illness described and treated in demeaning ways, being made to feel less capable than other staff, being paid less than others for commensurate roles, and being denied opportunities for career progression.[95]

Ms Jayakody told the Commission:

> In my experience, even when I have clearly disclosed I am a consumer worker, people say and get away with statements like 'peer workers can't work full-time'. There is lack of recognition that such statements are discriminatory. It is often left up to the consumer worker like myself to challenge these statements.[96]

Most people in the lived experience workforce are employed part-time.[97] There may be many reasons for this, including the worker's preference. However, the Commission heard that a commonly held view is that lived experienced workers can only manage part-time work, and that as a result, lived experience workers are often only offered part-time positions. The belief that lived experience workers are only capable of part-time work was something many lived experience workers had encountered, as reflected in the following statement:

> There is a fallacy that peer workers can't do full time work which I believe to be quite discriminatory.[98]

Stigma and discrimination can result in workers being passed over for promotion as a result of misguided concerns about their capability, or assumptions that they, as lived experience workers, cannot 'cope' with full-time work:[99]

> When the funding did become recurrent funding, my employer wanted me and my colleague to reapply for our positions. When we reapplied for our positions, they re-hired my colleague, and instead of also re-hiring me, they hired an external applicant instead of me, which is fine—it is all part of the process. I would have understood if the successful applicant simply had a higher level of skill than I had. However, my then supervisor said afterwards that they thought my diagnosis may not be a good fit for working in that area. When I brought this up as something that wasn't okay for them to say, they did not understand why it was not okay.[100]

The Commission also heard that the treatment of lived experienced workers reflected the community's and mental health system's tendency to make people with lived experience the problem, rather than examining their own behaviours or structures:

> I have repeatedly heard people say 'the peer worker can't cope so they're leaving', without having any regard to issues with the environment in which they are working. I am shocked by how prevalent these kinds of comments are … Why a peer worker decides to leave is never about working conditions, team dynamics, role clarity or personal choice. There is no examination about whether a person can actually flourish in the environment. This is not limited to lived experience workers in the mental health sector, it applies to lived experience workers across all sectors; whatever the role it is always about the person with lived-experience, and not the environment.[101]
>
> This standard is not extended to other disciplines and so is a double standard.[102]

As the *Leading the Change* report on consumer workforce challenges and opportunities finds, much of this relates to 'strong hierarchy and power imbalance in the mental health workforce, in which consumer workers occupied the lowest level'.[103] These examples and their drivers reflect discriminatory systems that undermine the development and sustainability of a lived experience workforce.[104]

As outlined in Chapter 33: *A sustainable workforce for the future*, there will be significant growth in the size and diversity of lived experiences workforces in Victoria's future mental health and wellbeing system. In addition, support will be provided to develop the leadership capabilities of people with lived experience of mental illness or psychological distress (refer to recommendation 28).

25.5.3 Stigma and discrimination in workplaces

The Commission heard evidence that people living with mental illness or psychological distress face dismissive treatment or lack of understanding of their illness at work.[105] In her witness statement, Associate Professor Nicola Reavley, Head of the Population Mental Health Unit and Deputy Director of the Centre for Mental Health, University of Melbourne, highlighted the following findings in the *National Survey of Mental Health Literacy and Stigma*:

> In the domain of the workplace or people searching for work, the most common types of discrimination included dismissive treatment or lack of understanding of the illness (identified by 27% of respondents), being forced to change responsibilities or being denied opportunities at work (24%), being fired (15%), or being treated as incompetent (13%).[106]

People with lived experience are reluctant to disclose their diagnosis to employers.[107] Witnesses have described it as being 'career limiting' to do so.[108] They have also described the risk of being 'time-capsuled,'[109] whereby a person is defined by the disclosure of their mental illness. As Dr Michelle Blanchard, Deputy CEO of SANE Australia and Founding Director of the Anne Deveson Research Centre, explains, non-disclosure can be detrimental because it can mean the person is 'unable to access flexible work arrangements or reasonable adjustments that they might find helpful to remain in the workforce'.[110]

However, people can experience stigmatising attitudes when they require flexibility—for example, to accommodate medical appointments or when they need 'reasonable adjustments' in order to work.[111] Ms Hilton, VEOHRC Commissioner, told the Commission that 35 per cent of mental health discrimination complaints relate to workplaces, many of which involve employers refusing to make 'reasonable adjustments' for people who disclose a mental illness.[112]

Fears about disclosing one's lived experience are not unfounded. Research by SuperFriend found that 45 per cent of working Australians with 'mental health conditions' reported experiencing stigma at work.[113] Research by the Monash Sustainable Development Institute indicates that Australian employers hold more stigmatising attitudes towards people with 'mental health issues' than towards those with physical disabilities, because they feel 'mental health issues' are 'unpredictable and often loosely defined'.[114]

Drawing on previous research, the Productivity Commission's *Mental Health Inquiry Report* highlights that employers 'expect workers with mental ill-health to have lower productivity and higher absenteeism than other workers, and will either fail to hire, or fail to promote those with mental ill-health'.[115] The report noted evidence that many employers are inclined to overlook a potential employment candidate when discovering they have a mental illness, believing 'they would be taking on an unreliable employee and possibly a liability'.[116] The Productivity Commission identified the reluctance to disclose mental illness, due to fears of discrimination and the lack of employer support, as a significant problem.[117]

Research also indicates that systemic discriminatory workplace practices exist towards people living with mental illness, based on the beliefs that they lack competence, that they need supervision, or that work is not healthy for them.[118]

Dr Blanchard told the Commission that for people diagnosed with 'complex mental health issues', structural discrimination manifests in the workplace in three main ways:

- poor mental health can lead to people not completing secondary or post-secondary education, which can limit their opportunities to join the workforce
- people can find it difficult to enter the workforce if they disclose they have lived experience of poor mental health. Where there are gaps in a person's CV due to periods of severe ill health, the person faces the choice of disclosing their illness, or not explaining the gaps. Either approach can make it difficult for people to secure work
- the episodic nature of many mental illnesses can make it difficult for a person to anticipate their ill health. In taking on a job, people can feel unsure how their illness will play out and affect their ability to participate in the workforce.[119]

During a community consultation hosted by the Commission, one participant described her daughter's experience in seeking work:

> My daughter went to Centrelink and at the end of her appointment they said we'll try to find you a job but just don't tell anybody you're schizophrenic.[120]

Ms Lisa Annese, witness and CEO of the Diversity Council of Australia, explained that employers may not see their actions as discriminatory, and may believe they are in fact looking after their fellow employees:

> I do think it is important though to note that some people might not view their prejudices as stigma or as harassment; they might view them as reasonable prejudices to have. For example: someone might think, I cannot hire this person or promote this person because you know this is a really challenging work environment and the pressure might be too much. They may think that they are being benevolent about their reasons for discriminating, but we need to be careful with 'benevolent discrimination'. People need to step back and realise that they are not the best decision-makers when it comes to the mental health and wellbeing of other people. [121]

Ms Annese also spoke of the 'self-editing' that happens, even in psychologically safe places, due to self-stigma and people's 'fear that if they disclose something, it will change the way they are perceived'.[122] In his witness statement, Mr David Pearl, innovator, author and public speaker of The Studios, London, giving evidence in a personal capacity, noted that it can be career limiting to disclose an ongoing issue:

> A common experience I've heard in organisations is that it's cool and accepted to talk about mental wellness; it's not career limiting to disclose to people that you have had a mental disturbance. But it is career limiting to say that you think you might have it in the future. In other words, people could accept that an employee has a history of mental disturbance. It's almost like 'Oh, you've got a history of diabetes,' it is something for HR, it is a kind of mitigated risk. But if employees say 'I'm okay but I'm really feeling the wheels might fall off,' they very often feel that, although nothing is said, people just pull away from them and start to assign the work in different ways. It is like it is a dangerous thing to say, which is interesting, because actually that's the thing you really want people to be able to say without fear of repercussion: 'Look, I'm fine, but I can feel … keep an eye on me'.[123]

A flow-on effect of workplace stigma for people with lived experience can be a reluctance to seek employment, in anticipation of stigma and discrimination.[124] Furthermore, 'a person's self-stigma will impact on whether or not they are going to put themselves forward for a job, a relationship or an opportunity in different environments'.[125]

The contrast between workplace understanding of, and responses to, physical and mental illnesses is stark. One witness, Theresa, highlighted the lack of social norms in relation to mental illness, and the isolation she felt as a result:

> If I had taken sick leave at work because of physical illness like breast cancer, everyone would be sending me flowers and could easily name the problem. However, when it comes to mental illness, I have the impression that people are unsure what to do. People seem to be hypersensitive [about] mental illness. It is not spoken about openly. It's ok to be unwell. But we aren't sure if it's acceptable to be mentally unwell. There seems to be a fear about naming mental health problems. I had never heard anyone at my workplace say that they have spent time in a psychiatric hospital. When a person disappears for a time and then returns on a special project, it is only talked about quietly. When I was the one experiencing this, it felt really lonely.[126]

One consequence of discrimination in the workplace is that people are not engaged in meaningful work. This can be distressing, isolating and financially disadvantageous:[127]

> Often the employee gets to a crisis point in the employment and ends up leaving, as they are unable to manage their health and wellbeing needs alongside their work. Some people end up under-employed, or end up working in areas that are different from those applicable to their qualifications. This can then have flow-on effects for their financial position and access to safe and secure housing.[128]

In its submission to the Commission, Beyond Blue relayed stories that had been shared with them describing the challenges people with lived experience of mental illness or psychological distress face in the workplace:

> Workplaces treat you differently. I am passed over for opportunities because I might not be able to handle extra stress … Co-workers see you as less competent or attention seeking. It's better not to ask for assistance because work tends to make a big issue…[129]

A 2014 report published by the Organisation for Economic Co-operation and Development highlighted that people living with mild or moderate 'mental health conditions' are two to three times more likely to be unemployed than the general population.[130] This figure increases to six to seven times for people with 'severe mental health conditions'.[131] Dr Blanchard told the Commission that people living with a psychological disability in Australia have the lowest workforce participation rate (29 per cent), and the highest unemployment rate (20 per cent).[132] This can have flow-on effects on the person's family and loved ones, as the person becomes more isolated and reliant on them. The experiences of caring for someone with mental illness are outlined in detail in Chapter 19: *Valuing and supporting families, carers and supporters*.[133]

In turn, the stigma associated with mental illness means some families, carers and supporters feel they cannot talk openly in the workplace about their caring responsibilities. This can result in an employer being less willing to provide flexibility to work non-standard hours or to work from home, because they are unaware of the employee's additional responsibilities:[134]

> A real difficulty for carers can be the episodic nature of mental illness … [which] is often all-consuming and requires carers to drop everything to provide support. This does not fit in neatly with the traditional structures of paid employment, particularly where people are expected to work set hours at the workplace, and have fixed amounts of leave.[135]

The significance of workplaces as sites for mental health promotion and prevention, and the crucial role that the mental health workforce plays in people's opportunities for mental health and wellbeing, are explored in detail in Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect,* and Chapter 33: *A sustainable workforce for the future.*

25.5.4 Stigma and discrimination in other settings

Evidence before the Commission indicates that people living with mental illness also face stigma and discrimination in many other domains of life, including the private rental market[136] and the insurance sector. These issues are explored in detail in the Productivity Commission's *Mental Health Inquiry Report* and SANE's 2020 *National Stigma Report Card.*

In the private rental market, there is a perception that people with lived experience are 'difficult' tenants.[137] As identified in the Productivity Commission's report, prospective renters who disclose a mental illness are less likely to receive a response to their rental inquiries, be told that an advertised unit is available, or be invited to inspect an available unit.[138] There is also a greater expectation on them than others to produce guarantees of support or references, in order to secure a private rental.[139]

As safe and secure housing is fundamental to recovery, and as there is very limited public and social housing in Victoria, these barriers to accessing the private rental market create a major challenge for recovery. Jenny Smith, CEO of the Council to Homeless Persons, told the Commission:

> In a competitive rental market, where real estate agents have multiple applicants for rental properties, this very commonly leads to discrimination. Real estate agents select the preferred tenant using objective criteria such as income, as well as subjective criteria, such as appearing to be someone who may be a 'good tenant'.[140]

Chapter 16: *Supported housing for adults and young people,* explores the intersection between mental health and housing in further detail.

The stigma towards, and discrimination against, people with lived experience of mental illness or psychological distress by the insurance sector is also well recognised.[141] People with a mental illness often find it difficult to obtain, and claim on, different types of insurance products, such as travel insurance, income protection, total and permanent disability, and life insurance.[142]

Ms Meagher recounted her experience of such discrimination:

> [because of a history of mental illness] I was never able to get income insurance and when I travel I struggle to get travel insurance.[143]

The widespread nature of discriminatory insurance denial is documented in the Mental Health Council of Australia and Beyond Blue survey *Mental Health Discrimination and Insurance: A Survey of Consumer Experiences 2011,* which was cited by the Productivity Commission in its *Mental Health Inquiry Report.*[144] Approximately 22 per cent of respondents who identified as a 'mental health consumer' reported having an insurance application declined due to mental health. When the applications concerned life insurance and income protection insurance, the rates of rejection reported were higher, increasing to 36 and 45 per cent respectively.[145]

25.5.5 Stigma and discrimination across Victoria's diverse communities and social groups

Some Victorian communities face multiple forms of stigma and discrimination. For example, Aboriginal people,[146] LGBTIQ+ people, people from culturally and linguistically diverse backgrounds, people who are deaf or hard of hearing, refugees and asylum seekers,[147] and people with dual disabilities[148] are subjected to intersectional discrimination.[149] Intersectional discrimination or psychological distress occurs where a person experiences intersecting forms of discrimination on the basis of multiple, personal attributes such as disability and race, which interact with and compound one another.'[150] This can worsen marginalisation and disadvantage.

As Rainbow Health Victoria outlined:

> The recognition of age, class, gender, race, sexuality, cultural background and disability offers a framework for inclusive consideration of multiple intersecting disadvantage. People who are LGBTIQ and from an Aboriginal and Torres Strait Islander or culturally and linguistically diverse background, or who have a disability can face multiple, compounding disadvantages, and are more likely to delay, avoid or prematurely cease mental health care. The effectiveness of programs and supports depends on intersectional needs being recognised and addressed in policy and service design, and service delivery.[151]

While discrimination on the basis of attributes other than mental illness is outside the Commission's letters patent, intersectionality (the meeting point of all components of one's identity)[152] means that attempting to distinguish discrimination based on mental illness from discrimination based on other attributes can be fraught. The Commission also acknowledges that stigma and discrimination contribute to psychological distress and that they are a risk factor for post-traumatic stress disorder, depression and anxiety.[153] This is often understood and examined through the Minority Stress Model, which conceptualises how greater vulnerability for some communities emerges from their subjection to unique stressors as a marginalised group.[154]

The issues underlying stigma and discrimination are not uniform across Victoria's diverse communities.

