

Your story,

your say

Consumers' **priority issues and solutions** for the Royal Commission into Victoria's Mental Health System

ACKNOWLEDGEMENT OF COUNTRY

Victoria Legal Aid acknowledges we operate on Aboriginal country throughout Victoria. We acknowledge the traditional custodians of the land and respect their continuing connections to land, sea and community.

We pay our respects to their Elders, both past and present.

We acknowledge the experiences of Aboriginal and Torres Strait Islander people with mental health issues, and their treatment by mental health services and connected systems, such as criminal justice and child protection systems. We appreciate the leadership, wisdom and resilience that arises from Aboriginal Victorians' approaches to social and emotional wellbeing.

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FOREWORD

At this time of opportunity in the history of mental health in Victoria, it is critical that the voices of people whose lives have been greatly impacted by the system now shape the way forward.

Given the system is 'broken', we cannot afford to merely apply a band aid. The Royal Commission into Victoria's Mental Health System must go beyond merely *hearing* people's voices, to truly *respecting* and *acting* on them.

The *Your story, your say* project has been incredibly respectful and supportive of people who want their stories and messages heard. Victoria Legal Aid needs to be commended on the work it has done to privilege consumers' voices in its engagement with the Royal Commission, specifically in how it has supported consumers to share their stories in this project.

This report's themes reflect what consumers have been saying for decades since before I began working in consumer roles in 2000. For many people who participated in this project, telling their story was not easy. People have confronted trauma, anguish and distress. That they do this in the hopes of a better mental health system makes them all the more compelling. Their stories are both heart-wrenching and heart-warming. Consumers' hopes must not be dashed. Let their pain be a true impetus for a mental health system that nourishes people in the ways that work for them.

So that we honour what is most important to people who will need services in the future, Victoria's new mental health system must be and feel safe to people using it. Mental health services must be of the highest standard. A standard that you would be happy to use yourself and have your family use. Consumers know what this looks like and how to do this. They know that this requires genuine choices, including alternatives to the current system.

The highest measure of success of Victoria's mental health system will be the endorsement of people who use it.



Wanda Bennetts
Senior Consumer Consultant,
Independent Mental Health Advocacy

1. EXECUTIVE SUMMARY



'[Y]ou walk in, there is a big fireplace, a beautiful rug, nice colours that sync well to your brain. When you need a psychologist, OT (occupational therapist) or your own private psychiatrist, they are there. There's horticulture, archery, dorms, horses and cows. You are connected to the ground and nature. There is no reason why you can't do this.'

This is how an Aboriginal woman we spoke to invited the Royal Commission to imagine her place of healing. Her place of healing is part of her broader story.

Stories are central to our understanding of who we are, how we fit in the world and our wellbeing. They are windows through which we can understand and analyse the social, political and legal dimensions of another person's experience. Stories, well-told, and listened to attentively, can be healing for individuals, informative for policy makers and illuminating for the broader community.

Victoria Legal Aid's (VLA) *Your story, your say* project supported people with experience of mental health issues and services to tell their stories to the Royal Commission into Victoria's Mental Health System (Royal Commission). These stories were in their own words.¹ People with experience of mental health issues and / or services have developed expertise over many years through their experience of distress, stigma and discrimination, as well as mental health systems which have shaped their daily lives. In recognition of this hard-won expertise, we refer to participants in this project as 'lived experience experts' or 'experts'. We also acknowledge that the language surrounding mental health and services is important and contested,² and have wherever possible, used the words of lived experience experts.

This report summarises the priority issues and solutions identified for the Royal Commission by these lived experience experts (n=34). Having experienced systems that often harm rather than help, they are acutely aware of the important opportunity for change the Royal Commission provides. The themes, language and structure in this report reflect the views expressed by a diverse community of lived experience experts, and do not necessarily reflect VLA's views (see Appendix 2 outlining our methodology for this project).


How the system is broken

Lived experience experts identified several issues in Victoria's current mental health system. They pinpointed a number of drivers for developing and exacerbating mental health issues including a lack of safe housing, family or gendered violence and discrimination or workplace bullying. Time and time again, experts reported barriers to accessing quality mental health services they needed – the right support, at the right time. They shared how they were treated by first responders (e.g. police, ambulance or the Crisis Assessment and Treatment Team (CATT) and what it felt like to be compulsorily admitted and detained in hospitals, or not provided adequate supports at a crisis point. When experts finally accessed effective supports for their mental health, they also identified barriers which abruptly cut off these supports due to strict and inflexible funding, eligibility or service rules.

When accessing mental health services, many lived experience experts reported relationships with clinicians based on power and control. The firsthand experience of being forced to take medication was a recurring issue raised – how being 'drugged' felt physically and emotionally, as well as how being under the influence of medication affected people's ability to maintain social relationships, engage in life-giving activities or meaningfully assert their rights. How mental health services provide, withhold and selectively record personal information was also raised by multiple lived experience experts.

¹ These stories are not provided in this report and have been provided directly to the Royal Commission. Parts of their stories are quoted with the consent of the lived experience experts who participated in this project.

² For further information on language, see: Victorian Mental Illness Awareness Council, *The Declaration*, (2019) <https://www.vmiac.org.au/declaration/>



The intersection of mental health and legal systems also arose for many lived experience experts. A number of the stories outlined negative experiences of restrictive practices, of feeling shut out of decision-making about their own treatment. Lived experience experts spoke about the flow-on consequences of discrimination and stigma, and violations of human rights without proper accountability. Some experts shared differing experiences about the Mental Health Tribunal (Tribunal), and former VLA clients with experience of therapeutic courts³ reported positively about the therapeutic model, particularly in comparison with non-therapeutic court and tribunal systems.

What needs to change

Consumers of mental health services should drive and be central to every stage of reforming Victoria's mental health system. As part of this project, lived experience experts identified system changes that would have helped them to avoid the suffering and hardship they have experienced in the current mental health system. They identified broader measures to address the social determinants of mental health, such as family violence, poverty, workplace bullying and harassment, as well as homelessness. Resourcing better service delivery and engaging in system re-design with mental health consumers was identified as essential to improving how our mental health system operates in practice. Training and development of mental health services and connected systems emerged repeatedly as a recommendation, as did education for young people and families as part of building a more nuanced understanding of mental health in homes and communities.

A number of lived experience experts identified the need to reconceptualise mental health issues and clinicians' approach to treatment and medication, particularly when administered without consent. Experts also made a series of suggestions about how to provide stronger protections for mental health consumers against abuse, mistreatment and coercion. Finally, solutions to improve accountability mechanisms to ensure any reforms are effective were raised, particularly for people under compulsory treatment and forensic mental health settings.

³ Therapeutic courts may also be known as "problem-solving courts" or "solutions-focused courts" and include the Drug Court, Assessment and Referral Court, Koori Court and Neighbourhood Justice Centre.