Indigenous Australians continue to suffer serious marginalisation and deprivation at a rate that is higher than any cultural group in the country. On various measures of wellbeing and prosperity, such as life expectancy, children's mortality, education, employment, income, and housing, Indigenous Australians are the most disadvantaged citizens.[155]

Ro Allen, Commissioner for LGBTIQ+ communities (formerly the Victorian Commissioner for Gender and Sexuality), highlighted how the 'pathologisation' of identity impacts LGBTIQ+ communities:

> One of the most profoundly negative experiences for a LGBTIQ person who seeks mental health support is when the clinician, service provider or support worker assumes that the person's mental health issues are the direct result of their sexuality, gender identity or intersex status.[156]

Commissioner Allen went on to highlight how homosexuality remained a 'diagnosed mental disorder' until the 1970s, and a criminal offence in Victoria until 1981.[157]

Some people from culturally and linguistically diverse communities can also experience double stigma, where racism in society and within mental health services compounds public and internalised shame around mental illness.[158]

Older Victorians (aged 65 and over) experience intersecting stigma and discrimination relating to both their age and mental health challenges. This acts as a barrier to accessing mental health and wellbeing treatment, care and support. Evidence suggests that older Australians are often subjected to ageist beliefs and stereotypes that do not accurately reflect the nature of this cohort.[159]

For some communities, stigma, and particularly self-stigma, can be a barrier to disclosing mental health concerns and seeking help. This is particularly apparent in some migrant communities, and in rural and regional communities.

Different cultural conceptions of mental health can make self-stigma particularly acute in some culturally diverse communities, where mental health issues are seen as taboo or as bringing shame on the family.[160]

Among parents in migrant communities, perceived stigma, combined with a lack of understanding of mental health, poses a barrier to children accessing care, with parents worried about the stigma of mental health negatively affecting a child's future study and work opportunities.[161] In a study carried out by Foundation House, young asylum seekers used the terms 'embarrassment', 'guilt', 'judgment', 'pity', 'mockery', and 'taboo' to describe how their peers, families and communities felt about mental illness and accessing mental health services.[162]

Similarly, the 'close-knit' nature of many rural and regional communities, combined with a culture of independence and stoicism, can cause shame about mental illness, and reluctance to risk 'exposure' by seeking help.[163]

As the Commission found in its interim report, the reluctance of people in rural and regional communities to seek help often stems from a fear of judgement or embarrassment or a fear that their circumstances might become public knowledge.[164]

In some communities, mental health workers are well known to the people they support. This kind of familiarity can sometimes be an asset, but it can also result in a perceived lack of anonymity or confidentiality when seeking support.

Mr Terry Welch, CEO of Maryborough District Health Service, observed:

> In regional towns, one of the challenges is that when a resident presents at the GP (which is the access point); they know the person who is at the reception desk. People are not likely to seek and engage with support in those circumstances.[165]

This reluctance to seek help can be exacerbated by what has been described to the Commission as the 'tough it out' attitude among rural people and the '"*we'll be right*" approach; the stoic rural way'.[166]

Small towns built on a culture of independence and self-sufficiency can restrict frank and open discussion about mental health, leading people to shy away from asking for help. The Royal Flying Doctor Service Victoria submitted:

> In rural and remote communities, stigma, in particular, self-stigma, is a key barrier to progress. There [is still a] strong cultural desire for independence and [an] attitude that [aligns] asking for help with failure.[167]

The Commission believes that community-led organisations and community members are best placed to understand the particular challenges faced by their community, and to design and deliver projects that challenge that stigma.

25.6 Confronting stigma and discrimination sets the foundations for mental health and wellbeing

A central goal of the Commission is to see the full participation of people with lived experience of mental illness or psychological distress in public life. Achieving this will require the entire Victorian community to take action to reduce barriers to participation in public life that exclude people with lived experience.

This duty is grounded in human rights obligations that extend to all Victorians, irrespective of whether they experience poor mental health. All people should enjoy human rights equally. Under the *Charter of Human Rights and Responsibilities Act 2006* (Vic), every person has 'the right to enjoy his or her human rights without discrimination', and the right to 'effective protection against discrimination'.[168] These rights are further embedded in the Equal Opportunity Act, which protects people with lived experience against direct and indirect discrimination.[169]

Unfortunately, routine experiences of stigma and discrimination against people with lived experience often reflect a failure to uphold human rights. This is despite existing measures designed to protect and safeguard their humanity.

The Commission appreciates that exclusion from services, education, housing and employment represent profound human rights issues. People with lived experience have described how this causes a sense of shame, through no fault of their own. One person, who had experienced compulsory mental health treatment, spoke about their combined experiences of stigma and discrimination:

> For all the bad things that happen in my life, my 'mental illness' is blamed, instead of my forced medication. Weight gain, being tired and lazy, having a boring brain and no motivation, physical issues—these are all apparently because of my 'mental illness', not because of my forced medication ...[170]

The person also spoke of being monitored by services, while at the same time being shut out from society:

> The other thing about living regionally is that everyone knows what's going on with you. Your business is everyone's business, and once you've been tagged with a mental illness, they won't answer their phones, talk to you or serve you. It's discrimination.[171]

These experiences of shame and exclusion are not isolated incidents—they reflect a failure of the broader Victorian community to be inclusive of people with lived experience.

In addition to the harm caused, stigma and discrimination prevents the community from enjoying the benefits and contributions that people with lived experience have to offer. The Victorian Mental Illness Awareness Council has told the Commission that:

> consumers are too often framed in the negative. We, as consumers must routinely respond to questions that presume we lack capacity, fortitude or 'insight'. Beyond the harm this causes us, it cuts the broader community off from the wisdom that can arise from our lived experience, or as some say, 'madness'. Our members present world views—through debate, music, and other forms of art—that enrich the community. The present problem is less that we lack any individual skills or capacities, and more that we have been systematically excluded from platforms to share these gifts.[172]

The failure to include and promote these voices diminishes the Victorian community's understanding of mental health and wellbeing. The Commission has received submissions from Hearing Voices groups across Victoria,[173] which tackle stigma by supporting individuals with lived experience of mental illness or psychological distress and encouraging the public to consider new ways of understanding and responding to hearing voices (refer to Box 25.5).

These approaches, and the voices of people with lived experience more generally, remain stigmatised by, or excluded from, the mainstream community.

This exclusion of people with lived experience of mental illness or psychological distress from the community and public also represents a continuing challenge to Australia's obligations under the *UN Convention on the Rights of People with a Disability* (CRPD). The CRPD—which the Australian Government ratified in 2009—makes clear that governments have the obligation to ensure that people with a disability enjoy equal participation in political and public life,[174] and that they are consulted and actively involved in decisions regarding the development and implementation of legislation and policies that affect them.[175] Evidence regarding stigma and discrimination in Victoria suggests there is still considerable work to do in realising these obligations.

The Commission understands that, as both an obligation and a practical necessity, stigma and discrimination must be addressed in order for Victorians to enjoy a more inclusive society that promotes, rather than undermines, mental health and wellbeing.

Box 25.3: Hearing Voices Networks

The Hearing Voices Network[1] is a collection of organisations and individuals who advocate for an alternative approach to hearing voices (often termed 'auditory hallucinations'), having seeing visions (often termed 'visual hallucinations'), and having unusual beliefs (often termed 'delusions') to what is typically offered within clinical mental health services.

Proponents of this approach describe alternative ways of understanding these experiences:

> hearing voices, seeing visions and related phenomena are meaningful experiences that can be understood in many ways; hearing voices is not, in itself, an indication of illness—but difficulties coping with voices can cause great distress; when people are overwhelmed by their experiences, support offered should be based on respect, empathy, informed choice and an understanding of the personal meaning voices have in someone's life.

In addition to providing support for people hearing voices and who may have experienced trauma,[2] these networks combat stigma by encouraging the public to consider new ways of understanding and responding to unusual experiences and behaviours like voice hearing.[3] These approaches ask the public to support people with lived experience to explore the meaning behind these experiences, and are supportive of individuals who choose to take, or abstain from taking, medication for these experiences. There are several Hearing Voices groups set up across metro and regional Victoria, with several witnesses endorsing their value for people with lived experience and the community.[4]

Source: 1. Rory Neirin Higgs, 'Reconceptualizing Psychosis: The Hearing Voices Movement and Social Approaches to Health', *Health and Human Rights Journal*, 22.1 (2020), 133–144 (p. 133); 2. Witness Statement of Indigo Daya, para. 26; 3.Dirk Corstens and others, 'Emerging Perspectives From the Hearing Voices Movement: Implications for Research and Practice', *Schizophrenia Bulletin*, 40. 4 (2014), S285–S294 (p. S285); 4. Witness Statement of Dr Chris Groot, para. 74.

25.7 Strategies to reduce stigma have not materially shifted attitudes

The Commission recognises that responding to stigma against mental illness requires long-term cultural change. Deeply embedded perceptions and stereotypes about mental illness are difficult to shift, particularly when reinforced by discriminatory policies and practices.

25.7.1 Changing community attitudes

Evidence before the Commission indicates it is possible to change public knowledge and attitudes in relation to mental illness.

In recent years, stigma about more common experiences of mental illness, such as anxiety and depression, has reduced. Between 1995 and 2011, people's mental health literacy—the ability to recognise a mental illness, beliefs about treatments, causes, prevention, prognosis and how to help others—has improved, particularly in relation to depression.[176] People are now much more willing to disclose that they have depression, and are much more likely to know someone with depression.[177]

Targeted and sustained awareness-raising campaigns, together with the high prevalence of anxiety and depression in the community, are likely to have contributed to the community's understanding of depression.

While there have been considerable efforts to reduce the stigma associated with more common diagnoses, such as depression and anxiety, other diagnoses that are considered more 'complex', such as borderline personality disorder and schizophrenia, remain poorly understood and highly stigmatised.[178]

In the community, there remains a 'desire for social distance'[179] from people with lived experience of mental illness or psychological distress—that is, an unwillingness to interact socially or professionally with people with mental illness, and a desire to avoid them.[180] Between 2003–2004 and 2011, this desire for social distance decreased, although there was no decrease in a desire for social distance from people with chronic schizophrenia.[181]

Of particular concern is that there has been 'an increase in perceptions of the dangerousness and unpredictability of people living with depression, depression with suicidal thoughts, or schizophrenia'.[182] This includes perceptions that people living with schizophrenia are violent, dangerous and unpredictable, unable to care for themselves, and that they have no chance of recovery.[183]

Box 25.4: Anti-stigma interventions

Beyond Blue has implemented several multi-modal and long-term anti-stigma interventions to improve public attitudes and behaviours around depression and anxiety. These interventions have included media advertising, community education programs, training prominent people as champions, disseminating print and digital materials, mental health literacy and community discussion forums.[184]

Other examples of interventions include:

- Mental Health First Aid training, which started as a small volunteer effort in 2000 and has since been replicated in other countries
- Mind Matters programs in high school that are incorporated into regular lessons
- RUOK Day, where people ask others about their mental wellbeing
- Rotary community forums on mental illness that bring elected officials into contact with ordinary citizens across the country
- Mindframe, a national media initiative that provides training programs and guidelines for responsible reporting about suicide.[185]

Evidence indicates that these initiatives have had a positive impact on raising depression awareness in Australia and have made progress in reducing stigma and social barriers.[186] However, it is unclear whether people with depression have experienced a reduction in stigma and discrimination as a result of the interventions.[187]

While tragic incidents have resulted from dangerous behaviour by people experiencing a mental health crisis, the perception that all people with lived experience are dangerous is unfounded and wrong. Such perceptions are a barrier to people's recovery and their meaningful social inclusion. Distinguished Professor James Ogloff AM, Executive Director, Victorian Institute of Forensic Mental Health, Distinguished Professor, Centre for Forensic Behavioural Sciences at Swinburne University, giving evidence in his personal capacity, said::

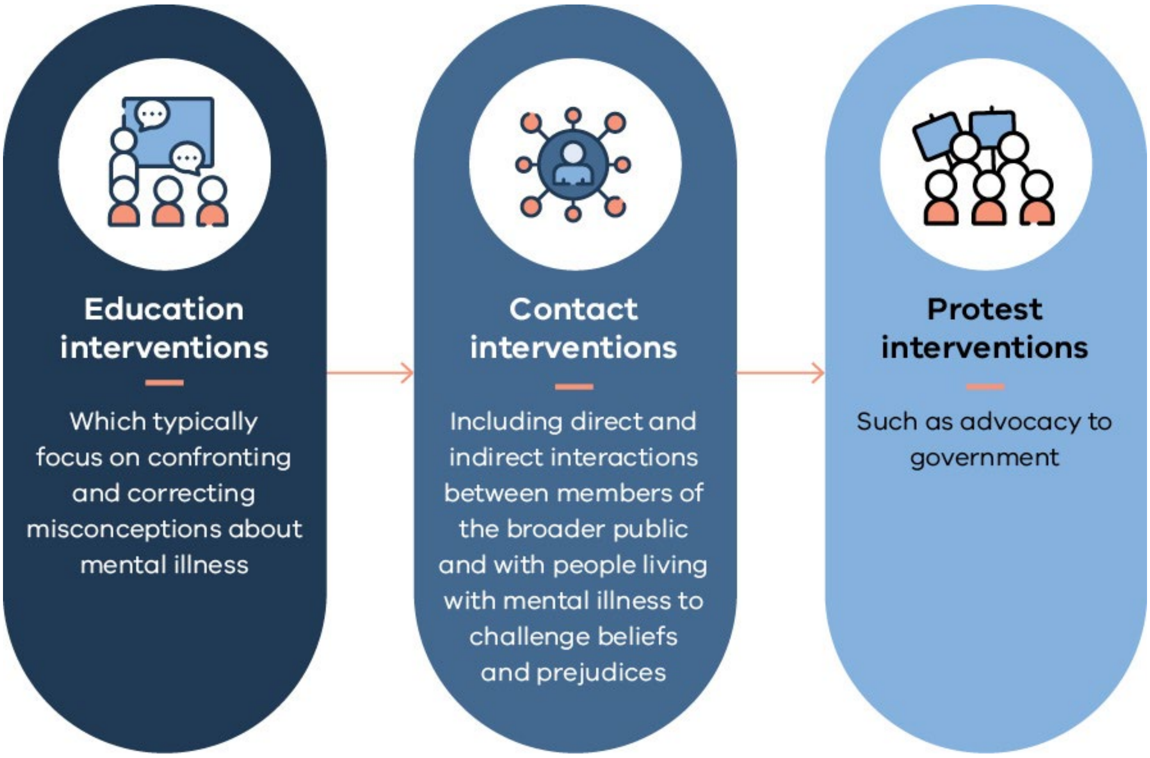
> The discourse needs to shift from people living with mental illnesses are dangerous, unpredictable, and should be in institutions to better reflect the reality of the situation, as conveyed in the research findings … That is, the vast majority of people living with mental illness are not violent and do not offend.[188]

Stigma researcher Dr Groot told the Commission that there is a long way to go in changing perceptions about severe and complex mental illness, noting, 'we certainly do not see schizophrenia regularly featuring in positive mass media stories about hope and help seeking, for instance'.[189] The Commission is aware, for example, of the widespread concern among Australian consumers and consumer peak organisations about the depiction of poor mental health in Australian television shows and the failure of those shows to interview a person with lived experience of mental illness or psychological distress when making links between mental health and violence.[190]

25.7.2 Lack of strong evidence about effective measures

There is also a lack of strong evidence about effective ways to eliminate stigma. Research focused on the main approaches currently taken (refer to Box 25.4) indicates there is limited evidence about the success of these approaches. Systematic reviews of these approaches found only small to moderate short-term benefits, and little evidence of the long-term benefits across multiple settings.[191] Evidence suggests that, on the whole, short-term stigma reduction programs may yield short-term, if any, benefits.