2. SUMMARY OF KEY THEMES IDENTIFIED BY EXPERTS

2.1 Systemic themes identified by lived experience experts

Drivers of mental health issues

- Low income and poverty
- Unhelpful family approaches to mental health
- Family violence and abuse
- Structural barriers affecting young people
- Housing and homelessness
- Discrimination, bullying and harassment
- Drug and alcohol use

Information, health records and privacy

- Lack of information about hospital processes
- Barriers to access, contribute to, or correct clinical notes
- Experiences of privacy breaches and unwanted family involvement

Barriers to accessing quality mental health services

- Lack of appropriate, affordable and voluntary community services
- Age limits and transitions between youth, adult and aged mental health services
- Mental health facilities and therapeutic activities
- Negative experiences of first responders and emergency departments
- A lack of staff and beds
- Experiences of feeling unsafe in inpatient services

Discrimination, compulsory treatment and restrictive practices

- Experiences of stigma and discrimination
- Failure to involve lived experience experts in their own treatment
- Negative experiences of restrictive practices

Experiences of power and control

- Power imbalances between consumers and clinicians
- Lack of accountability
- Benefits of legal and non-legal advocacy

Courts, tribunals and legal issues

- Mixed experiences of the Mental Health Tribunal
- Positive experiences of Therapeutic Courts

Experiences of medication

- Positive experiences of medication for some consumers
- Most consumers reported significant harmful psychological and physical effects of medication
- Experiences of harmful effects were often minimised or reframed as behavioural issues

2.2 Systemic solutions identified by lived experience experts

Address the social determinants of mental health

- Address family violence through better policing and housing responses
- Enable meaningful employment
- Address workplace bullying and harassment

Training and development

- Community training and education on mental health
- Training on collaboration, rights and specialist mental healthcare for clinicians

Funding better service delivery

- Close the gaps in the mental health system
- Reforming age-limits and transitions between youth, adult and aged mental health services
- Everyone should have an advocate

Embarking on systems re-design

- Increasing the number of peer support services, co-design and consumer leadership
- Increasing the number of voluntary, responsive and community-based services
- Demedicalising mental health

Embedding safeguards, integrity and accountability systems

- Increasing the number of legal and non-legal advocates
- Reforming compulsory treatment, access to health information and first responders
- Improving transparency and oversight
- Reducing barriers in the compensation process

3. SYSTEMIC THEMES IDENTIFIED BY LIVED EXPERIENCE EXPERTS

While experiences of lived experience experts are rich and unique, central themes emerged across stories, many of which overlap. This section summarises the common themes emerging from the stories shared with the Royal Commission.

3.1 Drivers of mental health issues

Over half of the stories (n=20) had a focus on the **drivers of mental health issues** and emotional distress. These factors were regularly reported by some experts as interconnected, and as both drivers and accelerators of distress.

Systemic themes

Experts identified the following are systemic drivers of mental ill-health:

- Low income and poverty
- Unhelpful family approaches to mental health
- Family violence and abuse
- Structural barriers affecting young people
- Housing and homelessness
- Discrimination, bullying and harassment
- Drug and alcohol use

Low income and poverty were identified in several stories as both a driver of mental health issues as well as a barrier to accessing quality services (see 3.3(a) Challenges in accessing appropriate, affordable community services).

Unhelpful family approaches to mental health were seen by some as a foundation for later mental health issues. One lived experience expert reported their family's denial of mental health issues:



'I grew up in a family that was under the impression that 'mental health didn't exist', mainly due to my parents coming from very difficult and traumatic family backgrounds of their own. Since they did not have the tools to understand differently, when I started experiencing mental illness, it went widely unnoticed for years until I could not hide it anymore. In my family, there were not many discussions about mental health and when there were, they were always negative and dismissive, leading me to become very closed off towards most people. This reaction towards mental health taught me to bury any pain/confusion/concern so deep down that it took my life being under threat for me to take any action towards what had become a debilitating mental illness and lifestyle.'

These unhealthy environments often included **family violence and abuse**. This was commonly reported by young people. In some circumstances, people reported protective services failing them:



'Young people are often at risk of violence in their homes, which risks their mental health issues. I was experiencing a violent home life, and this can affect young people's mental health. My case manager contacted Child Protection at this time as she was concerned about me, but they never contacted me. Someone should have contacted me from Child Protection.'

This was not limited to young people. Several lived experience experts reported gendered violence towards women (including older women) from male partners, including coercive and controlling behaviours that produced trauma and mental health issues.

Others reported the impact of a lack of safe housing or experiencing homelessness. Several participants also reported discrimination and workplace bullying as factors that drove their mental health issues or drove them to be admitted to services compulsorily.

Finally, several participants reported that drug and alcohol use or dependence was a trigger or major driver of their mental health issues.

3.2 Information, health records and privacy

Information access and management issues emerged as a theme across approximately a third of stories (n=13).

Systemic themes

- A lack of information within services on hospital processes and consumer rights
- Barriers to accessing, contributing to, and correcting, health information and records
- Breaches of privacy by services

(a) 'It is all very uncertain' – a lack of information within services

Several lived experience experts reported frustration at a **lack of information about service processes and consumer rights** from clinicians.

Specific themes

- Extended periods in forensic mental health units without information
- Positive and negative experiences accessing communication technologies
- A lack of available information about how consumers can exercise their rights

There were concerns about **forensic hospital processes** and clinical **decision-making regarding transitions** through units and discharge from the service. For example, one expert stated:

'I've been at [a forensic mental health unit] just over 3 years. At first, I progressed quickly but then once I got to [my current unit] I progressed more slowly. I've been here longer than most of the male patients now. Only one other male patient has been here since I got here. Some people seem to get out of here who shouldn't, while other people who should get out have to wait years and years.'

They also spoke of **differences in access to communication technologies** while in forensic mental health units. For example, they stated:

'It's good having increased freedoms on the unit. Things like having my own tv and gaming console in my room. Music is a major one for me too. I listen to a lot of heavy metal – it helps me with stress so it's nice having that. That's better in [this unit] because it's possible to get a better MP3 player. In the [acute units] you're not really allowed on the internet, so you've got to get the [staff member] to pick it up for you from JB Hifi, but he only buys the basic brand. In [this unit], I can go online and find something decent.'

Some experts spoke about the **lack of information on their rights** on wards, while others reported staff **taking down rights** information.

(b) 'A wall of frustration' – barriers to access, contribute to, or correct clinical notes

Lived experience experts regularly reported that **information management issues** impacted their rights and treatment.

Specific themes

- Difficulty accessing their clinical notes during admissions
- Selective and incorrect recording of information in the clinical notes by clinicians
- Incorrect recording of information raising questions about the quality of care
- Limited avenues to participate in writing or correcting their clinical notes

One expert noted the difficulty in **accessing clinical notes** to exercise their rights:



'It's not easy to exercise your rights when you don't have any of the information you need. In there I tried to access my own clinical notes, to understand what they were saying about me. Instead they said that I would have to go through this rigorous freedom of information process, to access the notes that they were writing about me! I just gave up. For someone doing worse than me, this would be impossible.'

Other experts reported that mental health services engaged in **selective recording of information**, where information which would reflect unfavourably on clinicians or be contrary to a clinician's preferences was unlikely to be recorded. One lived experience expert surmised that 'they either don't record the things you want them to record, or they put false and misleading information in there.'

Incorrect recording of information led them to **question the quality of care** and whether this put them at medical risk:



'Every time I go into [the service], I look at the medications list and there is information missing and false information. I have tried to get them to update this so many times. What if they give me the wrong medication, do I have to re-experience the horrific side-effects of these medications or die?'

Other experts stated they were **excluded from the clinical notes writing process**, and that this put them at a disadvantage when attempting to exercise their rights:



'I have no meaningful way to be involved in how these are written, to see them or to correct them when they are wrong. This then goes to places like the MHT [Mental Health Tribunal] where it defames me.'

(c) 'Privacy... is not taken as seriously as it should be' – experiences of privacy and family involvement

Privacy issues were raised by some lived experience experts.

Specific themes

- Privacy is not always respected, particularly in relation to young people and people living in regional areas
- Services sometimes involve family members or other people, contrary to lived experience experts' wishes

One expert spoke about the tendency of the mental health system to undermine young people's privacy in talking with family members. She provided the following example where the service ignored her **boundaries and privacy**:



'The first time I tried to access hospital care I was 16 and my school counsellor had come along with me due to my parents opposing my decision to go to a hospital, leaving it up to my school to care for me. This attempt to access care was short-lived due to my father showing up half-way through the meeting with the psych triage nurse without asking me or the nurse. I had said that I would be comfortable talking if my dad wasn't in the room and my counsellor tried their best to help but the nurse didn't see any issues with it. After my father was able to manipulate the situation, dismissing my distress to the nurse, she decided that I wasn't at a high level of risk to myself and I was denied access into inpatient care. A few months after this I would have an attempt on my life.'

Further stories spoke of how mental health services, along with other agencies, **involved family contrary to experts' wishes** and preferences. For example, one expert reported that:



'This admission brought me into contact with Child Protection, who were concerned for my son. This meant that my ex-partner was made to come in to live at my home if I was to be discharged from hospital. This was a distressing experience as I care for my children deeply – I am a mother before anything.'

Some experts living in **regional areas** spoke of the heightened importance of privacy, but the greater difficulty in protecting your privacy once you have been diagnosed. They reported that this is because your actions become more scrutinised after a diagnosis:



'I remember once just hanging out near a trainline – which everyone else is entitled to normally do – and someone called the police and they came and grabbed me saying I was suicidal. Once you're labelled with a mental illness in a regional area, your life changes.'

3.3 The quality and accessibility of existing mental health services

Approximately two thirds of the stories (n=21) highlighted issues around accessing quality mental health services.

Systemic themes

- Challenges in accessing appropriate, affordable and voluntary community services
- Issues with age-limits and transitions between youth, adult and aged mental health services
- The quality of mental health facilities and activities
- Experiences of emergency departments (EDs)
- A lack of staffing and beds

(a) '10 sessions bulk-billed is inadequate' – challenges in accessing appropriate, affordable and voluntary community services

Lived experience experts reported their positive and negative experiences of accessing appropriate, affordable and voluntary community services.

Specific themes

- Inadequacy of 10 Medicare funded psychological sessions per year
- Limitations with many online and national counselling and crisis phone services
- Variability in using general practitioners (GPs) as an entry point to mental healthcare
- Limited mental health supports in housing or homelessness services

There were common difficulties accessing quality mental health services in the community. Several lived experience experts spoke about the **inadequacy of 10 sessions** under Medicare's Mental Health Access Program:



'I have found it so difficult to get the supports I need. Getting a private psychologist is tricky and there is always a gap in the payments. The Medicare rebates can also take a couple of days to come back, meaning I often don't have the upfront money to pay for sessions or have to go without something else. This is unsustainable for people like me living off the Disability Support Pension or small wages.'

Another expert reiterated that '10 sessions bulk-billed is inadequate to deal with my periods of severe distress'. Experts spoke about how limited psychological sessions made it difficult to access specialist psychological care and did not enable a **continuous relationship** with their psychologist.

One lived experience expert spoke about how **national web, telephone and crisis counselling services** were mixed in quality, noting that there is often long wait-times as well as generic responses from practitioners.

There were mixed stories about experiences of **GPs as access points** to the specialist mental health system and as supports in their own right. One lived experience expert reported:



'I think there is a lack of mental health awareness in the community and amongst GPs, especially as it relates to young people. When I spoke about my mental health issues, my GP hadn't even heard of [clinical youth mental health service]. GPs need to know what services are out there and what treatment options there are.'

However, another expert reported that their **GP was a real ally**, particularly in guarding against more difficult engagements that they had with clinical mental health services.

Some lived experience experts reported a **lack of mental health-informed homelessness services** in the community. One expert detailed their recent experience with a homeless service:



'I accessed crisis accommodation services due to not having anywhere to live at the time. I resided there for 2 weeks before I was hospitalised again. During my time there I tried to speak to the workers about issues I was having but was met with the response that they were not equipped to deal with mental health issues and that I should seek help elsewhere. While in hospital again, I received a voicemail from the crisis accommodation basically saying I was too much of a risk and was being removed from that service. They packed up my stuff and dropped it off at the hospital. This left me feeling defeated and stressed as I then had to find somewhere else to live.'

(b) 'I felt as if I wasn't ready quick enough' – age-limits and transitions between youth, adult and aged mental health services

Young and older lived experience experts expressed concern about the **differences in quality of**, as well as **transitions between**, youth, adult and aged care mental health services.

Specific themes

- Positive experiences of youth clinical mental health services (e.g. more therapeutic engagements, reduced wait-times and more personalised service delivery)
- Time and age-limits in clinical youth mental health programs had negative impacts on experts' wellbeing and care
- Transitions from youth to adult mental health services were often distressing for young people
- Aged mental health services reflected a further drop in quality from adult mental health services

All young experts who reported accessing youth clinical mental health services stated that they had **positive experiences** of these services. The reasons for this included positive relationships with case managers, additional time for therapeutic engagements, reduced wait-times, and more personalised service delivery. Their concerns, however, were that there was a **two-year use or age limit** which capped their access to some clinical youth mental health services. For some, the pressure to be 'well' within the two-year timeframe **caused distress and feelings of rejection**:



'I felt like if I wasn't ready quick enough there was something wrong with me. I began trying to convince myself and them that I was well enough. It made me feel like they wanted me out.'

Another young lived experience expert highlighted that these limits **undermined therapeutic relationships** by 'breaking good relationships with services.'

Depending on when you entered youth services, it meant you could be **transitioned into adult services** at a very young age:



'I found the two-year timeframe on [clinical youth mental health] services was very restrictive. For example, I went in when I was 16 or 17. That means I was exited from [clinical youth mental health service] by 18 and put into adult services. I was still so young. It was confronting.'

When transitioned to adult services, all young lived experience experts reported a significant **drop-off in quality** of service delivery.

However, this concern was not just for young people. An **older lived experience expert** also spoke about the drop-off in quality from adult to aged mental health services when they lost access to a de-funded community mental health service and was subsequently transferred to aged mental health services:



'That my access to care and support should not be so dramatically affected by a birthday. From the time I have turned 65, I have gradually lost access to the support and care that I need and used to enjoy.'

(c) Mental health facilities and therapeutic activities

Several experts spoke about the state of mental health facilities and therapeutic activities.

Specific themes

- Mixed experiences of therapeutic and leisure activities based on whether they were meaningful or distracting, and how frequently they were provided
- Access to information and communication technologies
- Outdated state of aged mental health services

There were mixed feelings about activities in inpatient units. For example, multiple lived experience experts spoke about the personal benefits of activities on forensic mental health units. They reported that the difference was that these were **meaningful activities** while activities they had participated in at clinical mental health services had been more aimed at **distracting them**.

The views of activities in clinical inpatient units, by contrast, were generally negative. Where there were interesting activities, such as music, one lived experience expert was concerned that it was **too infrequent** (once a week):



'there are no books to read or exercise facilities in these inpatient units, leading to boredom and a depressed state. The activities in place made me feel like I was 5 years old e.g. cooking class and colouring in.'

The use of technology on forensic units was also an issue, with some experts noting that the **lack of communication and information technologies** impeded their opportunities to undertake personal and professional opportunities online.

Concerns about the state of **aged mental health services** was noted by one older man, later suggesting it reflected a broader issue of **age discrimination**:



'That the lived environment of aged care mental health units such as [aged inpatient unit] are exceedingly outdated and reflect the de-prioritisation of aged mental health – it feels as if the mental health system is forgetting people, letting them grow old and mentally decay.'