Figure 25.3: Main types of stigma interventions



Source: Nicolas Rüsch and others, 'Mental Illness Stigma: Concepts, Consequences, and Initiatives to Reduce Stigma', *European Psychiatry*, 20.8 (2005), 529–539; Patrick W. Corrigan and others, 'Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies', *Psychiatric Services*, 63.10 (2012), 963–973 (p. 963).

An intervention that works in one setting or within one population group may have little impact in another. For example, contact approaches that work generally for adults may be less effective for youth,[192] or may, in fact, be detrimental.[193] This makes it difficult to draw conclusions about the effectiveness of different approaches to reducing stigma.

It is important to note that the absence of strong evidence does not necessarily mean stigma reduction efforts are of little value. There are a number of factors that affect the ability to draw conclusions about the effectiveness of interventions, including factors related to study design and quality, differences in indicators used to assess the effectiveness of interventions, and difficulty in attributing changes to specific interventions.[194]

The Commission has also heard that use of 'biogenetic explanations' of mental illness, for example reducing distress to heredity brain disease and a 'chemical imbalance', can inadvertently reinforce negative stereotypes, by promoting the idea that symptoms associated with mental health are inevitable and permanent.[195]

Research also indicates that this stereotyping endorses notions that people with psychological problems are dangerous and that they are unlikely to recover.[196] Ultimately, where they reinforce negative stereotypes, biogenetic explanations can increase, rather than decrease, the desire for social distance.[197]

25.7.3 Efforts to reduce stigma are too often designed and delivered without the input or leadership of consumers

The Commission recognises the importance of lived experience participation and leadership in the planning, design, development and implementation of mental health programs.[198] A criticism of current approaches to stigma research and interventions is a failure to draw on the expertise of people with lived experience of mental illness or psychological distress. It has been noted that many social scientists and researchers do not come from groups who experience stigma. This can mean that theories are given more weight than the lived experiences and perceptions of the people who are the subjects of those theories.[199]

In addition, stigma reduction programs that do not involve the meaningful participation of people living with mental illness or psychological distress, but instead appropriate lived experience stories, may replicate the same power dynamic that the lived experience movement seeks to disrupt.[200] Lived experience advocates point out that anti-stigma campaigns effectively 'sanitise' stories (by removing details the public may find too confronting), and 'do little to change the way that agencies function or to address broader issues such as poverty, unemployment and discrimination'.[201]

The Commission has also heard that there are few opportunities for lived experience researchers to lead, co-design or deliver stigma programs, and that a range of barriers stand in the way of people with lived experience becoming researchers and academics. This includes an increased risk of socioeconomic disadvantage,[202] or interruption to traditional education. Low incomes can present a barrier to entry into higher education research degrees,[203] and there are limited scholarships to redress inequality.

More than a decade ago, the University of Melbourne was the first university in Victoria to establish a lived experience academic role. Ms Cath Roper now holds this role in the Centre for Psychiatric Nursing. In her witness statement, Ms Roper discussed the importance of lived experience researchers in co-producing programs and services. She also noted that while there are lived experience researchers in Victoria, there has not been any appreciable increase in these roles.[204]

It can also be difficult to pursue the research interests of consumers and survivors, because research roles are often tied to a clinical discipline, such as nursing, social work or psychology. Consequently, people with lived experience of mental illness or psychological distress may not be able to pursue research interests that do not also relate to a clinical discipline.

As service user academic, Professor Diana Rose, said:

> Conventional research has focussed on clinical issues and interventions such as pharmacological and psychological ones and outcomes measured largely in terms of symptoms reduction with occasional nod towards measures of quality of life. These concerns may not be those that matter most to service users and patients.[205]

A related issue is that lived experience researchers are likely to be less successful in competitive research funding grants. Funding programs are typically geared towards clinical researchers (and clinical research), and few recognise and support the different experience and qualifications of people with lived experiences of mental illness or psychological distress.

The limited scope of consumer-led research is a lost opportunity to improve the quality of mental illness research across multiple domains. Australian National University academic, Dr Michelle Banfield, describes how lived experience researchers can break down the barriers between consumers and researchers, and in the process, change perceptions about the importance of consumers in research:

> Academic researchers who also have lived experience have the potential to bridge the gap between the consumer sector and traditional academic researchers, bringing together the lived experience of mental health issues with academic training (Griffiths 2002). By breaking down the dichotomy between 'lay consumer' and 'academic researcher,' lived experience researchers may increase the acceptance of people with lived experience as equal partners in the research process by other researchers and may influence both the research sector and the wider community on the importance of involving other consumers in the research process.[206]

Effective stigma prevention and reduction approaches in other jurisdictions—including the programs See Me in Scotland[207] and Like Minds, Like Mine in New Zealand—demonstrate that consumer expertise is central to success.[208] The appointment of at least one lived experience Commissioner in the Mental Health and Wellbeing Commission is a key part of the reforms described in Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress,* and Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*. This Commissioner will be responsible for the design and delivery of anti-stigma efforts described in this chapter.

Scotland's Lived Experience Research Collective provides another example of an anti-stigma program that has developed a strong and influential lived experience research workforce. In 2015, See Me formed the Lived Experience Research Collective, a consortium of applied researchers, all of whom have lived experience of mental illness or psychological distress. The consortium's role was originally to share and develop new anti-stigma initiatives for See Me.[209] It has now moved from See Me to the Mental Health Foundation in Scotland, where it 'acts as a think tank for the Foundation on emerging issues and topics that might form the basis for future research projects and validates and comments on the Foundation's ongoing research activities'.[210] It also 'bids for research projects that require or benefit from the active involvement of people with lived experience', and 'champions and promotes co-production, inclusivity, collaboration and consensus in the way it works with the Foundation and with other research partners.'[211]

The Commission encourages the Victorian Government to create pathways to higher education research degrees for people with lived experience of mental illness or psychological distress, including fellowships and scholarships focused on anti-stigma efforts.

Box 25.5: Like Minds

'The Like Minds, Like Mine (Like Minds) programme was established in 1997 by the [New Zealand] Ministry of Health in response to the 1996 Mason Report. It was one of the first comprehensive national campaigns in the world to counter stigma and discrimination associated with mental illness. The programme has combined national television and other media and communication activities with community action to bring about social change'.[212]

Like Minds, Like Mine is founded on the following core principles:

- the social model of disability, which views disability as a process that happens when one group of people creates barriers by designing a world only for their way of being
- a human rights approach, which values the dignity of all people and asserts their right to be free of discrimination
- the power of contact, encouraging equal contact between members of excluded groups and those that exclude. This approach has been shown to promote attitude change.[213]

Like Minds, Like Mine was developed and delivered with people with lived experience of mental illness. This approach built lived experience capability, expertise and skills, including increasing the capacity for people with lived experience to advocate for their rights and for material changes to discriminatory policies and practices.[214]

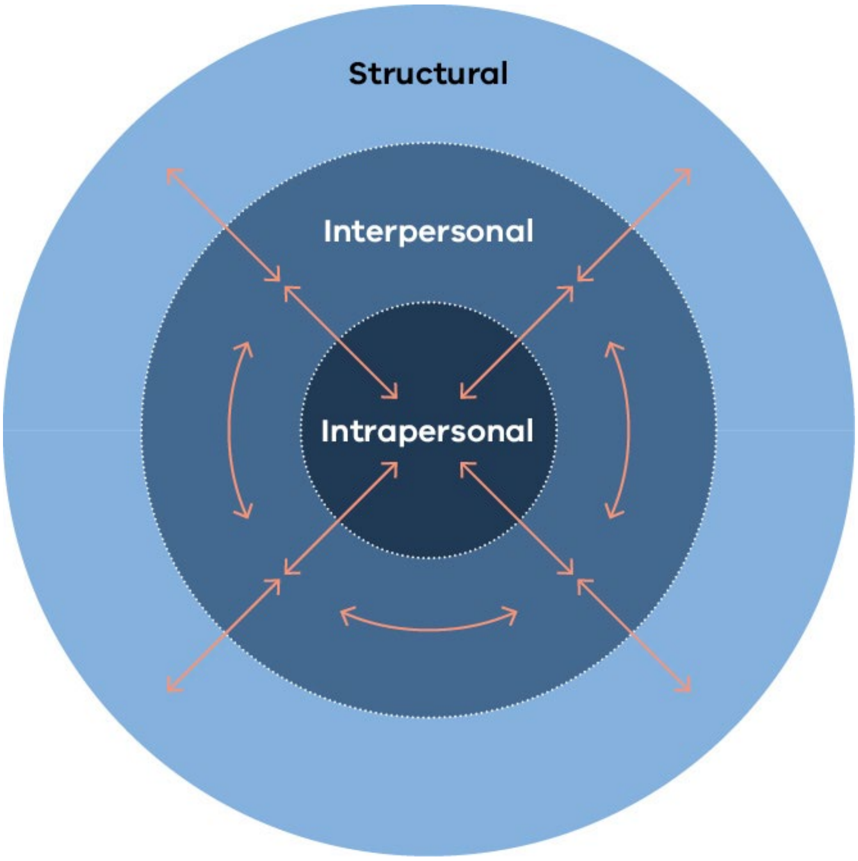
25.7.4 Efforts to reduce stigma usually focus on public stigma

A further limitation of stigma interventions is that they almost exclusively focus on reducing public (interpersonal) stigma (attitudes towards people living with mental illness),[215] without sufficiently recognising or acknowledging the impact of other forms of stigma.

As noted earlier in this chapter, stigma manifests at many levels—public (interpersonal) stigma, self-stigma (intrapersonal stigma), structural stigma and stigma by association. These layers are deeply linked and bi-directional.[216] Research has indicated that stigma reduction efforts at one level can influence stigma, either positively or negatively, on other levels.[217]

The emphasis on public stigma has meant that investment in stigma reduction has typically focused on public media campaigns, or education and awareness training in organisational settings.[218]

Figure 25.4: Stigma reduction efforts at one level can influence stigma at other levels



Source: Adapted from Jonathan Cook and others, 'Intervening within and across Levels: A multilevel approach to stigma and public health', *Social Science Medicine* 103(2014),101–109.

This focus on widespread awareness is warranted to some degree; public stigma is easily identifiable, and its existence points to a need for improvements in knowledge and attitudes. However, not enough attention has been paid to the impact of structural stigma, including discriminatory policies, organisational cultures and a lack of opportunities for people living with mental illness, which can undermine anti-stigma efforts.

Efforts to change attitudes and behaviours of health professionals towards people with lived experience have had limited success against a 'backdrop' of low levels of funding and the historically coercive philosophy of care.[219] Similarly, an entrenched organisational culture in health care that describes some experiences in purely biogenetic terms and labels people as 'difficult' can undermine interventions to improve the attitudes and behaviour of individual staff members.[220]

Ensuring there is genuine cultural change requires confronting the role stigma plays in determining someone's chances in life, and the influence it has on health and wellbeing for people with lived experience.

Ms O'Hagan discussed the importance of thinking beyond interpersonal stigma when considering what constitutes success in stigma interventions, saying:

> Programs that are effective at reducing stigma and discrimination of people with mental distress are those that promote human rights and greater social inclusion. I think the ultimate indicators of whether people who use mental health services are socially included at a population level are things like: What is our participation in the labour market? How many of us are partnering and having children and keeping them? How many friends do we have? What are our relationships like with our families of origin? Are we in stable housing? The challenge is that we don't have very good data on these indicators.[221]

25.7.5 The potential benefits of targeting organisational settings

The Commission has also heard of the need for, and potential benefits of, targeting organisational settings for stigma reduction, particularly in healthcare settings and workplaces.[222]

Box 25.6: Targeted settings for stigma reduction

Healthcare settings:[223] Stigma towards people with lived experience is entrenched in many healthcare settings. Inadequate funding and resources, the historically low priority given to mental health, and the use of restrictive practices have contributed to this stigma. While the Commission's structural reforms, including workforce reforms, will go a significant way to changing practices and recalibrating norms, there remains a need for programs specifically directed to stigma in healthcare settings. This will enable the progressive realisation of Victorians' right to the highest standard of health and health care.

Workplaces:[224] Workplace stigma has long been identified as a barrier to participation in the workforce, and social and economic inclusion.[225] While considerable effort has gone into building work environments that promote good mental health,[226] stigma remains prevalent. People with lived experience need to be supported and resourced to design and deliver programs that will call out stigma and outline practical steps to overcome stigma embedded in workplace cultures. However, these programs will only be effective with meaningful leadership, support and 'buy in' from employers, unions, and industry leaders.

Schools: Another priority setting for anti-stigma programs is schools. As detailed in Chapter 4: *Working together to support good mental health and wellbeing* and Chapter 11: *Supporting good mental health and wellbeing in the places we work, learn, live and connect*, the Commission's reforms place strong emphasis on prevention and early intervention. Researchers have observed stigmatising or discriminatory perspectives and behaviour in even the youngest school children. [227]

Schools offer an important setting through which to break the cycle of stigma and shame and to make it easier for children and young people to talk about mental health and to seek help. Anti-stigma programs in schools are also fundamental to encouraging understanding, compassion and empathy, in relation to mental illness. Schools need to be a focus to ensure cultural change and to promote good habits long term.

25.7.6 Data is a necessary foundation for future strategies

As noted above, there is a lack of consistent, high-quality data on the nature, extent and impacts of stigma and discrimination on people with lived experience of mental illness or psychological distress in different domains of life. The data gaps include longitudinal Australian data on trends in mental health stigma, particularly regarding diagnoses termed ‘severe’ mental illness, and data in relation to specific target groups, such as employers and families.[228] This lack of data has hampered efforts to monitor and address stigma.[229]

The collection of data is an important tool for identifying patterns of disadvantage caused by discrimination, and determining the most suitable course of action to tackle it.[230] Data on practices, policies and procedures inside institutions and organisations can provide evidence of discrimination, by indicating that disparities in treatment and outcomes are not random, but are the consequence of individual prejudices and structural biases.[231] Data also enables targeted policy efforts to prevent discrimination occurring in the first place.

The National Stigma Report Card seeks to address the existing data gap. It is a multi-year partnership between SANE Australia’s Anne Deveson Research Centre and the University of Melbourne, with the support of the Paul Ramsay Foundation. Between October 2019 and March 2020, the project conducted the *Our Turn to Speak* survey to examine how Australians living with 'complex mental health issues' experience stigma and discrimination across a range of areas, including housing, education, employment, health services, interpersonal relationships and media representations.[232]

The Commission regards the specialist knowledge of people with lived experience as indispensable for understanding mental health and psychological distress. It recognises the advantages of seeking out that knowledge in order to gain a proper appreciation of the extent and nature of stigma and discrimination. The Commission envisages the Mental Health and Wellbeing Commission, through the leadership of at least one Commissioner with lived experience of mental illness or psychological distress, being an important source of information, and a critical link into the broader lived experience community in Victoria, about the stigma and discrimination affecting people with lived experience. The Commission foresees the consumer advocacy function playing an important role in engaging with consumers to understand where stigma and discrimination remain an issue.

25.8 The success of international programs in reducing mental health-related stigma

There are several international examples of long-term, targeted and evidence-based programs that have achieved positive results in reducing mental health-related stigma,[233] including Canada's Opening Minds program,[234] Sweden's Hjärnkoll,[235] Scotland's See Me,[236] and Like Minds, Like Mine in New Zealand.

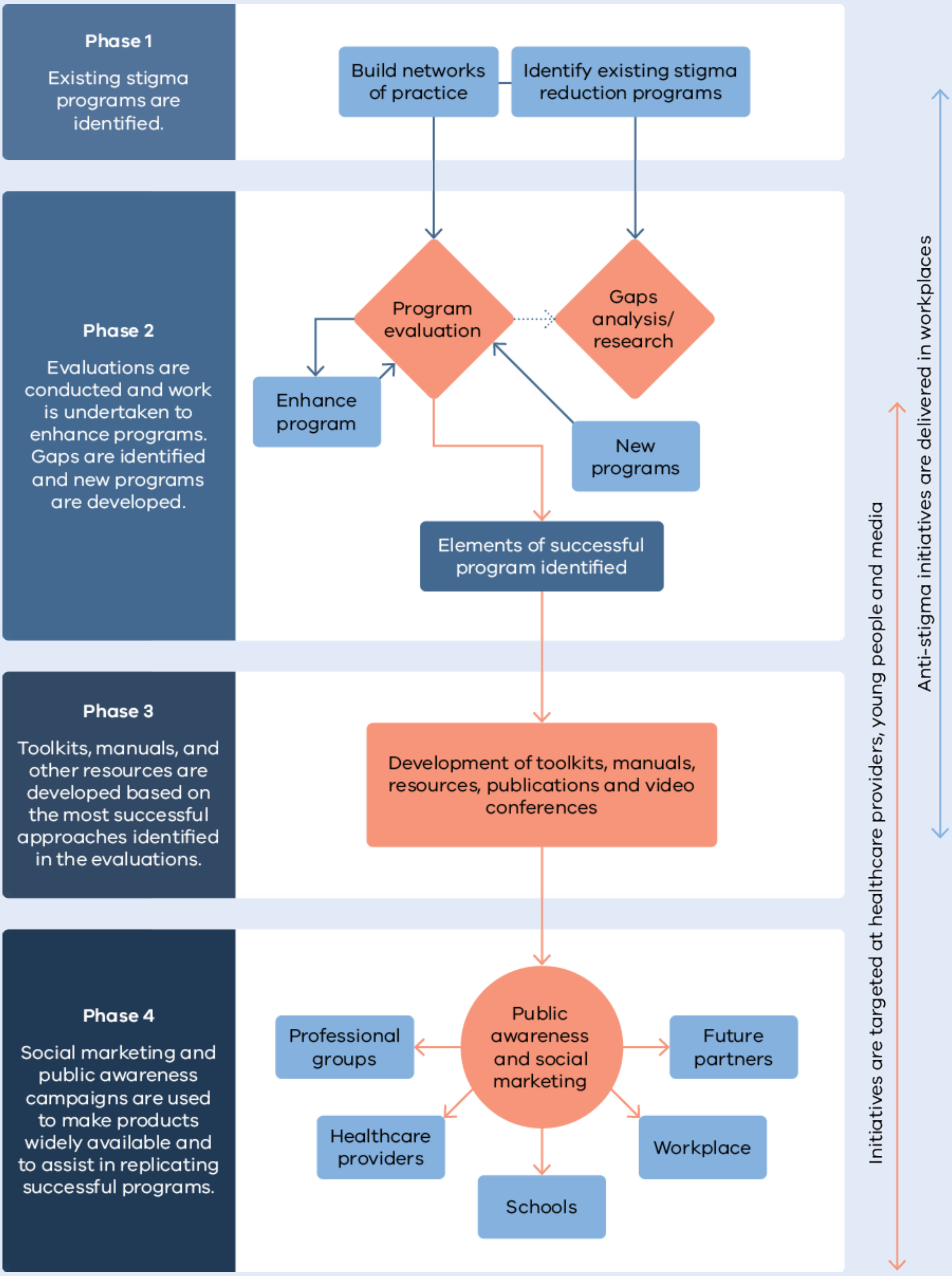
While each of these comprehensive stigma-reduction programs differs in its approach, many share several common features, including:

- a mix of intervention types (with extensive use of contact with people with lived experience of mental illness or psychological distress)
- a focus on particular groups in addition to, or instead of, the general public
- rigorous evaluation by academic researchers[237]
- being well funded and long running.[238]

Mike Pietrus, Director of Opening Minds, and the Opening Minds team, told the Commission the critical success factors of the Opening Minds program were:

- the **long-term nature** of stigma reduction approaches, and the need to manage expectations around the speed and depth of impact, noting that significant change may take a generation
- the **input of lived experience** through a lived experience advisory group
- the need for **sustained funding commitment**—Opening Minds is delivered by the Mental Health Commission of Canada, the source of funding security that allowed the program to be established and rolled out. Secure funding was also important because the time it took to establish programs differed across settings
- the **cost effectiveness** of the approach—the program was cheaper to implement than a mass media campaign. It is now self-sustaining, with Opening Minds charging (on a cost-recovery basis) to deliver interventions. Organisations such as workplaces pay for Opening Minds to deliver interventions
- the **importance of partnerships** to the success of program. This includes partnerships with academics and universities, as well as with grass roots community organisations and businesses who deliver stigma programs. Buy-in from business leaders was integral to the success of the workplace programs
- the role of the program in **developing research capability**—the Opening Minds model has significantly expanded stigma research capacity in Canada. The approach sees one or more senior researchers overseeing young researchers and students to develop an evidence base for interventions. Research is published in academic journals and used to inform program development
- the **ability to adapt** programs as new evidence emerges. For example, the program has responded to evidence of the benefits of 'top up' sessions in workplaces to improve the long-term impact, and tangible practical tools such as workbooks, which have proven effective in workplaces.[239]

Figure 25.5: Opening Minds process model



Source: Adapted from Mental Health Commission of Canada, *Opening Minds: Interim Report*, November 2013.

Box 25.7: Opening Minds

The Canadian stigma reduction campaign, Opening Minds, which is delivered through Canada's Mental Health Commission, is arguably the most comprehensive approach to stigma reduction of the international models.[240]

Opening Minds has taken a different approach to what has been practised in most other countries. Instead of launching a large-scale social marketing campaign, the program focuses on developing evidenced-based interventions for specific groups—health care, youth and workplaces (and media, which has taken a slightly different approach). The main features of the program are:

- identifying and evaluating existing anti-stigma programs in each of the target groups
- developing anti-stigma program toolkits based on these findings for each target group—including tailoring toolkits for specific subgroups, for example, community health centres, emergency departments
- working with partners to replicate interventions across the country
- ongoing monitoring and evaluation of the programs.

Opening Minds involves a network of partnerships with various universities, research organisations and service providers. The program also aims to foster networks of practice so local programs found to be effective can develop a wider reach and program leaders can act as mentors to newly established programs.

The program is also informed by lived experience, through a 10-person consumer group from across Canada that provides input and feedback into research and intervention design.

Figure 24.5 outlines the development process. The key process components include:

- **Phase 1**—establishing a research network and doing a stocktake of existing interventions
- **Phase 2**—evaluating the effectiveness of programs and identifying gaps
- **Phase 3**—creating toolkits based on best practice
- **Phase 4**—rolling out within targeted settings.

25.9 Confronting stigma will require a coordinated, multilevel response

The slow-to-change, pervasive and multilevel nature of stigma means a coordinated long-term and multilevel response is required to bring about cultural and structural change.[241] This must start by placing consumers at the centre of Victoria's leadership and response to stigma, including the design and delivery, research and evaluation of stigma interventions.

A key part of the reforms described in Chapter 18: *The leadership of people with lived experience of mental illness or psychological distress*, and Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*, is the appointment of at least one Commissioner with lived experience of mental illness or psychological distress in the Mental Health and Wellbeing Commission. This Commissioner will be responsible for the design and delivery of anti-stigma efforts described in this chapter.

The Commission's recommended approach focuses on confronting stigma within organisational settings, including healthcare settings, workplaces and schools, and supporting community organisations and people with lived experience to design and deliver anti-stigma approaches tailored to the needs of different communities.

The Commission's recommended program to tackle stigma will draw on the strengths of the various international approaches discussed in this chapter, including:

- developing a strong evidence base for interventions and adapting as new evidence emerges
- building on existing programs where possible, as well as trialling new approaches
- addressing settings or groups most in need of intervention, including healthcare settings, workplaces and schools
- building and supporting research and lived experience researcher capacity
- supporting community-led organisations (particularly those with lived experience capacity) to deliver programs
- building community, academic and industry partnerships to effect long-term change.

The approaches will be founded on three core principles:

- that anti-stigma efforts are co-designed with people with lived experience (as a minimum level of participatory design), and that some funding and initiatives must be coproduced, and others entirely consumer-led
- that consumers are engaged in anti-stigma projects as academics, co-leaders, co-researchers and leaders, not just as participants
- that anti-stigma efforts recognise and respond to the diversity of Victoria's population.

In November 2020, the Productivity Commission made a recommendation in its *Mental Health Inquiry Report* for the implementation of a 'national stigma reduction strategy'.[242] The Commission's view is that efforts at the state and national level ought to be complementary and mutually reinforcing, and that this will create the level of momentum required to engender change.

The Commission understands that, in addition to formal government or academic efforts, one of the greatest potential opportunities to respond to stigma lies in the lived experience community, which is already working to change societal attitudes. The Commission has heard that when people with lived experience of mental illness or psychological distress find the agency and resources to speak and stand up for themselves, society changes. Ultimately, this is what anti-stigma work is striving for.

Box 25.8: The role of the arts sector in reducing mental health stigma

Art can influence the way we think about the world and the way we behave. Throughout the ages, drama, music, painting, sculpture, storytelling, poetry and other forms of art have inspired movements for change by criticising established traditions, raising awareness about issues, and mobilising action for a cause. Messages conveyed through art can shift attitudes and prompt thinking about long-held beliefs. As an expressive outlet, art opens up public conversations and has the potential to shift the wider cultural context of society by challenging negative stereotypes and exposing oppressive dynamics. As Darren Walker, president of the Ford Foundation, summed it up, the arts are 'a space where we can give dignity to others while interrogating our own circumstances'.[243]

In Victoria, the arts sector has a long history of challenging negative stereotypes and attitudes about mental illness.

For example, the Arts Wellbeing Collective is a body made up of hundreds of arts and cultural organisations working together to promote positive mental health within the arts sector. Since launching, the Arts Wellbeing Collective has delivered more than 200 workshops and presentations, 18 mental health first aid courses, 220 hours of consulting and approximately 150,000 copies of digital print resources.[244] Through this engagement, the Arts Wellbeing Collective has shared knowledge, skills and ideas for reducing stigmatising attitudes and behaviours, and supported organisations to implement changes that promote positive mental health.

Another arts sector program involved in mental health advocacy is run by the Listening to Voices Theatre based in Wodonga.[245] In this program, theatre methods are used to share the many realities of living with mental health challenges in the hope that audiences gain a better appreciation of people's lived experiences of mental illness or psychological distress. Through this process, empathy is built, and stigma is reduced. The performances of the program include scenes on such themes as accessing and navigating the mental health system, trauma, understanding and listening to voices that other people cannot hear, diagnosis, and stigma.

Art has potential to be an important vehicle for reducing the stigma that surrounds mental illness. Mr Justin Heazlewood, actor and humourist, and witness to the Commission, shared his views on how the transformative potential of the arts can be further realised in relation to schizophrenia:

> I think a dedicated, funded body which includes writers, artists, publicists and social media strategists should be employed with the express purpose of raising awareness of schizophrenia, and in turn other aspects of mental illness. It isn't always enough to provide dry, corporate information. The material needs to be dazzling, intimate and original enough to engage with a subject they are used to putting to one side.[246]

The power of art to influence our thoughts and feelings, and to start a process of internal reflection on taken-for-granted assumptions, is an important reason why the arts sector should receive further support in its efforts to reduce mental health stigma.

25.10 Confronting discrimination and ensuring equality

It has been unlawful to discriminate against people on the basis of mental illness in Victoria for almost 40 years.[247] For decades, organisations such as the Victorian Mental Illness Awareness Council (VMIAC) and the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) have passionately advocated for the equal treatment of people living with mental illness.

Despite this legal protection and sustained advocacy, the Commission has heard that people with lived experience of mental illness or psychological distress continue to be treated less favourably, because of their mental health, across multiple domains of life, including in health care, when seeking to access the workforce, in the workplace, in education, when securing a home, and obtaining goods and services such as insurance. The problem should not be misunderstood as discrete and isolated instances of discrimination; instead, discrimination against people with lived experience of mental illness or psychological distress is long standing, entrenched and pervasive.

People with lived experience of mental illness or psychological distress need to be better supported to enforce their right to equal treatment and to redress discrimination. Fundamentally, though, to engender systemic change—particularly for people who are unwilling or unable to bring individual complaints—greater legal powers are needed to redress systemic discrimination.

25.10.1 People should be better supported to bring individual complaints of discrimination

Currently, the system relies on individuals to enforce their right to protection against discrimination. As noted earlier in this chapter, 'it is likely that the number of people experiencing discrimination on the basis of mental illness greatly exceeds the number of complaints made'.[248] There are likely to be several reasons for this.