(d) 'They drag you in and drug you' – negative experiences of first responders and emergency departments

Several lived experience experts wrote about their experiences of first responders (ambulance, police, Crisis and Assessment Treatment Teams (**CATT**) and EDs.

Specific themes

- Negative experiences of police, ambulance and CATT emergency responses
- Positive experiences in more recently designed EDs
- Negative experiences through the regular use of restrictive interventions
- Concern that some ED staff lacked competency in assessing and responding to distress

Delays and a lack of timeliness by first responders was raised by one expert, who spoke about overdosing and waiting four hours for an ambulance to arrive.

All experts who reported on their interactions with **police had negative experiences**. One expert surmised their involvement as ‘unhelpful and inhumane’, and another expert said that it made her feel like ‘a common criminal.’ One expert described this experience:



‘My story in the system came when the Police rocked up at my doorstep after I was hearing voices. They threw me to the ground and maced me with two mace cans, threw me in the divvy van and took me to the hospital. I was strapped to the bed, with my eyes on fire on all night. This is when my hell started in the mental health system.’

Some experts said that emergency-response issues are **magnified in regional areas**. In one case, an expert reported that this was because you became ‘tagged’ by police and the community, and in another, an expert reported that there was an increased use of police due to a **shortage of ambulances**.

There was mixed experience of EDs. One expert reflected on a recent positive experience at a metropolitan ED, because it had been re-designed recently to improve care.

However, the majority of experts expressed negative views. One expert detailed the use of **restrictive practices** in emergency settings:



“EDs in general, are just terrible. They drag you in and drug you... So, I ended up in [...] hospital for another 4 days. They forced me to take medication. I refused, so they restrained me and forced it on me. The medication absolutely slammed me. It was horrifying.’

Another young expert spoke about the **lack of competency** of some ED staff resulting in inappropriate assessments, and the impact this had on them when they were seeking help:



‘When I got there, I had the world’s worst triage nurse. She was just the rudest, most awful person. Not very smart either. When I spoke about my suicidality, she decided – without any context or discussion with me – that my suicidality was just attention seeking brought on by watching 13 Reasons Why. It was such a stupid thing to say. She didn’t know how real this was for me. This was the first time I had spoken openly about this – I had made myself vulnerable. I had hidden it for so long. We made a “safety plan” and I was discharged but I never touched it.’

(e) ‘Chronically understaffed’ – a lack of staff and beds

Some people reported a **lack of staff and beds** available within inpatient units and EDs. For these experts, staffing shortage led to a **lower standard of care**:



‘[M]ental health services are chronically understaffed, making it hard to access the kind of support that you need, especially when staying in an inpatient facility. The less staff available to support individuals, the more crises that go unnoticed and the more underequipped facilities become.’



‘You can request help, and not hear from them for hours. Then they change shifts and you start again. The ratios of staff to consumers is too much.’

One lived experience expert reflected that understaffing leads to **restrictions on rights**, such as the availability of staff to undertake the mental state examinations required to take leave in forensic mental health units.

(f) A lack of safety on wards

Several experts reported feeling unsafe in wards.

Specific themes

- Experiences of powerlessness connected to experiences of feeling unsafe
- Experiences of harassment and vilification
- Drug and alcohol issues on the ward
- Safety issues affecting women
- Positive developments from Safewards program

Other experts reported that there was an inherent **lack of safety** arising from power imbalances with clinicians, and that inpatient environments 'feel unsafe, restrictive, and lifeless.' Some of the reports of **harassment and vilification** from lived experience experts included being called a 'homo' and 'she-man' by other consumers, being told by another consumer that they would get their 'fucking head kicked in', and overhearing two nurses say, 'don't you just want to slap her in the face?' about them.

Other experts spoke about feeling unsafe due to **behaviour from other consumers** in inpatient units who appeared to be affected by drugs or alcohol:

'Many people in there are drug-affected, and this makes me feel unsafe. At one point someone who was ice-affected tried to strangle me after I asked him to stop abusing someone else.'

Some experts spoke about the **threats to women's safety** in inpatient units:

'The hospital was an unsafe environment for women. I regularly had male staff entering my room to do observations on me – I believe this is inappropriate in a female only ward. There were also issues with male patients who were sexually suggestive. I know of one person who was sexually assaulted while she was in the unit with me. It made me feel unsafe. This was made much worse by the medication which impaired my ability to think and act quickly.'

There were also positive experiences reported, such as the **benefits of Safewards⁴** in **improving relationships** between consumers and clinicians by bringing the two groups together.

⁴ Safewards is a model with associated interventions aimed at reducing conflict and containment, and increasing a sense of safety and mutual support for staff and consumers. See further: Victorian Government, Safewards Victoria, < <https://www2.health.vic.gov.au/safewards#:~:text=The%20Safewards%20story,interventions%2C%20including%20seclusion%20and%20restraint>.

3.4 Power and control

Experiences of **control by services, a lack of accountability** and the **value of advocacy** featured in over 80% of stories (n=27), irrespective of whether people accessed services voluntarily or compulsorily.⁵

Systemic themes

- Power imbalances between experts and clinicians
- A lack of accountability for clinicians and mental health services
- The benefits of legal and non-legal advocacy

(a) 'Demigods' - power imbalances between experts and clinicians

Several experts spoke to the **inherent power imbalance** between lived experience experts and mental health workforce members, particularly psychiatrists, and police.

Specific themes

- Losing agency and opportunity to make choices
- Feeling alone and isolated
- Loss of self, relationships and a sense of normality

For some experts, being a consumer in a mental health unit meant having to **give up their agency** across several dimensions of their life and daily routine:

'[I]t was not uncommon to be left knocking on a window for 30 minutes or more to gain access to one's room. Rooms were ransacked daily searching for unknown contraband. Nurses referred to the psychiatrists as "demigods" who were not to be argued with.'

⁵ While power and control have significant overlap with section 3.5 Discrimination, compulsory treatment and restrictive practices, this section focuses more on the lived experience of powerlessness, feeling controlled, and the relationships between experts and the clinicians.

This power imbalance and fear **narrowed opportunities for experts to make choices**. For example, one expert reported having to choose silence over speaking up about their medication concerns so that they could leave a service:

'I was too scared to raise it with them. Talking to the other patients, I was told that "if you say no, you will just stay longer". So, I took the medication that left me sedated and drooling.'

While some lived experience experts reported solidarity with other patients, many articulated their time in an inpatient unit as a **lonely and isolating** experience where they felt exposed:

'When I got to the hospital, I was not assessed for three days. I was eventually put in front of a psychiatrist. I felt like I was railroaded and bullied by him. He had five other people there - I was never asked if I wanted them there. I was not allowed an advocate, a support person, or to record the conversation. When I demanded a support person, I was given a nurse, but the nurses never advocated for me, they just sit there silently.'

Another lived experience expert noted the power behind the term **'insight'**, stating that it 'manages to become suitable for any clinician's aims'. Other experts spoke about how power imposed on them resulted in a **loss of self, relationships and normality**:

'[T]he system impresses itself upon you and imprisons you. You can't think from the medication. People stop calling your phone. Relationships are gone. Your life changes. Your person is dead. But you are meant to go on pretending that everything is normal. And you never have any choice about the matter. It's an invisible and symbolic prison.'

One older lived experience expert spoke about how her loss of freedom in an inpatient unit **disconnected her from her world**, which was her cat Cinnamon:



'I was worried about Cinnamon too. He was quite old, and my friend who was taking care of him was concerned too, because he wasn't eating. I pleaded for them to give me leave so that I could go home and visit him. They dragged their heels and ultimately refused. Cinnamon died while I was in hospital. It still crushes me to think he died without me there.'