First, many people are not aware of their legal rights, or the channels through which to enforce those rights.[249] The current complaints process is complex and formal, and people can find it difficult to navigate.[250]

The Equal Opportunity Act categorises mental illness under the umbrella attribute 'disability' (as opposed to regarding it as a standalone attribute), which might be leading to less reporting. Because it is not immediately obvious that mental illness is a disability, people may be unaware that mental health discrimination is unlawful.[251] As Ms Kristen Hilton, VEOHRC Commissioner, explained in her witness statement, 'people who have experienced mental health discrimination might not necessarily consider themselves to have a disability'.[252]

Dr Blanchard highlighted that 'people with lived experience don't always see mental illness as a disability, and in fact, seeing it as a disability is quite counter to the recovery framework'.[253] The Commission acknowledges that many people would find the term 'disability' (and the definition 'malfunction of part of the body including a mental or psychological disease or disorder'[254]) stigmatising.

Second, the Commission has been told that people avoid the formal complaints process in order to preserve their mental wellbeing. Currently, an aggrieved individual must lodge a complaint in order to activate the legal process. This is a substantial task, which many people find daunting.[255] Commissioner Hilton explained the issue:

> Presently, the burden of complaint making rests with the individual who has suffered discrimination. As a result, the system relies on people who have had traumatic experiences knowing that their rights have been infringed, and then finding the correct place to make their complaint. They are then required to go through a complaints process which can be re-traumatising despite VEOHRC's best efforts. This can deter a person from making a complaint. Of those who do make a complaint, one in six of all the people who disclosed to us that they are living with a mental health condition withdrew their complaint before attempting dispute resolution.[256]

Victoria Legal Aid highlighted the burden on people with lived experience:

> A significant weakness of Victorian Discrimination laws is its reliance on a complaints-based system, where people experiencing discrimination, including on the basis of their mental health, bear the burden of bringing a complaint against services and people who have discriminated against them to access justice. Through our casework we also see the mental health strains of bringing a discrimination complaint.[257]

Third, the majority of complaints to VEOHRC on the basis of mental health discrimination relate to the workplace, and it is likely that the threat of retaliation from a person's employer plays an important part in the reluctance to embark on a legal path of recourse to remedy discrimination.[258]

Fourth, intersecting forms of disadvantage are a barrier to people exercising their legal rights. People living with mental illness are at greater risk of financial instability, poverty, unemployment and housing insecurity,[259] and are less likely to complete a high school education.[260] As a result, people may lack the resources necessary to pursue discrimination complaints.

These issues are compounded by the limited availability of free or affordable legal services. Without the benefit of legal advice, representation and advocacy, complainants must identify their legal rights; identify where to bring the claim and how to make a claim; articulate the unlawful conduct; and respond to any counter arguments, all unaided.[261] Discrimination, and particularly indirect discrimination,[262] raises difficult legal questions.

As outlined in this chapter, despite being unlawful, there remains widespread, systemic discrimination against people with lived experience of mental illness or psychological distress. While everyone has the legal right to equal and effective protection against discrimination, many people find it difficult to exercise that right. People with lived experience need to be better supported, through legal advocacy and representation, to bring individual complaints to redress discrimination and to uphold their rights.

The Commission recommends increased and continuing funding to independent legal services that have a demonstrated connection or capacity to connect with people with lived experience, in order to enhance individual access to legal advocacy and support, and the protection of the legal right to equality.

This reform measure is designed to overcome the disadvantages and constraints that people face when exercising the legal protection against discrimination. It will increase the accessibility and availability of legal services.

Most obviously, legal services give people the opportunity to be represented in courts and other legal proceedings, when they would otherwise not have the benefit of legal expertise and advocacy. However, the benefits of legal services go much further. Legal services can be a source of moral support, guidance, advice and information on how best to navigate a complex legal system. Legal services can also provide assistance to settle discrimination claims on terms that respect the person's rights. This spares people from a potentially arduous path of legal action.

Mr Julian Gardner, member of the Expert Advisory Committee, a human rights expert and former Public Advocate of Victoria, highlighted the value of such public interest advocacy from legal services:

> **This approach empowers people by providing them with information so that they can resolve their own disputes in a way that is consistent with the Act. It meets the objective of facilitating the earliest possible resolution of disputes and removing the burden of pursuing complaints from the complainant.** [263]

The Victorian Government should allocate funding to legal services in ways that encourage them to apply their skills and expertise towards the elimination of mental health discrimination. Legal services that receive such funding should be required to use it to assist people who have experienced mental health discrimination. They should also be required to consult people with lived experience in designing, delivering and evaluating the services. The funding should be allocated so that clients can receive free expert advice and representation in relation to mental health discrimination.

The effectiveness of this proposed reform depends on people with lived experience being aware of it. People are only likely to take advantage of legal services that are dedicated to ending mental health discrimination if they know those services are readily available and affordable. As such, the Victorian Government should resource the Mental Health and Wellbeing Commission to support awareness-raising of the availability of these legal services.

Discrimination on the basis of mental health is pervasive and widespread. Progress will require sustained efforts over many years. The Commission therefore recommends the Victorian Government commits to a long-term program of funding for legal services, to ensure a consistent supply of financial resources is available to target mental health discrimination.

Box 25.9: Justice Connect and public interest legal services

Justice Connect is a not-for-profit legal referral service that operates from Melbourne and Sydney. It was founded in 2013 through a merger of the Melbourne and Sydney arms of the Public Interest Law Clearing House (PILCH). The organisation follows the model of 'New York Lawyers for the Public Interest', a non-profit civil rights law firm located in New York City that specialises in the areas of disability rights, access to health care and environmental justice.

Justice Connect aims to improve access to justice by providing pro bono legal services to people who would otherwise be unable to obtain legal services. This includes helping 'people who are chasing stolen wages, older people facing abuse, and those who are struggling to pay the rent or experiencing homelessness.'[264]

The organisation is also involved in campaigns to achieve systemic change. As stated on its annual report:

> When laws are unfair, we advocate to change them. When systems and policies are confusing or hard to navigate, we develop ways to improve them.[265]

There are over 10,000 pro bono lawyers who offer their time and expertise to support the organisation's services, 88 staff who run its offices, and numerous volunteers and secondees who are also a part of the organisation's workforce.[266] The specific services offered by the organisation are in the fields of homeless law, seniors law, public interest law, domestic building legal services, self-representation services and not-for-profit law.[267]

Justice Connect provides a useful example of a legal service that could receive government support to address mental health discrimination.

25.10.2 The need for stronger mechanisms to confront systemic discrimination

As outlined above, the current legislative framework places the burden on individuals, who may be marginalised and disadvantaged,[268] to make sure people, particularly employers, are compliant with the Equal Opportunity Act. This is problematic because the number of people experiencing discrimination on the basis of mental illness is likely to greatly exceed the number of complaints made.[269]

VEOHRC submitted to the Commission that:

> Reducing the onus on individuals to enforce the law is important in a mental health context, since people with mental health issues are likely to find bringing a complaint stressful and the process may exacerbate their existing condition.[270]

Various legal and human rights experts drew attention to this shortcoming in the legal framework.[271] As Mr Gardner, told the Commission:

> I do think as long as we rely upon some of the most disadvantaged and oppressed people to run a system, whereby they're required to enforce the law rather than it being enforced on their behalf, it's just not going to work.[272]

Another participant in the Commission's Anti-Discrimination roundtable, Professor Penelope Weller, told the Commission:

> I do support all of the calls for broader systemic powers of investigation for various governance bodies. It's been a long-standing problem in Victoria, that complaints-driven systems don't produce the systemic outcomes that we need.[273]

In addition, the existing laws do not provide a mechanism for redress against systemic discrimination:

> When the discrimination is 'systemic' in that it results from policies, practices and attitudes that are entrenched in organisations or broader society, it can be difficult, if not impossible, to successfully bring an individual claim.[274]

In 2019, VEOHRC conducted an investigation into the travel insurance industry, and found that discrimination on the basis of mental health was 'prevalent and widespread'.[275] The investigation was launched following a successful individual complaint against an insurance company, and since it was conducted, all insurers removed (or are taking steps to remove) blanket mental health exclusions from their travel insurance policies.[276] However, given VEOHRC lacked the powers to compel their participation and attendance, the investigation 'was only possible because the insurance companies chose to cooperate'.[277]

Given the adverse impacts of discrimination on people's wellbeing—'including worsening of psychological distress, inhibition of help seeking and treatment adherence, limiting of personal relationships, and a reduction in their ability to achieve educational and vocational goals'[278]—and the current burden on people with lived experience to take action against discrimination, it is the Commission's strong position that there is a need for greater mechanisms to identify and redress systemic discrimination.

A multilevel approach is required. First, the Commission recommends that the Victorian Government support and establish mechanisms to identify and address systemic issues of discrimination on the basis of mental health. The Commission has received strong calls for power to conduct own-motion inquiries into discrimination, including powers to compel information, enter enforceable undertakings and issue compliance notices.[279]

The appropriate powers and body to enforce legal protections against discrimination are outside the Commission's letters patent. They are properly a matter for the Attorney-General of Victoria, as the First Law Officer of the State, and the Department of Justice and Community Safety. In considering the appropriate powers and body to enforce legal protections against discrimination, the Attorney-General and the Department of Justice and Community Safety should give due consideration to the harm caused by all forms of discrimination, and the potential challenges of distinguishing discrimination on the basis of mental health from discrimination on the basis of other attributes.

Second, as outlined in Chapter 27: *Effective leadership and accountability for the mental health and wellbeing system—new system-level governance*, the Mental Health and Wellbeing Commission will have own motion inquiry powers that will extend to stigma and discrimination related to mental illness and psychological distress. In considering the matter of mental health discrimination, it is the Commission's view that powers to address systemic discrimination on the basis of mental health are conferred to the Victorian Equal Opportunity and Human Rights Commission. However, in considering the matter of discrimination in full, the Victorian Government may determine that the Mental Health and Wellbeing Commission or another body is better placed to address systemic mental health discrimination and confer powers accordingly. Regardless, the Commission envisions the consumer advocacy function playing an important role in engaging with consumers to understand where stigma and discrimination, particularly structural stigma and systemic discrimination, remain an issue, and should play a key role in advising the relevant body of the lived experience community's observations and experiences. Where the Mental Health and Wellbeing Commission finds there has been discrimination, such findings will be referred to the appropriate body for any enforcement action.

Third, the Commission recommends that the Victorian Government fund independent legal services with a demonstrated connection or ability to connect with people with lived experience of mental illness or psychological distress, to initiate legal claims of systemic mental health discrimination.

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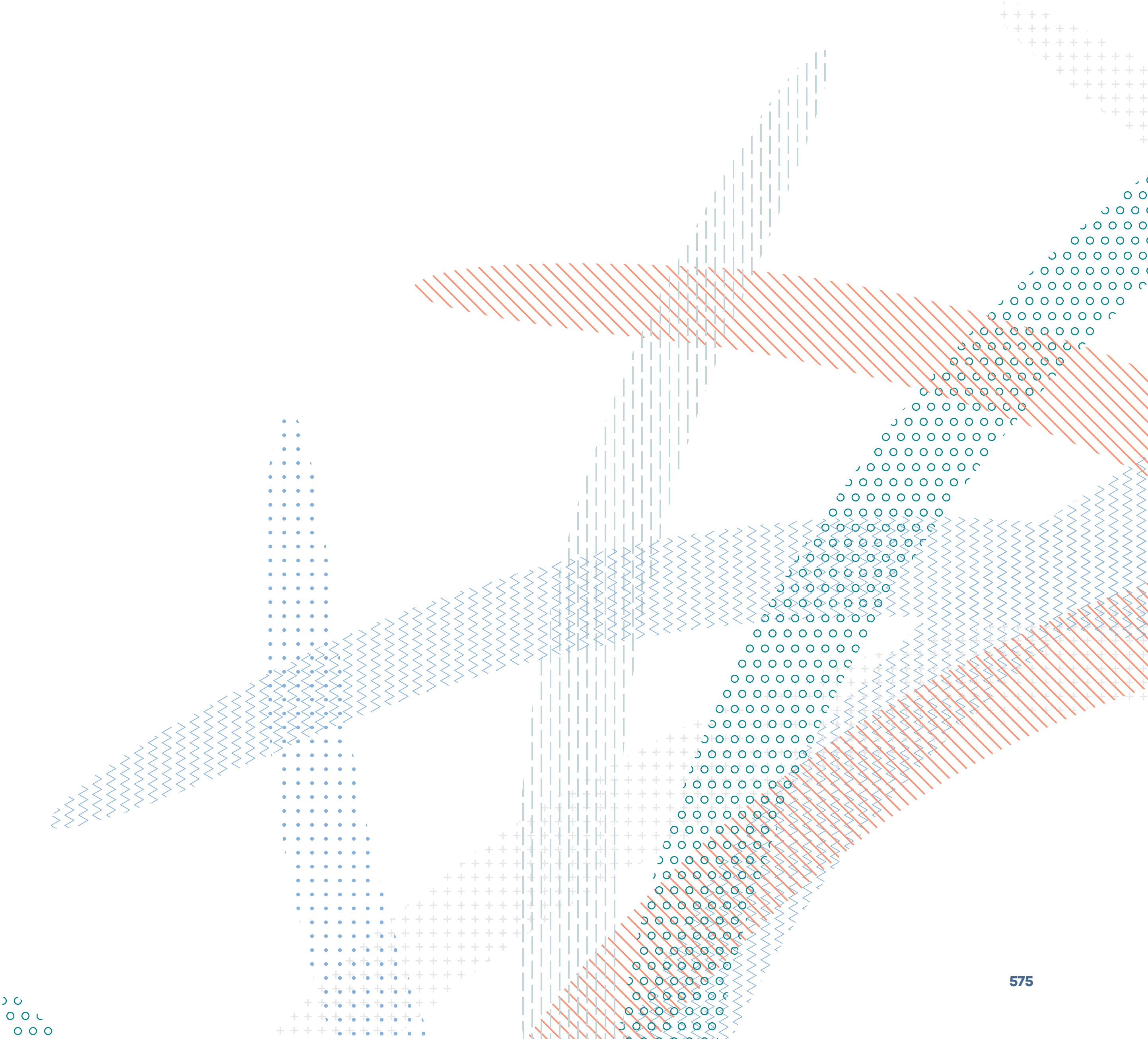

Glossary

The Commission notes that several of the terms within this glossary differ from phrasing used in its letters patent. Where this is the case, the Commission has either made a deliberate choice to provide greater clarity on a term, or to enable a more inclusive interpretation. The Commission has inquired into all matters as per the expectations set in the letters patent.

Aboriginal community controlled health organisation	A primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive and culturally appropriate health services to the community that controls it, through a locally elected board of management. This definition is consistent with that stated by the National Aboriginal Community Controlled Health Organisation.[1]
Aboriginal people	We recognise the diversity of Aboriginal people living throughout Victoria. While the terms 'Koorie' or 'Koori' are commonly used to describe Aboriginal people of south-east Australia, we have used the term 'Aboriginal' in this report to include all people of Aboriginal and Torres Strait Islander descent who are living in Victoria. This approach is consistent with the language conventions of key Victorian frameworks such as the *Aboriginal Affairs Framework 2018–2023*.[2]
Activity-based funding	While similar to a fee-for-service funding model, an activity-based funding model distributes funding to providers for the number of times they provide services to a person, with the amount based on each person's individual needs.[3]
Acute mental health inpatient services	Acute mental health beds, or acute inpatient units, support people experiencing an acute episode of mental illness that calls for treatment in hospital. These services include acute mental health beds for young people, adults and older adults.

Adult and Older Adult Area Mental Health and Wellbeing Services	Future services that will provide tertiary-level, high-intensity and complex support responses via multidisciplinary teams to people aged 26 years or older in both community and bed based settings. Adult and Older Adult Area Mental Health and Wellbeing Services will deliver all the core functions of community-based mental health services for those requiring a higher intensity of treatment, care and support than can be provided through local services. Services will be delivered through a partnership between a public health service or public hospital and a non-government organisation that delivers wellbeing supports (currently known as psychosocial supports). Access to these services will require a referral from a medical practitioner or Local Mental Health and Wellbeing Service.
Adult and older adult community mental health and wellbeing system	Future system that will provide treatment, care and support to Victorians over the age of 26 years. The Commission has taken an expansive view of what makes up the community mental health and wellbeing system, beyond mental health and wellbeing services. The system can be considered to span six levels, where the top level engages with the most people and each subsequent level supports a decreasing proportion of the population. The six levels are: • families, carers and supporters, informal supports, virtual communities and communities of place, identity and interest • a broad range of government and community services • primary and secondary mental health and related services • Adult and Older Adult Local Mental Health and Wellbeing Services • Adult and Older Adult Area Mental Health and Wellbeing Services • statewide services. Within this system, there will be an older adult mental health and wellbeing service stream that provides treatment, care and support for people with complex and compounding mental health needs generally related to ageing who are over the age of 65.
Adult and Older Adult Local Mental Health and Wellbeing Services	Future services that will deliver treatment, care and support to people aged 26 years or older. They will be delivered in a variety of settings where people first access services and receive most of their treatment, care and support. People will access these services either directly or via referral, and services will operate with extended hours. Services will deliver the Commission's recommended core functions for community mental health and wellbeing services. Service delivery may involve Area Mental Health and Wellbeing Services.

Area Mental Health and Wellbeing Services	Future services that will provide tertiary-level, high-intensity and complex support responses via multidisciplinary teams in both community and bed based settings. Area Mental Health and Wellbeing Services will deliver all the core functions of community-based mental health services for those requiring a higher intensity of treatment, care and support than can be provided through local services or in partnership with them. Services will be delivered through a partnership between a public health service and a non-government organisation that delivers wellbeing supports. There will be separate Area Mental Health and Wellbeing Services for infants, children and young people and for adults and older adults. For infants, children and young people there will be two service streams: Infant, Child and Family Area Mental Health and Wellbeing Services (0–11); and Youth Area Mental Health and Wellbeing Services (12–25). There will also be Adult and Older Adult Area Mental Health and Wellbeing Services (for people over the age of 26).
Area mental health services	The current state-funded area mental health services provide clinical community-based and inpatient care. Seventeen of Victoria's public health services operate area mental health services. Note: For the purposes of clarity, the current system is referred to in lower case and elements of the new service system have been capitalised in this report.
Allied mental health service	A service delivered by a diverse workforce such as psychologists, social workers and occupational therapists, working in a range of public, private, community and primary care settings.
Ambulatory care	Care provided to hospital patients who are not admitted to the hospital, such as patients of emergency departments and outpatient clinics. The term also refers to care provided to patients of community-based (non-hospital) healthcare services.[4]

Assertive outreach	A term applying to a broad range of models of care delivered in different service contexts. Generally, assertive outreach recognises that some people may require services to be more proactive in engaging or following up with them. Traditionally, assertive outreach models have included low caseloads, a multidisciplinary team, availability outside business hours, team autonomy and psychiatrist input. A variety of assertive outreach models are now in operation in Australia and internationally.
Assessment Order	An order made under the *Mental Health Act 2014* (Vic) that authorises a person to be compulsorily examined by an authorised psychiatrist to determine whether the treatment criteria, specified in the Mental Health Act, apply to the person. The order can either be an Inpatient Assessment Order or a Community Assessment Order, which reflects the location of where the examination is to occur.[5]
Authorised psychiatrist	A psychiatrist appointed by a designated mental health service to exercise the functions, powers and duties conferred on this position under the *Mental Health Act 2014* (Vic), the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* (Vic) or any other Act.[6]
Blended care	Providing care through integrating digital and face-to-face supports. In blended care, digital supports are used to complement face-to-face services and to build on the gains achieved in face-to-face delivery.[7]
Capitation funding	Under a capitation payment model, providers receive a fixed amount of funding for each person who registers with them for a specified period, usually a year.[8] Capitation funding is similar to block funding; however, the funding is based on the number and mix of people who are registered with the service.
Care	The provision of ongoing support, assistance or personal care to another person.[9]
Carer	A person, including a person under the age of 18 years, who provides care to another person with whom they are in a relationship of care.[10]

Clinical governance	'[T]he systems and processes that health services need to have in place to be accountable to the community for ensuring that care is safe, effective, patient-centred and continuously improving'.[11]
Coercion	The action or practice of persuading in a way that uses or implies force and threats—forcing someone to do something.
Commissioning	While there is no single agreed definition, commissioning can be understood as a cycle that involves planning the service system, designing services, selecting, overseeing and engaging with providers, managing contracts and undertaking ongoing monitoring, evaluation and improvement.[12] Co-commissioning or joint commissioning refers to the ways in which organisations work together and with their communities to make the best use of limited resources in the design and delivery of services and to improve outcomes.[13]
Community care unit	A unit that provides clinical care and rehabilitation services in a homelike environment.
Community health services and integrated care services	Services that provide primary health, human services and community-based supports to meet local community needs.
Community mental health and wellbeing services	Services provided outside a hospital setting—in community settings such as clinics or centres, in people's homes or other places, or delivered by phone or videoconferencing, or online.[14] Community mental health and wellbeing services delivered by hospitals are sometimes referred to as 'community ambulatory services' and include care delivered by hospitals, but not always in the hospital itself, such as through outpatient or day clinics.[15]

Community mental health and wellbeing services core functions	The core functions are recommended by the Commission to ensure consistency in treatment, care and support delivered across Victoria. The core functions, which are common across all age ranges, are: • integrated treatment, care and support proportionate to consumers' needs, consisting of: – treatment and therapies—including a broad range of psychological and psychiatric therapies, other therapeutic interventions, support for physical health, and support for substance use or addiction – wellbeing supports—including supports for community connection and social wellbeing, building life skills, securing and maintaining housing, and education, training and employment supports – education, peer support and self-help—through education, peer self-help and guided self-help – care planning and coordination—to ensure that treatment, care and support is proportionate to needs and to provide continuity of care • services to help people find and access treatment, care and support and in Area Mental Health and Wellbeing Services to respond 24 hours a day, seven days a week to people experiencing a mental health crisis • support for primary and secondary services (for example, GPs), including primary and secondary consultation and comprehensive shared care.
Comorbidity	A situation where a person has two or more health problems at the same time. Also known as multimorbidity.
Compulsory patient	Under section 3 of the *Mental Health Act 2014* (Vic) a compulsory patient means a person who is subject to an Assessment Order, Court Assessment Order, Temporary Treatment Order or Treatment Order under the Act. Compulsory patients are sometimes referred to as 'involuntary patients'.

Compulsory treatment	The treatment of a person for mental illness subject to an order under the *Mental Health Act 2014* (Vic), the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* (Vic) or the *Sentencing Act 1991* (Vic). This can include the administration of medication, hospital stays, electroconvulsive treatment or neurosurgery for mental illness. Compulsory treatment is sometimes referred to as 'involuntary treatment'.
Consecutive order	When a person is placed on a new compulsory treatment order, in anticipation of the current order ending,[16] to create a continuous duration and includes an Assessment Order, a Temporary Treatment Order and a Treatment Order.
Consumer	People who identify as having a living or lived experience of mental illness or psychological distress, irrespective of whether they have a formal diagnosis, have used mental health services and/or received treatment, care or support.
Consumer-completed measures and family-, carer- and supporter-completed measures	These measures collect information on the effectiveness of mental health and wellbeing services directly from the people who access services. They are a direct measure of experiences or outcomes, as determined by the individual. This information can be collected using a range of tools including questionnaires or standardised surveys.[17]
Consumer streams	The Commission uses the streams to describe how, at any given point in time, a person experiencing mental illness or psychological distress will need one of: • support from their communities and primary care services (communities and primary care stream) • treatment, care and support from primary and secondary mental health and related services (primary care with extra supports stream) • short-term treatment, care and support from a Local Mental Health and Wellbeing Service or an Area Mental Health and Wellbeing Service (short-term treatment, care and support stream) • ongoing treatment, care and support from a Local Mental Health and Wellbeing Service or an Area Mental Health and Wellbeing Service (ongoing treatment, care and support stream) • ongoing intensive treatment, care and support from a Local Mental Health and Wellbeing Service or an Area Mental Health and Wellbeing Service (ongoing intensive treatment, care and support stream).

Co-production	This involves people with lived experience of mental illness or psychological distress leading or partnering across all aspects of an initiative or program from the outset—that is, co-planning, co-designing, co-delivering and co-evaluating.[18]
Cultural safety	An environment that is safe for people—where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning, living and working together with dignity and truly listening.
Culturally appropriate	'An approach to policy, intervention, service delivery and intergroup interaction that is based on the positive acceptance of the cultural values and expectations of Aboriginal people.'[19] Culturally appropriate care is important for people from a broad range of cultures.
Culturally diverse	Term used in this report to reflect the fact that the Victorian population is diverse and that culture and language can influence people's needs and their access to mental health services that meet their needs.
Designated mental health service	A health service[20] that is prescribed in the Mental Health Regulations 2014 (Vic) to provide compulsory treatment[21] (includes Forensicare).
Digital mental health technology	The use of online and other digital technologies to improve mental health and wellbeing, including access to information, service delivery, education, promotion and prevention. It encompasses a vast range of technologies including apps, portals, social media, smartphones, augmented or virtual reality, wearables, activity tracking, e-referral, notifications and artificial intelligence. Other common terminology includes 'e-mental health' (health services that are online), 'm-health' (mobile and app-based support) and 'virtual health'.[22] This report uses 'digital mental health technology' as an overarching term that encompasses many types of technology. Where relevant, however, the report names specific technologies.

Discrimination	At its most basic, discrimination refers to the prejudicial treatment of people based on their individual or collective characteristics. In Victoria, the *Equal Opportunity Act 2010* (Vic) makes it unlawful to discriminate on the basis of 'disability' (which is defined to include a 'mental or psychological disease or disorder')[23] in certain settings including health care, employment and schools. This can be through 'direct discrimination' such as when someone is treated unfavourably because of a personal characteristic like mental illness.[24] This could be a refusal to treat someone, provide them access to services or admit them to a school because they have a mental health diagnosis. The law also protects against 'indirect discrimination', where an unreasonable requirement, condition or practice disadvantages a person or group of people based on a characteristic.[25]
Dual diagnosis service	Term historically used to describe services in Victoria that provide treatment, care and support to consumers living with mental illness and substance use or addition.
Dual disability	Term defined in the Commission's interim report as people living with both mental illness and an acquired or neurodevelopmental disability (such an intellectual disability, autism spectrum disorder, attention-deficit/hyperactivity disorder or a communication disorder).[26]
Early intervention	Includes prevention and early treatment. Early intervention can involve equipping people to deal with the signs and symptoms of illness or distress and helping people as soon as possible once mental distress is identified in order to improve the prospect of recovery (for example, following exposure to trauma).
Electroconvulsive treatment	The 'application of electric current to specific areas of a person's head to produce a generalised seizure'.[27] Also known as electroconvulsive therapy.
Enrolment	Refers to a consumer voluntarily enrolling with a service provider who is responsible for coordinating their comprehensive care. The consumer is free to get care through this 'responsible' provider, or through alternative providers. Enrolment may or may not be associated with a 'capitated' payment that is linked to the number of consumers enrolled (refer to definition: 'Capitation funding').

Family	May refer to family of origin and/or family of choice.
Fee for service	Under a fee-for-service funding model, service providers receive funding based on the number and mix of procedures, treatments and services they deliver.[28]
Forensic mental health service	A service that provides treatment, care and support services to people living with mental illness who have come into contact with the criminal justice system.
Forensic patient	A person under the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* (Vic) through an order of a court and detained at a designated mental health service (usually at Forensicare's Thomas Embling Hospital).[29]
Good mental health	A state of wellbeing in which a person realises their own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to their community.
Harm minimisation	A health policy approach that recognises there are complex and interrelated health, social and economic consequences of substance use or addiction that affect individuals, families and the community. A harm minimisation approach recognises that drug use is individual and occurs from occasional use to dependency. The approach does not condone drug use but recognises a range of strategies are required to support a progressive reduction in substance-related harm. A harm minimisation approach is based on three pillars: • Harm reduction aims to reduce high-risk behaviours associated with substance use and providing safer settings such as smoke-free areas or free water at music festivals. • Demand reduction is about preventing uptake of substances. Demand reduction also involves helping people who use substances to recover through a range of evidence-based care, treatment and support options. • Supply reduction is about controlling the supply and availability of substances.

Indicators	Qualitative or quantitative measures that can help determine change or progress and can be used to determine whether short-, medium- or long-term outcomes are being achieved. When indicators are used to measure the outcomes of a particular program or intervention (for example, resulting from reforms) they are measured from a baseline (before the program or intervention), at regular intervals after the intervention starts, and at the end.[30]
Infant, Child and Family Health and Wellbeing Hubs	Future local mental health and wellbeing services for people aged 0–11 years that will take the form of Infant, Child and Family Health and Wellbeing Hubs. These hubs will take a one-stop shop approach to child health by prioritising infants and children with emotional (for example, mental health challenges), developmental (for example, intellectual disability, autism spectrum disorder, speech delay) and physical health challenges (for example, asthma, allergies, chronic disease) that have continued to affect their wellbeing despite previous support. The hubs will provide age-appropriate treatment, care and support, use a whole-of-family approach, conduct a range of assessments as needed and be supported by Infant, Child and Family Area Mental Health and Wellbeing Services.
Infant, Child and Family Area Mental Health and Wellbeing Services	Future services that will provide tertiary-level, high-intensity and complex support responses via multidisciplinary teams to people aged 0–11 years. Infant, Child and Family Area Mental Health and Wellbeing Services are a service stream of the 13 Infant, Child and Youth Area Mental Health Services. These services will deliver all the core functions of community-based mental health services for those requiring a higher intensity of treatment, care and support than can be provided through local services or in partnership with them. Infant, Child and Youth Area Mental Health Services will be delivered through a partnership between a public health service (or public hospital) and a non-government organisation that delivers wellbeing supports.