(b) 'There is no justice' – a lack of accountability

Lived experience experts were concerned about a **lack of accountability** within the mental health system.

Specific themes

- Failures of systems to standardise the quality of care between different psychiatrists
- Cultural and systemic issues in services about their approaches to consumers' rights
- Safeguarding and oversight bodies not working effectively
- Oversight undermined by inaccurate clinical notes

Several experts spoke about accountability as a service failure to **standardise the quality of care** among psychiatrists. One lived experience expert spoke about the experiences of two contrasting admissions in 2020:



'[G]etting the right psychiatrist shouldn't be a lottery. You should get the right access to care no matter who you see. But in my experience, one psychiatrist respected me and gave me care, while the other did the opposite and took away my rights.'

This was reiterated by experts who accessed regional mental health services. The lack of accountability was described by some lived experience experts as a **cultural or systemic issue**:



'This highlights a culture where they believe they are above everything else. Above the patients and the law. They gather and become strong in their packs, but we're alone. They will see something wrong happening, but 99.9 per cent of them will turn their backs or pretend to not see it. I had heaps of nurses injecting me when I didn't have psychosis. Just following one another, dragging me to the slaughtering shed.'

Some experts reported turning to **safeguarding and oversight bodies** for assistance. For example:



'[T]he safeguarding systems don't work. I have used Legal Aid, Independent Mental Health Advocacy and the Mental Health Complaints Commissioner. They're toothless tigers. I made a complaint to the MHCC over the phone and never heard from them. The Mental Health Tribunal never gave me a fair shot – they were only ever interested in hearing from clinicians. I'm currently hoping to get a 2nd opinion from the Second Psychiatric Opinion Service. I am hoping that this will address my diagnosis and treatment order and that the person will be open-minded, less likely to label me, and undertake an impartial assessment – time will tell.'

Other experts also spoke about making complaints to the Mental Health Complaints Commissioner (MHCC). For some, this was a positive experience, and an opportunity to feel heard by an independent body. For others, complaints recommendations from the MHCC were not implemented:



'I have sought help and refuge from the mental health services. I made a complaint to the Mental Health Complaints Commissioner, after being entertained by them that I would be taken seriously. But the real issues were not addressed, because neither the MHCC or the service were willing to acknowledge the harm that they have caused me. The service was meant to sit down with me and engage in the kind of collaborative conversation about my experiences that I needed. This never happened on anything except what they chose. It was to fulfill a formality.'

Some lived experience experts reported that many of the **mechanisms for oversight are undermined** by clinical notes that experts said were often false or misleading (see 3.2 Information, health records and privacy).

(c) 'In your corner' – the benefits of legal and non-legal advocacy

Experiences of powerlessness led many to access legal and non-legal advocacy.

Specific themes

- Legal and non-legal advocacy is necessary to protect rights
- Timing of these supports is critical to them achieving positive outcomes

One lived experience expert spoke about advocacy as critical because 'the system and psychiatrists take away your rights, you need lawyers and advocates in your corner.' Another added that **knowing your rights** was often not enough to exercise them, and that **advocates were necessary**:



'I'm a disability support worker, and I know very well that I have rights, but that these clinicians are not respecting them. They say that they will help you to earn your trust, but they don't. I've now had to get my advocate from IMHA to help me, because the clinicians don't care what you have to say.'

One lived experience expert stated that 'my support from IMHA and VLA helped protect me when I needed it most.' Often lived experience experts reported how access to **coordinated legal and non-legal advocacy** worked well together:



'I was fortunate to get help from an advocate and lawyer. The doctor tried to up my Lithium to 450mg on top of my Olanzapine, but the lawyer and advocates helped me to understand and speak up for my rights. It helped me make my stand.'

One expert, however, went on to say that they 'only came across [advocates] by chance though'. The **timing of accessing supports was critical**:



'The "protections" in place for my rights were too late and ineffective. I didn't get access to the Independent Mental Health Advocacy until three weeks into my admission, so many decisions had already taken place. It was made clear there was no room for negotiation.'

3.5 Discrimination, compulsory treatment and restrictive practices

Over half (n=19) of the lived experience experts' stories raised themes that interacted with key areas of law regulating Victoria's mental health system.

Systemic themes

- Experiences of stigma and discrimination
- Failure to involve experts in their own treatment
- Experiences of restrictive practices

(a) 'You are treated like a second-class citizen' – experiences of stigma and discrimination

Several people shared experiences of **stigma and discrimination**.

Specific themes

- Certain diagnoses may attract stigma and discrimination
- Stigma and discrimination are worse in regional communities where you become 'known'
- Experts felt silenced or undermined in talking about their experiences
- Different standards of treatment and rights for mental health consumers compared with general health consumers

Some experts had concerns with stigma and **discrimination arising from diagnoses**. Not all diagnoses prompted these concerns; particular concern focused on diagnoses such as schizophrenia and borderline personality disorder. For some experts, their concern related to stigma and discrimination from services, meaning that they did not seek treatments that they later found helpful (such as Dialectical Behaviour Therapy). Other experts spoke about how incorrect diagnoses such as schizophrenia, rather than post-traumatic stress disorder (PTSD), were distressing as they led to incorrect or worse treatment from the mental health service.

People's experiences of stigma, discrimination and problems with the Mental Health Act 2014 (Vic) (Act) were often reported as **worse in regional communities**, where you become 'known' to mental health services and police, and have to take additional steps to conceal your diagnosis from the community.

One lived experience expert spoke about the **different standards** faced by people diagnosed with mental health issues as opposed to other medical issues:



'If the person has a heart disease, you don't put them in front of a panel [Mental Health Tribunal] and make them look like a fool. People with mental health issues are often just worn out.'

Another expert spoke of **denial of their decision-making capacity**, and the contrast between their autonomous decision-making in some parts of their life, as opposed to their experience of mental health services:



'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.'

(b) 'They never ask me what I want or need' – failure to involve lived experience experts in their own treatment

Lived experience experts reported failures by services to support them to make or participate in decisions about their treatment (see also 3.4(a) Power imbalances between experts and clinicians).

Specific themes

- Failures by services to involve consumers during clinical reviews
- A tendency to make decisions before communicating with experts
- Loss of agency

Several experts reported clinicians **excluding consumers from decision-making** or psychiatrists ignoring their views and preferences. For example:



'Psychiatrists and mental health services don't listen to you. If I had a meeting now, the psychiatrist would have already made up their mind, because they had read the notes. They have run through the whole conversation in their head. They have their aims, and they will get those by either pushing the issue, or just lying and doing it behind your back. Meeting with you is just a formality.'

Another expert reflected on being excluded from their own mental health decisions over decades:



'Mental health services have never been helpful to me. They never ask me what I want or need. I am bent out of shape to fit what they need. Sometimes they're so focused on what they want and need, it's like the train is so busy trying to be on schedule that it's leaving all of the passengers behind.'

(c) 'Why was I shackled?' – experiences of restrictive practices

Restrictive practices such as bodily restraint, mechanical restraint, chemical restraint, and seclusion featured in several stories. For example, one expert spoke about multiple instances of **seclusion and restraint**:



'When I was admitted to a unit after my 4-hour delay, I was put in a cold white seclusion room with one chair. I had been self-harming and was upset and distressed. Their solution was to take my blood with invasive tests and give me 5mg of Valium. And this was not an isolated incident. For example, another time when I had presented at the ED for mental health issues, I was treated with the same rash course of action. Once I was medically cleared, I decided to leave, but was made involuntary and pinned down by 4 large security guards to keep me at the hospital.'

An older expert spoke about her experiences of forced medication and the **threat of restrictive practices** in an aged mental health service:



'It was scary. At one point, one of the nurses came over and said I was going to have an injection. I said, "no I'm not". She said, "yes you are". This went back and forth until I realised there were two extra security guards standing behind her. Next thing I knew they had come over and forced the injection on me. I was an older lady who had difficulties moving. This was unnecessary. I felt like I had been assaulted and I sat there crying afterwards.'

One expert questioned the necessity of **extended use of mechanical restraints**, after she had been asleep for most of the 24 hours she was restrained.

3.6 Courts, tribunals, and legal issues

The impact of courts, tribunals and other legal issues were raised in just under one third of stories (n=11).

Systemic themes

- Mixed experiences of the Mental Health Tribunal
- Positive experiences of therapeutic Courts

(a) 'A fair shot' – mixed experiences of the Mental Health Tribunal

There were mixed views about the effectiveness of the Mental Health Tribunal.

Specific themes

- Some experts felt heard when attending the Mental Health Tribunal
- Many experts reported negative experiences before the Mental Health Tribunal, noting a lack of fairness and issues of bias
- Limited opportunities to self-represent due to medication by service

For some, the Tribunal was a fair forum with processes and support, meaning they **felt heard**. For example, one expert who used IMHA and VLA's services (see 3.4.c The benefits of legal and non-legal advocacy) stated that:

'At the MHT I was able to finally get a fair hearing. [The doctor] tried to get another order, but they didn't grant it to him.'

The majority of experts involved in the project who had experiences of the Tribunal reported **negative experiences**, with some describing it as a 'sham process', that they were 'never listened to', and that it granted a 'blank cheque' to medicate them. One expert explained:

⁶ Therapeutic courts may also be known as "problem-solving courts" or "solutions-focused courts" and include the Drug Court, Assessment and Referral Court, Koori Court and Neighbourhood Justice Centre.



'My experience of the Mental Health Tribunal was distressing. The members showed condescension towards me and my family. They were racist towards my lawyer. They just granted the clinicians orders, but never held them to account or properly investigated the issues I raised despite the bundles of evidence I produced.'

Another lived experience expert said that 'they were only ever interested in hearing from clinicians.' One expert reported that they were **restricted from self-representing** due to high doses of compulsory medication. Another expert stated that they had been treated unfairly at the Tribunal due to false and misleading information being uncritically accepted, describing this in terms of wanting the Royal Commission to 'look into the Tribunal and examine their corrupt practices and decision-making.'

(b) 'It seemed to give me back my dignity' – positive experiences of therapeutic courts

Four lived experience experts spoke about using therapeutic courts as part of being sentenced in the community for an offence.⁶ All experts we spoke to who had used therapeutic courts – notably the Drug Court and Assessment and Referral Court (ARC) – spoke positively about them.

Specific themes

- Experts reported having had long-term negative past experiences of the state-based systems, such as criminal justice, child-protection, family violence and clinical mental health systems
- Therapeutic courts provided a different experience to traditional state-based systems
- The positive elements of therapeutic courts were strong relationships between the experts and the court, as well as better access to helpful services

Many experts had long and **negative experiences with state systems**, including the criminal justice, child-protection, family violence and clinical mental health systems. Their experiences of therapeutic courts, by contrast, were supportive. A key factor reported by several experts was **positive relationships and care in therapeutic courts**:



'The reason ARC was such a positive experience was because everyone in the program gave me a chance. When I was in the program, I just kept crossing the line, because I had given up. My first judge, however, saw a lot of potential in me and believed there was so much more to me. Because of that, she was very lenient with me and never gave up on me. I really appreciated that. Even when she moved to a different area because they opened up ARC there, she was still keeping an eye on me and checking on the case. I think if I had gone through the normal court system, I would not be where I am today and would not have had a chance at life.'

Another expert reported:



'I found this experience very positive and empowering. Over many years of domestic violence, I had built up a very negative attitude to the whole policing/court system that just didn't protect me. I realised this during the ARC process, it seemed to give me back my dignity and sense of hope in the system.'

It was clear for many that the **journey through this system** was different to others:



'From getting off the elevator, to going into the court room there is a respectful, positive, quiet, relaxed feeling coming from all the staff. It had a profound impact after years of negative experiences of magistrates and police.'

In general, the lived experience experts viewed the **ARC magistrate as being on their side** or looking out for them:



'The Magistrate without exception handled some very mentally ill people with respect and you could really see the effect this was having on some people, not all, but I really think this sort of approach is worth expanding.'

Other experts spoke about the benefits that therapeutic court services enabled access to 'wrap around' support services, such as housing, that had not been available to them previously.

3.7 'When I'm on antipsychotics, the voices start to toy with me' – experiences of medication

The use of medications, and in particular, antipsychotics, featured heavily across stories, particularly for people experiencing compulsory treatment (see 3.5(b) Failure to involve lived experience experts in their own treatment).

Systemic themes

- In some instances, medication was helpful for consumers
- Most consumers reported significant harmful psychological and physical effects of medication
- Experiences of harmful effects were often minimised or reframed as behavioural issues

Some experts spoke about the positive impacts of medication for them. In particular, some experts in forensic units spoke about how medication, along with other psychosocial supports, stabilised their mental health issues.

However, the majority of experts spoke negatively about their experiences of medication. Some experts stated that medication had **harmful psychological effects**. For example, one expert stated that:

'Antipsychotics take away your thinking and thought processes. I feel like a lot of my heightened abilities and awareness that is taken away on these medications. These medications destroy me and they destroy others.'

'I hear voices. I don't mind having them there. They can change and evolve over time. They are people who change in their attitudes. It can be tricky when you can't see them. It gets worse trying to make sense of these voices when you're on antipsychotics.'

'When I'm on antipsychotics, the voices start to toy with me. They become more aggressive and like to watch me. It's way worse. I'm better off without them.'

Other experts reported significant **physical health risks and changes** arising from medications, including weight gain, tardive dyskinesia (involuntary repetitive movements), sleeplessness, sore joints, and difficulty moving:

'It makes me lethargic and restless at the same time. I'm in a state where I can't focus...I will try to clean my house, but I can't. It wouldn't be accurate to say I'm "sedated", because I'm so restless. One day I spent two hours walking to the bus-stop and back because I couldn't sit still. It's hard to sleep. Honestly, sedation would be nice.'

One expert spoke about an incident with **serious injury and near-death consequences**:

'I've had compulsory treatment for decades. When I was first in the services, they had me on 7 pills in the morning, and 11 at night. When I was in [hospital] last year, they over-medicated me so much that I almost died. I now have [an injury] that I am seeking compensation for.'

Some experts reported that their medications' **harmful effects were minimised or reframed** as being a behavioural issue. For example, a lived experience expert reported that her psychiatrist compulsorily prescribed Olanzapine, which resulted in increased appetite and weight gain. When she raised this with the psychiatrist, he said that the issue was her eating habits, not the medication.

We also asked experts for their recommendations, advice or solutions for the Royal Commission. We have identified the systemic and specific solutions experts raised.

4. WHAT SYSTEMIC SOLUTIONS WERE CALLED FOR BY LIVED EXPERIENCE EXPERTS?

4.1 Address the social determinants of mental health

Approximately one third of experts (n=11) asked the Royal Commission to **address the social determinants** of mental health.