Infant, child and family mental health and wellbeing service stream	Future service stream that will provide treatment, care and support to Victorians under the age of 12 years. It is one service stream within the broader infant, child and youth mental health and wellbeing system. The Commission has taken an expansive view of what makes up this service stream, beyond mental health and wellbeing services. The service stream can be considered to span six levels, where the top level engages with the most people and each subsequent level supports a decreasing proportion of the population. The six levels are: • families, carers and supporters, informal supports, virtual communities and communities of place, identity and interest • a broad range of government and community services • primary and secondary mental health and related services • Infant, Child and Family Local Health and Wellbeing Services • Infant, Child and Family Area Mental Health and Wellbeing Services within Infant, Child and Youth Area Mental Health Services • statewide services.
Infant, Child and Youth Area Mental Health and Wellbeing Services	Future services that will provide tertiary-level, high-intensity and complex support responses via multidisciplinary teams to people aged 0–25 years in both community and bed based settings. The 13 Infant, Child and Youth Area Mental Health and Wellbeing Services will deliver all the core functions of community-based mental health services for those requiring a higher intensity of treatment, care and support than can be provided through local services. Within these services will be two service streams: Infant, Child and Family Area Mental Health and Wellbeing Services and Youth Area Mental Health and Wellbeing Services. Services will be delivered through a partnership between a public health service or public hospital and a non-government organisation that delivers wellbeing supports (currently known as psychosocial supports). Access to these services will require a referral from a medical practitioner or Local Mental Health and Wellbeing Service.

Infant, child and youth mental health and wellbeing system	Future health system that will provide treatment, care and support to Victorians aged 0–25 years. Within this broad system, there are two service streams—the infant, child and family mental health and wellbeing service stream for people aged 0–11 years and the youth mental health and wellbeing service stream for people aged 12–25 years. At the area level, there will be shared clinical governance across the age range of 0–25 years through the 13 Infant, Child and Youth Area Mental Health Services.
Information collection, use and sharing	'Information collection' refers to mental health information a service provider or entity may collect as part of its organisational functions. 'Use' refers to the use of information for the purpose of delivering services to consumers, or for directly related purposes, such as administration. 'Use' also refers to who can see and use this information, and in what circumstances. It includes the protections and securities put in place to ensure privacy standards are met. 'Information sharing' broadly refers to the disclosure of information to another worker, provider, organisation or person for the purposes of treatment, support or accountability.
Inpatient	Relating to an admission to an inpatient unit of a designated mental health service.
Integrated care service	A service that provides a range of services and supports, including primary care and mental health care.
Intersectionality	Drawing on the Victorian Government's 2019 *Everybody Matters: Inclusion and Equity Statement*, the Commission describes intersectionality as a theoretical approach that understands the interconnected nature of social categorisations—such as gender, sexual orientation, ethnicity, language, religion, class, socioeconomic status, gender identity, ability or age—which create overlapping and interdependent systems of discrimination or disadvantage for either an individual or group.[31]
Lived experience	People with lived experience identify either as someone who is living with (or has lived with) mental illness or psychological distress, or someone who is caring for or otherwise supporting (or has cared for or otherwise supported) a person who is living with (or has lived with) mental illness or psychological distress. People with lived experience are sometimes referred to as 'consumers' or 'carers'. The Commission acknowledges that the experiences of consumers and carers are different.

Lived experience workforces	A broad term to represent two distinct professional groups in roles focused on their lived expertise—people with personal lived experience of mental illness ('consumers') and families and carers with lived experience of supporting a family member or friend who has experienced or is experiencing mental illness. Within each professional discipline there are various paid roles, among them workers who provide support directly to consumers, families and carers through peer support or advocacy, or indirectly through leadership, consultation, system advocacy, education, training or research.
Local Mental Health and Wellbeing Services	Future services that will provide treatment, care and support in a variety of settings where people first access services. People will access these services either directly or via referral, and services will operate with extended hours. Services will deliver the Commission's recommended core functions. Service delivery may occur in partnership with area services. These services will be a combination of primary and secondary responses supported by some tertiary-level responses. There will be separate local services for each of three age groups: Infant, Child and Family Local Health and Wellbeing Services (0–11), Youth Local Mental Health and Wellbeing Services (12–25) and Adult and Older Adult Local Mental Health and Wellbeing Services (over 26).
Medicare-subsidised mental health-specific service	Service in which the Medicare Benefits Scheme and the associated Better Access Initiative provide subsidised access to GPs and other health professionals such as psychiatrists, psychologists and other allied health practitioners.
Mental health and wellbeing	An optimal state of mental health, including as it relates to people with lived experience of mental illness or psychological distress. It can also be used to refer to the prevention, avoidance or absence of mental illness or psychological distress.

Mental Health and Wellbeing Commission	A new independent statutory authority recommended by the Royal Commission to: • hold government to account for the performance and quality and safety of the mental health and wellbeing system • support people living with mental illness or psychological distress, families, carers and supporters to lead and partner in the improvement of the system • monitor the Victorian Government's progress in implementing the Royal Commission's recommendations • address stigma related to mental health.
Mental health and wellbeing information	Information or an opinion about a consumer's physical, mental or psychological health, a health service provided, a consumer's expressed wishes about future service delivery, and personal information collected to provide health services. Information from others, including families, carers and supporters may also be included in mental health information, where appropriate.
Mental health and wellbeing system	The Commission outlines in this report its vision for a future mental health and wellbeing system for Victoria. Mental health and wellbeing does not refer simply to the absence of mental illness but to creating the conditions in which people are supported to achieve their potential. As part of this approach, the Commission has also purposefully chosen to focus on the strengths and needs that contribute to people's wellbeing. To better reflect international evidence about the need to strike a balance between hospital-based services and care in the community, the types of treatment, care and support the future system offers will need to evolve and be organised differently to provide each person with dependable access to mental health services and links to other supports they may seek. The addition of the concept of 'wellbeing' represents a fundamental shift in the role and structure of the system.
Mental health system	Overarching term that takes in services (with various funders and providers) that have a primary function of providing treatment, care or support to people living with mental illness and/or their carers. This term is used to describe the current and historical system.
Mental Health Tribunal	Independent statutory tribunal established under the *Mental Health Act 2014* (Vic) to hear and determine the making of Treatment Orders and other applications, including applications to perform electroconvulsive treatment when a person does not have decision-making capacity or is under the age of 18 years and applications to perform neurosurgery for mental illness.[32]

Mental illness	A medical condition that is characterised by a significant disturbance of thought, mood, perception or memory.[33] The Commission uses the above definition of mental illness in line with the *Mental Health Act 2014* (Vic). However, the Commission recognises the Victorian Mental Illness Awareness Council Declaration released on 1 November 2019. The declaration notes that people with lived experience can have varying ways of understanding the experiences that are often called 'mental illness'. It acknowledges that mental illness can be described using terms such as 'neurodiversity', 'emotional distress', 'trauma' and 'mental health challenges'.
Mental wellbeing	A dynamic state of complete physical, mental, social and spiritual wellbeing in which a person can develop to their potential, cope with the normal stresses of life, work productively and creatively, build strong and positive relationships with others and contribute to their community.
Neurosurgery for mental illness	Any of the following three procedures, provided to treat a person meeting the criteria for mental illness: a) 'any surgical technique or procedure by which one or more lesions are created in a person's brain on the same or on separate occasions for the purpose of treatment b) the use of intracerebral electrodes to create one or more lesions in a person's brain on the same or on separate occasions for the purpose of treatment c) the use of intracerebral electrodes to cause stimulation through the electrodes on the same or on separate occasions without creating a lesion in the person's brain for the purpose of treatment'.[34]
Nominated person	The formal nomination of a person under the *Mental Health Act 2014* (Vic) by a person to provide them with support and help and to represent their interests and rights at times when they are at risk of receiving compulsory treatment or are receiving compulsory treatment. The nominated person also receives information from the authorised psychiatrist at certain points and is consulted as part of decision-making processes under the Act.[35]

Older adult mental health and wellbeing service stream	Future service stream that will provide treatment, care and support to Victorians with mental health support needs generally related to ageing. It is a service stream within the broader adult and older adult mental health and wellbeing system. The Commission has taken an expansive view of what makes up this service stream, beyond mental health and wellbeing services. The service stream can be considered to span six levels, where the top level engages with the most people and each subsequent level supports a decreasing proportion of the population. The six levels are: • families, carers and supporters, informal supports, virtual communities and communities of place, identity and interest • a broad range of government and community services • primary and secondary mental health and related services • Adult and Older Adult Local Mental Health and Wellbeing Services • Adult and Older Adult Area Mental Health and Wellbeing Services, which will include older adult mental health and wellbeing specialist multidisciplinary teams • statewide services.
Outcome domains	Categories or groups of outcomes relating to broad areas of mental health and wellbeing. For example, outcome domains could relate to providing safe and high-quality mental health services or could relate to consumer satisfaction with service delivery and treatment and care.
Outcomes	Changes to the health or wellbeing of a person, group or population that results from some kind of intervention or multiple interventions. Interventions are defined very broadly and include particular models of care or treatment or making health services more accessible or acceptable to consumers.[36] Individual health outcomes are measures of individual health and wellbeing status. These can be measured in the short, medium and long term. Population-level outcomes are measures of aggregated data on the health of a population—for example, the population of Victoria or Australia.[37] Outcomes are measured using indicators.
Output funding model	The Victorian Government uses an 'output funding model' whereby departments use the investment allocated in the budget process to deliver on the government's objectives[38] and outputs.[39] Output performance measures are used to specify the expected performance standard at which these services are to be delivered,[40] covering measures such as the quantity of services provided, timeliness, quality and cost.[41]

Postvention bereavement support	A range of support services provided to people who have been bereaved by suicide.
Prevention and recovery care unit	Generally a short-term service (up to 28 days) that provides recovery-focused treatment in a community-based residential setting.
Primary care	Health services where consumers access care, treatment and support without the need for a referral or without needing to meet certain eligibility criteria. Primary care settings include general practices, community health services and some allied health services. Primary care services are widely distributed, are the most accessible form of health care and are provided in most local communities across Victoria. Typical primary care providers are GPs or allied health professionals such as social workers or mental health nurses. However, primary care can be offered by a wide range of professionals including psychologists, paediatricians and maternal child and health workers.
Primary consultation	A consultation between a mental health clinician or multidisciplinary mental health team and a consumer that may be conducted in person or through teleconferencing or phone. A primary consultation can occur following a referral—for example, where a GP makes a referral for a consumer to have a primary consultation with a psychiatrist.
Primary Health Networks	Networks that commission a variety of mental health, alcohol and drug, and suicide prevention services. Services commissioned can vary but may include: referral and support services; primary and specialist consultation services; prevention and early intervention services; services to reduce the harm associated with alcohol and other drugs; and capacity-building activities such as workforce education and training.[42] Refer to Box 29.4 in Chapter 29: *Encouraging partnerships* for detail.
Primary prevention	Strategies that aim to stop the onset of a health condition or disease from ever occurring by addressing the underlying causes or determinants of that condition. Primary prevention is distinct from secondary prevention, also referred to as early intervention, which aims to minimise the progress of a condition or disease at an early stage. It is also distinct from tertiary prevention, which aims to stop further progression of the condition and address the impacts that have already occurred.

Private hospital	Includes acute care and psychiatric hospitals, as well as private freestanding hospitals that provide day-only services.
Professional practice supervision	Refers to a formal professional relationship between two mental health practitioners that is designed to enable reflective practice, support professional self-care, maintain standards of professional practice, refine relational and clinical competencies and explore ethical issues. It is distinct from line management and performance management and is not a form of therapy.
Psychiatric assessment and planning unit	A unit that offers assessment and treatment for people experiencing an acute episode of mental illness and that minimises the need for an extended hospital stay in an inpatient unit.
Psychological distress	'One measure of poor mental health, which can be described as feelings of tiredness, anxiety, nervousness, hopelessness, depression and sadness.'[43] This is consistent with the definition accepted by the National Mental Health Commission.
Public specialist mental health services	Services that provide both clinical and non-clinical mental health services. These are largely delivered by area mental health services operated by 17 public health services in Victoria.
Quality assurance	A range of strategies, including regulation, used to provide assurance that services are meeting minimum quality or safety standards and expectations.
Quality and safety oversight	Monitoring either system or service performance to identify and report on the quality and safety of mental health treatment, care and support. This can include oversight of specific practices (such as monitoring the use of electroconvulsive treatment), of the performance of an individual service, or of the whole system. Oversight often involves a degree of independence from the practice or service that is subject to oversight.
Recovery-oriented practice	Practice that supports people to autonomously build and maintain a self-defined, meaningful and satisfying life and personal identity, whether or not there are ongoing symptoms of mental illness.[44]

Reflective practice	Interprofessional and collaborative group-directed processes of learning through and from experience to gain new insights via: • reflection on experiences of delivering care, treatment and support to consumers, families, carers and supporters • examining and critically reflecting on assumptions underlying everyday practices • reflecting on challenging interpersonal dynamics.
Regional Mental Health and Wellbeing Boards	Skills-based boards (rather than a representative board) recommended by the Commission that will include people with lived experience. Regional Boards will seek to support communities to achieve the highest attainable standard of mental health and wellbeing through achieving the following objectives: • Services respond to the needs of local communities. • Services respond to individual needs and preferences, with a focus on community-based service provision. • Services are integrated. • Safe services are incentivised. • Resources are allocated to improve outcomes. • Resources are allocated in a way that maximises value. Regional Boards will have a range of responsibilities. This includes being responsible for understanding need and planning services, supporting collaboration, funding and monitoring service providers, workforce planning and engaging with communities.
Regional Multiagency Panels	New coordinating structures recommended by the Commission in each region to bring together different service providers to support collaboration and accountability in providing services to consumers by multiple service agencies.
Restrictive interventions	May include 'bodily restraint', which is defined as a form of physical or mechanical restraint that prevents a person from having free movement of their limbs (excluding the use of furniture), or 'seclusion', which is the sole confinement of a person to a room or any other enclosed space from where the person is not free to leave.[45]

Seclusion and restraint	The *Mental Health Act 2014* (Vic) currently defines two forms of 'restrictive interventions': • **Bodily restraint** is a form of **physical** or **mechanical** restraint that prevents a person having free movement of their arms or limbs but does not include the use of furniture (including beds with cot sides and chairs with tables fitted on their arms) that restricts the person's ability to get off the furniture.[46] • **Seclusion** is the sole confinement of a person to a room or any other enclosed space from which it is not within the control of the person confined to leave.[47] Under the Act, seclusion and restraint can only be used in designated mental health services.[48] The Act also prescribes that restrictive interventions (including seclusion and restraint) may only be used after 'all reasonable and less restrictive options have been tried or considered and have been found to be unsuitable'.[49] Restrictive interventions can also be called 'restrictive practices'. This term is used throughout the report when necessary to reflect the use of the term in source data or evidence.
Secondary care	Health services that require a referral from a primary care provider (usually a GP). A common example is a referral from a GP to a private psychologist under the Better Access scheme. Another common form of secondary care is where a GP refers a consumer to a psychiatrist for a mental health assessment.
Secondary consultation	A discussion between mental health clinicians about a particular consumer. This can enable different care providers to work collaboratively to discuss issues with the consumer's care. Other models of secondary consultation focus on the needs of consumers more generally—for example, consumers with particular mental health needs or a specific diagnosis. This model focuses on sharing knowledge and expertise between different care providers.
Secure extended care unit	A unit offering secure services on a general hospital site for people who need a high level of secure and intensive clinical treatment for severe mental illness.