Systemic solutions

- Address family violence through better policing and housing responses
- Enable meaningful employment
- Address workplace bullying and harassment
- Ensure schools provide better supports to children

Some experts focused on specific determinants that had an impact on their life and story, while others spoke more generally. Several experts highlighted solutions relating to family violence. For example, that the government and mental health services should:

'[Develop a] better understanding of WHY older women are so at risk of violence and homelessness.'

'[E]nsure that young people who are experiencing violence at home have access to the supports that they need to feel safe.'

One expert made a specific recommendation for **police responses** to reports of violence by other community members:

'More training for police so they understand older single men intimidating older single women, particularly in public housing. Just telling women to "get a PSIO" [personal safety intervention order], does not solve the problem, and only exacerbates it when mental health issues are involved.'

Secure access to safe housing was important to several experts, with one expert stating 'it is the foundation of everything'. Another lived experience expert who secured housing through the Drug Court said that 'it's the first time in my life I've had stability except for when I was a kid'. This means that there need to be better housing options:

'Something that would be helpful is better housing when you come out instead of boarding houses. They're not good. You need transitional housing when you're coming out of hospital or jail.'

For these lived experience experts, this required a change in **government departments and bodies' housing approaches** for people with mental health issues, recommending:

'More training and understanding of the difficulties of placing people with severe mental conditions in public housing. The waste of police, courts and DHHS [Department of Health and Human Services] time, and distress caused to residents is huge.'

Other experts spoke of the need for 'supports designed to keep families together', supporting people on low incomes to improve their situation, and enabling **access to meaningful employment** and economic mobility. Lived experience experts also spoke about employers taking mental health seriously to prevent **workplace bullying and discrimination**, and the need for **action in schools** to combat and prevent mental health issues by providing counsellors, psychologists and other supports.

4.2 Training and development

Just over half (n=18) of the stories suggested education and training to address issues within the system. This education and training should be targeted at several stakeholders, including the community, workplaces, housing and homelessness services as well as professions within the mental health system.

Systemic solutions

- Education for the community
- Education and training for clinicians

(a) 'There should be more education' – the need for community training and education

Community education was recommended, targeting different stakeholders and covering different content.

Specific solutions

- Education for young people on identifying and responding to mental health issues and abuse
- Education for family and friends on being better supporters
- Education for housing and homelessness services to support people with lived experience

For example, one expert focused on **education for young people**, stating that:

'[T]here should be more education for young people about mental health and abuse. I felt like I was the only person who this was happening to, but it turns out I wasn't. I should have been told where to go to get help. We learn about our bodies, but we never learn about our mind, emotions and mental health.'

Another expert suggested that **education campaigns for family and friends** should support understandings of 'how hard it is for people with mental illness and be able to better support them'.

One young expert who had been turned away from a homeless service due to her mental health issues recommended **mental health training for homeless services**, to ensure they have the capacity to:

'[Care for] someone who is experiencing mental health problems. There should be more on-site specialised supports that are trained to be compassionate and trauma-informed.'

(b) Training for clinicians to promote collaboration, rights and specialist mental healthcare

Lived experience experts also saw training as critical to develop the capacity of the clinical workforce.

Specific solutions

- Ensuring that training was mandatory and/or assessed
- Skills to build collaborative relationships with consumers
- Understanding when it is appropriate to involve family and carers
- Skills to better identify underlying distress
- Reflective practice and supports to prevent workforce burnout

In several stories, experts stated that this **training should be mandatory** and assessed for clinicians to work in the mental health system.

Experts identified several areas where training should focus. Some focused on the need for more **collaborative relationships**:

'[M]ake sure that doctors don't just jump straight to medical problems and medication. Some emotional issues are resolved over a cup of tea and a good conversation. Maybe they should be trained to do that too.'

For some, this required that clinicians are made to understand what it is like to **experience mental health treatment**.

Other experts spoke about the need for training to think more critically about involving family and carers. Experts often spoke about the adult mental health system's challenges in supporting young people. Multiple young experts reported that **clinicians fail to respond to distress** by instead focusing on whether a person is 'functioning':



'I have experienced and witnessed that mental health services and clinicians often assess your wellness based on your ability to "function". If you function, then you can't be unwell, when in many cases being busy is a trauma-response.'



'[O]ver my journey I have learnt that the only way to get help is to risk your life. The system only responds to risk and isn't trained to deal with distress. A lot of people die trying to get the help they need.'

Others focused on **who** should be trained. Several experts focused on **psychiatrists** as decision-makers. Some training focused on **competencies** like clinical assessment and decision-making:



'[T]here needs to be better training for psychiatrists so that they can better respond to people's needs rather than just giving antipsychotics. They should have to go back to university regularly to keep up to speed on the newest issues and solutions.'



'[D]octors and psychiatrists should be trained to take better care when diagnosing people, so that they accurately identify and respond to trauma rather than misdiagnose it as something else. They need to learn more about trauma and PTSD. They should not just rely on notes when diagnosing people – they should be required to engage with you.'

One expert who had described the failure of her psychiatrist to properly **understand and apply the Act**, made the following recommendation:



'[P]sychiatrists need to have training on human rights and the Act...They must be trained in a comprehensive program if they are going to be using the Act.'

Other training recommendations focused on better diagnostic processes, ethics guidance and reflective practice opportunities.

4.3 Funding better service delivery

Just over half (n=18) of lived experience experts called for increased funding to provide better service delivery and undertake more fundamental system re-design.

Systemic solutions

- 'Add the missing pieces' where people fail to receive support
- Addressing the differences between youth, adult and aged mental health services

(a) 'Add the missing pieces' – closing gaps in the clinical mental health system

Many experts called for governments to fill gaps in the current system.

Specific solutions

- More staffing and more beds
- Increased psychosocial supports
- More therapeutic and leisure activities
- Culturally safe and accessible services
- Expanding Medicare for mental health sessions

This often reflected calls for **more staff and more beds**:

'[E]nsure that mental health services are funded adequately so that there are enough beds and trained staff on hand to help during a crisis. These new beds should not come at the expense of the old beds – they should be added to the existing body of beds. More broadly, they need to find and fix the missing pieces in the system where people are not getting the care they need.'

'[T]here needs to be further staffing for ED's so that there are multiple psych triage nurses or mental health staff on hand to accommodate for the number of individuals accessing emergency services at one time.'

However, one expert provided a caution about expanding the workforce, stating that they need to 'employ the right people and ensure they are there for the right reasons, know what they're doing and are passionate about what they're doing.'

Others spoke of the need to fund and ensure access to more **psychosocial supports**:

'[T]here should be more psychological, counselling, peer and other supports available to people within and outside hospitals. Consumers should be able to choose these supports themselves.'

This included **community-based care** that was voluntary, and that would prevent people from accessing crisis services. For example, one expert suggested **increases to the Mental Health Care Plan** from 10 Medicare-covered sessions per year, to 40 sessions per year.

There were also calls for increased funding for sporting, exercise, music, art and other **therapeutic and leisure activities** that improve people's experiences in an inpatient setting.

One expert urged the Royal Commission do this work while ensuring that services are 'more accessible to communities such as Aboriginal and Torres Strait Islander Australians, refugees and people with language barriers'.

(b) '[H]owever long they need it' – reforming age-limits and transitions between youth, adult and aged mental health services

Younger and older lived experience experts recommended that the government **expand clinical youth mental health services** and **remove 2 year gaps**. There should be the option of expansion beyond 2 years where it is indicated.

Another recommended that the government **improve transitions between youth and adult services**.