Security patient	A prisoner who is placed on an order under the *Mental Health Act 2014* (Vic) or the *Sentencing Act 1991* (Vic) and detained at a designated mental health service (usually at Forensicare's Thomas Embling Hospital).[50]
Self-determination	In a collective sense, this term is used to refer to the 'ability of Aboriginal peoples to freely determine their own political, economic, social and cultural development as an essential approach to overcoming Indigenous disadvantage'.[51] Some materials referenced by the Commission also use the term 'self-determination' to refer to individual autonomy and each person's ability to make choices about themselves and their life.
Service and capital plan	A plan that 'identifies present and, as best as possible, future demand for services' and is intended to 'guide the future allocation of resources'.[52] Also called a 'service and infrastructure plan'.
Service standards	The Commission has developed service standards to assist the Victorian Government and Regional Mental Health and Wellbeing Boards to select service providers—including new providers, such as consumer-led providers—with adequate capacity and capability to deliver mental health services. Refer to Chapter 28: *Commissioning for responsive services* for detail.
Shared care	A structured approach between two or more health services that each take responsibility for particular aspects of a consumer's care. This responsibility may relate to the particular expertise of the health service. Shared care is supported by formal arrangements, including clear care pathways and clinical governance, and all health services involved share a joint and coordinated approach to the health and wellbeing of the consumer. Shared care approaches can also benefit health providers—for example, by providing them with access to expert advice, which can increase their capabilities over time.
Social and emotional wellbeing	Being resilient, being and feeling culturally safe and connected, having and realising aspirations, and being satisfied with life. This is consistent with *Balit Murrup*, Victoria's Aboriginal social and emotional wellbeing framework.

Social determinants of mental health	A person's mental health and many common mental illnesses are shaped by social, economic, and physical environments, often termed the 'social determinants of mental health'. Risk factors for many common mental illnesses are heavily associated with social inequalities, whereby the greater the inequality the higher the inequality in risk.[53]
Social housing	Term covering two distinct forms of subsidised rental housing: public housing, which is owned and operated by the Victorian Government, and community housing, which is owned and operated by community housing providers.[54]
Statewide services	Based on the evidence presented, the Commission characterises statewide services as those that usually involve: • a workforce with a high level of expertise and knowledge • a dedicated research focus • the provision of treatment, care and support to a proportionately small number of people, often with higher levels of needs.
Stigma	The World Health Organization defines stigma as a 'mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society'.[55] Stigma is a fundamentally social process—different characteristics or traits are not inherently negative, 'rather, through a complex social process, they become defined and treated as such'.[56] This process leads to social exclusion.[57]
Structural stigma	Refers to the 'societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and wellbeing for stigmatised populations'.[58]
Substance use or addiction	Substance use means the use of alcohol, tobacco or other drugs (prescription or illicit). Substance use may become harmful to a person's health and wellbeing or can have other impacts on someone's life or that of their family and broader social network. Addiction to substances means compulsive substance use that is outside a person's control, even when it has harmful effects on that person or their family.
Substituted decision making	Where a third party makes treatment decisions for the consumer.

Supported decision making	The process that supports a person to make and communicate decisions with respect to personal or legal matters. This may be achieved by offering consumers access to a variety of tools and resources such as non-legal advocates and peer workers.[59]
Systemic discrimination	Term that 'describes patterns or practices of discrimination that are the result of interrelated policies, practices and attitudes that are entrenched in organisations or in broader society'.[60]
Telehealth	Video teleconferencing using some form of online software or phone-conferencing to deliver services and supports directly to a consumer.[61]
Temporary Treatment Order	An order made under the *Mental Health Act 2014* (Vic) by an authorised psychiatrist following an examination under an Assessment Order that requires a person to be provided with compulsory treatment. The order is either an Inpatient Temporary Treatment Order or a Community Temporary Treatment Order.[62]
Tertiary care services	Highly specialised medical care usually over an extended period of time that involves advanced and complex procedures and treatments performed by medical specialists in state-of-the-art facilities.
Treatment	When 'a person receives treatment for mental illness if things are done in the course of the exercise of professional skills to remedy the person's mental illness; or to alleviate the symptoms and reduce the ill effects of the person's mental illness'.[63]
Treatment, care and support	The Commission uses this phrase consistently with its letters patent. This phrase has also been a deliberate choice throughout this report to present treatment, care and support as fully integrated, equal parts of the way people will be supported in the future mental health and wellbeing system. In particular, wellbeing supports (previously known at 'psychosocial supports') that focus on rehabilitation, wellbeing and community participation will sit within the core functions of the future system.
Treatment Order	An order made under the *Mental Health Act 2014* (Vic) by the Mental Health Tribunal following a period of treatment under a Temporary Treatment Order that requires a person to be provided with compulsory treatment. The order is either an Inpatient Treatment Order or a Community Treatment Order.[64]

Value-based care	Care whose goal is to create more value for consumers by focusing on the outcomes that matter to them, rather than just focusing on cost-efficiency. Some funding approaches are designed to encourage greater value, such as bundled payments.[65]
Voluntary patient	A person who receives treatment for a mental illness or psychological distress who is not subject to a compulsory assessment or treatment order.
Wellbeing supports	Used to describe supports for wellbeing in the future system. Includes supports currently known as 'psychosocial supports'.
Whole of government	Although there is no universally agreed definition of 'whole-of-government' approaches (often interchangeably referred to as 'joined-up' approaches), the Commission uses this phrase to denote different areas of government (for example, health, human services, justice and corrections) working together to achieve shared outcomes.[66]
Whole of system	The Commission's terms of reference define the mental health system by reference to mental health services that are funded wholly, or in part, by the Victorian Government. When the Commission refers to 'whole of system' in relation to the mental health system, the reference is to a broader system. This includes not only public sector bodies and organisations at the federal, state and local government levels; it includes all people and organisations who participate in—or are connected with—the new mental health and wellbeing system recommended by the Commission.
Youth Area Mental Health and Wellbeing Services	Future services that will provide tertiary-level, high-intensity and complex support responses via multidisciplinary teams to people aged 12–25 years. Youth Area Mental Health and Wellbeing Services are a service stream of the 13 Infant, Child and Youth Area Mental Health Services. Youth Area Mental Health and Wellbeing Services will deliver all the core functions of community-based mental health services for those requiring a higher intensity of treatment, care and support than can be provided through local services or in partnership with them. Infant, Child and Youth Area Mental Health Services will be delivered through a partnership between a public health service (or public hospital) and a non-government organisation that delivers wellbeing supports.

Youth Local Mental Health and Wellbeing Services	Future services that will deliver treatment, care and support to people aged 12–25 years or older. The role of Youth Local Mental Health and Wellbeing Services in the youth mental health and wellbeing service stream will be predominantly played by the network of headspaces across Victoria, although, over time, other providers may also choose to deliver this level of service. Youth Local Mental Health and Wellbeing Services and Youth Area Mental Health and Wellbeing Services will be formally networked within each of the 13 areas. They will work together in partnerships to provide treatment, care and support to young people.
Youth mental health and wellbeing service stream	Future service stream that will provide treatment, care and support to Victorians aged 12–25 years. It is one service stream within the broader infant, child and youth mental health and wellbeing system. The Commission has taken an expansive view of what makes up this service stream, beyond mental health and wellbeing services. The service stream can be considered to span six levels, where the top level engages with the most people and each subsequent level supports a decreasing proportion of the population. The six levels are: • families, carers and supporters, informal supports, virtual communities and communities of place, identity and interest • a broad range of government and community services • primary and secondary mental health and related services • Youth Local Mental Health and Wellbeing Services • Youth Area Mental Health and Wellbeing Services within Infant, Child and Youth Area Mental Health Services • statewide services.

Shortened forms

The following shortened forms are frequently used in this report. Other shortened forms are explained where they are used.

AC	Companion of the Order of Australia
AM	Member of the Order of Australia
AO	Officer of the Order of Australia
CEO	Chief Executive Officer
DNA	deoxyribonucleic acid
GP	general practitioner
IT	information technology
LGBTIQ+	lesbian, gay, bisexual, trans and gender diverse, intersex, queer and questioning
MP	Member of Parliament
OAM	Medal of the Order of Australia
PSM	Public Service Medal
TAFE	Technical and Further Education

1 National Aboriginal Community Controlled Health Organisation, *Submission to the Productivity Commission Inquiry into Human Services: Identifying Sectors for Reform*, 2016, p. 4.

2 Victorian Government, *Victorian Aboriginal Affairs Framework: 2018–2023*, 2018, p. 1.

3 Department of Health and Human Services, *Clinical Mental Health Funding Reform: Building a Stronger Foundation for Funding Adequacy, Growth and Fairness*, 2020, p. 3.

4 Australian Institute of Health and Welfare, *Mental Health Services in Australia 2004–05*, 2007.

5 *Mental Health Act 2014* (Vic), sec. 28.

6 *Mental Health Act 2014* (Vic), sec. 150.

7 Doris Erbe and others, 'Blending Face-to-Face and Internet-Based Interventions for the Treatment of Mental Disorders in Adults: Systematic Review', *Journal of Medical Internet Research*, 19.9 (2017), 1–15 (p. 2).

8 Michael E Porter and Robert S Kaplan, *How Should We Pay for Health Care? Working Paper 15-041*, 2015, p. 3.

9 *Carers Recognition Act 2012* (Vic), sec. 3.

10 *Carers Recognition Act 2012* (Vic), sec. 3.

11 Department of Health and Human Services, *Targeting Zero: Supporting the Victorian Hospital System to Eliminate Avoidable Harm and Strengthen Quality of Care. Report of the Review of Hospital Safety and Quality Assurance in Victoria*, 2016, p. 3.

12 Karen Gardner and others, 'A Rapid Review of the Impact of Commissioning on Service Use, Quality, Outcomes and Value for Money: Implications for Australian Policy', *Australian Journal of Primary Health*, 22.1 (2016), 40–49 (p. 40); Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Inquiry Report*, 2017, p. 21.

13 Helen Dickinson and others, 'Making Sense of Joint Commissioning: Three Discourses of Prevention, Empowerment and Efficiency', *BMC Health Services Research*, 13.S6 (2013), p. 1.

14 Royal Commission into Victoria's Mental Health System, *Interim Report*, 2019, p. 615.

15 Australian Institute of Health and Welfare, *State and Territory Community Mental Health Care Services*, 2019, p. 15; Productivity Commission, *Mental Health Inquiry Report, Volume 2*, 2020, p. 570.

16 Note: Where there is a gap of no more than five minutes between the orders.

17 Kathryn Williams and others, *Patient-Reported Outcome Measures: Literature Review* (Australian Commission on Safety and Quality in Health Care, 2016), pp. 1 and 18.

18 Cath Roper, Flick Grey and Emma Cadogan, *Co-Production: Putting Principles into Practice in Mental Health Contexts*, 2018, p. 2.

19 Pet Dudgeon, Helen Milroy and Roz Walker (eds.), *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing*, Second Edition (Canberra: Commonwealth of Australia, 2014), p. 544.

20 *Health Services Act 1988* (Vic), sec. 3. Note: the reference to a health service includes a public hospital, public health service, denomination hospital, privately-operated hospital or private hospital within the meaning of the *Health Services Act 1988* (Vic).

21 *Mental Health Act 2014* (Vic), sec. 3.

22 Ana Hategan, Caroline Giroux and James A. Bourgeois, 'Digital Technology Adoption in Psychiatric Care: An Overview of the Contemporary Shift from Technology to Opportunity', *Journal of Technology in Behavioral Science*, 4 (2019), 171–77 (p. 171).

23 *Equal Opportunity Act 2010* (Vic) secs. 4 and 6. The Commission recognises that terms such as 'psychological disease or disorder' can be pathologising and stigmatising.

24 *Equal Opportunity Act 2010* (Vic), sec. 9.

25 *Equal Opportunity Act 2010* (Vic), sec. 10.

26 Royal Commission into Victoria's Mental Health System, *Interim Report*, p. 35.

27 *Mental Health Act 2014* (Vic), sec. 3.

28 Porter and Kaplan, p. 2.

29 *Mental Health Act 2014* (Vic), sec. 305.

30 Centers for Disease Control and Prevention, United States, Indicators: CDC Approach to Evaluation, <www.cdc.gov/eval/indicators/index.htm>, [accessed 3 December 2020].

31 Royal Commission into Victoria's Mental Health System, *Interim Report*, p. 50; Family Safety Victoria, *Everybody Matters: Inclusion and Equity Statement*, 2018.

32 *Mental Health Act 2014* (Vic), sec. 153.

33 *Mental Health Act 2014* (Vic), sec. 4.

34 *Mental Health Act 2014* (Vic), sec. 3.

35 *Mental Health Act 2014* (Vic), sec. 24.

36 Peter C Smith, Elias Mossialos and Irene Papanicolas, *Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects* (World Health Organization, 2008), p. 4.

37 Smith, Mossialos and Papanicolas, p. 4.

38 Department of Treasury and Finance, *Performance Management Framework: For Victorian Government Departments March 2016*, 2017, p. 18.

39 *Witness Statement of David Martine PSM*, 28 June 2019, para. 17.

40 Department of Treasury and Finance, p. 12.

41 *Witness Statement of David Martine PSM*, para. 17.

42 PHN Eastern Melbourne, Mental Health, AOD and Suicide Prevention, <www.emphn.org.au/what-we-do/mental-health>, [accessed 24 October 2019].

43 National Mental Health Commission, *Monitoring Mental Health and Suicide Prevention Reform: National Report 2019*, 2019, p. 87.

44 Department of Health, Victoria, *Framework for Recovery-Oriented Practice*, 2011, p. 2; Geoff Shepherd, Jed Boardman and Mike Slade, *Making Recovery a Reality Policy Paper*, 2008, p. 2.

45 *Mental Health Act 2014* (Vic), sec. 3.

46 *Mental Health Act 2014* (Vic), sec. 3.

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