Another young expert, noting the broad age range (15 to 25 years of age) of eligibility for some clinical youth mental health services, suggested that the government fund a **new youth clinical mental health service**:



'[T]hat specifically targets the need of young people who are legally adults however have varying mental health needs that specific service provision could target.'

Another expert spoke about the need to ensure that transitions from adult to aged mental health services do not reflect a significant drop in quality, meaning that significant improvements need to be made to living conditions.

4.4 Embarking on systems re-design

Just under half of expert stories (n=20) called for actions that reflected systems re-design.

Systemic solutions

- Increase and embed peer workforce, co-design and consumer-leadership
- More voluntary, responsive and community-based services
- Reframing our understanding of, and responses to, mental health

(a) 'They don't know what it's like' – the need for more peer support services, co-design and consumer-leadership

Several experts made recommendations to expand the **peer support and lived experience workforce**.

Specific solutions

- Increasing peer support and lived experience roles
- Providing training and professional development for all staff in mental health services
- Embedding consumer leadership within service processes
- Need to co-design services

Several experts wanted **more peer support**, for example, so that 'they are staffed on an equal basis with nurses and other staff'.

This, however, required specific actions beyond merely funding roles. Drawing on their own experience, one expert recommended that:



'There should be a free TAFE course in Intentional Peer Support, as this was a wonderful experience for me, but I was only able to do it because [clinical youth mental health service] paid for me to do it.'

Experts also highlighted the opportunity to utilise **clinical and peer expertise together** by developing 'some mechanism to bridge the gap between clinical and peer workforce members... this may realise the best of both worlds.'

Lived experience experts also looked at the lived experience workforce more generally, and the need to build consumer leadership into the mental health system. For example, the need to ensure that lived experience members were on **all interview panels** for recruitment. Another expressed concern that 'there seems to be no easy way I know of for people to give feedback after their experiences of the system.' They recommended that 'this should be part of any follow up after someone is discharged.'

An older lived experience expert, who had expressed concern about the state of aged mental health services asked the government to '[c]ommit to embedding consumer leadership and co-design throughout all levels of aged mental health services.'

(b) 'Create alternatives to the current system' – more voluntary, responsive, and community-based services

Specific solutions

- Remove crisis care from hospitals
- Create specialist care such as drug and alcohol informed services

Many experts had negative experiences of the clinical mental health system, leading them to make recommendations for improvements, but also for the creation or promotion of **alternative systems**. For example, an Aboriginal woman spoke about the need to take care providers **out of hospitals** and into nature, where people can have natural healing and therapies.

One expert spoke about the need to:



'[C]reate alternatives to the current system. There should be places for people to go when they are having breakdowns. Mental healthcare should be taken out of hospitals so that these can be places of care and healing.'

Another expert suggested moving away from ‘basic crisis lines’ towards **different types of crisis services**. Other experts spoke about the need for **specialist care**. For example, one expert who had negative experiences with people he stated were affected by drugs and alcohol stated that they:



‘[S]hould get the specialist rehabilitation care they need outside the mental health system. It is not good for them, and it is not safe for mental health consumers for everyone to be in hospitals together.’

(c) ‘God gives you tears, laughter and sighs’ – reframing understandings of, and responses to, mental health

Several experts spoke about the need for the system to reframe mental health issues and how they respond to them.

Specific solutions

- Demedicalising understandings of mental health issues and becoming more inclusive of experiences
- Only using medical interventions as a last resort

Some stories asked the government and the Royal Commission to consider **other ways to understand distress**. One expert spoke about their experience hearing voices inside and outside the compulsory mental health system:



‘Now that I’m off the medication, I’m more in tune with my reality. I’ve had to fight for my own reality though, because services and medication tried to take it away from me. Being closer to my reality, I can make the right choices about what I want to do and who I want to be around. The doctors and psychiatrists never understood me in there. They only know one thing: antipsychotics. They can only see and understand what their university told them. They don’t know what it’s like to have been on drugs or been on the streets. Instead of listening to me, they just say I’m paranoid. They aren’t interested in listening to me, to what the voices are saying, or what I care about.’



‘You’re mentally ill. It’s an illness. You have a mental illness.’ This is all they say because they don’t understand me. Just because you don’t see, feel and hear the things I do, doesn’t mean I’m not right. I have my own truth and see the world differently.’

Another expert spoke of how distress could be better understood by services and the community:



‘God gives you tears, laughter and sighs. I don’t believe tears are a form of weakness. It is a form of strength. If people who want to cry for 50 years. You don’t give women who have lost their child, electrocutions to their brain. When people cry. They cry because they’re sad and overawed. Why not cry? We’re only human beings. Not computers.’

Several lived experience experts spoke about the need for mental health services to shift their focus from **medical to psychosocial** and other forms of support, for example:



‘[M]edication should only be given as a last resort when all other less restrictive alternative measures have been considered, such as therapies and peer work.’



‘[There should be] more holistic front-line care, rather than a limited Western focus on medication. There should be independent research to guide this, alongside clear information regarding what the literature already shows about medication and young people in particular.’

Alongside this, some experts had requested greater access to counsellors, occupational-therapists, art-therapists and music-therapists.

4.5 Improving support and oversight: more advocates, better laws and policies

Just under half (n=16) of lived experience experts identified the need to improve safeguarding, integrity, and accountability systems within the mental health system.

Systemic solutions

- Increased advocacy services
- Reforming laws and policies around mental health
- Improve oversight bodies

(a) 'There needs to be more advocates' – calls for more legal and non-legal advocates

Several lived experience experts argued for an increase to legal and non-legal advocacy.

Specific solutions

- Increasing access to legal and non-legal advocacy for compulsory treatment and in other settings

Multiple experts who used both legal and non-legal advocacy recommended **increased access to advocacy services**. For example:

'[E]veryone who goes through the system should have access to a legal and non-legal advocate to help with the MHT and clinicians. There should be a place in the hospital that advocates, and lawyers have, that consumers can go to without interference – kind of like an embassy.'

'[T]here needs to be more advocates to support us. The services don't like it; they just take down the posters. You need to always have the opportunity to have an advocate.'

Another lived experience expert explained that the advocates are necessary 'so that people like me don't go through the system alone.' One lived experience expert suggested that advocacy should extend beyond compulsory mental health treatment settings to examples such as where:

'[Y]ou try to access housing, when you try to talk to your GP, talking with your family, or navigating various processes that can be daunting.'

(b) 'Change the laws' – law and policy reform for compulsory treatment and health information

Lived experience experts made several recommendations to change laws and policies.

Specific solutions

- Law reform to end compulsory treatment
- Better process to review specific treatment decisions
- Easier access files and health information, including to make corrections
- Increased accountability for the accuracy for clinical notes
- Removal of police from first-responder duties relating to mental health

For example, one lived experience expert asked the government to:

'[A]bolish compulsory mental health treatment. It is barbaric and totally wrong...there should be opportunities to appeal specific medical decisions made by the psychiatrist, particularly where they didn't follow the law.'

Other experts recommended that consumers have the right to **review specific treatment decisions** through the Tribunal where, particularly ‘where they [services] didn’t follow the law.’

Several experts made recommendations to improve health information management systems and rights for consumers. For example, one recommendation focused on improving **access to files and health information**:



‘[P]eople should have more meaningful access to their notes. It shouldn’t be such an ordeal getting access to your notes, especially when they are being relied upon for compulsory treatment.’

Another expert wanted a process to **correct information**:



‘[T]here should be better processes about making information accurate in files. I should have the ability to more easily correct false information about me, especially because it is used for diagnosis.’

Finally, one lived experience expert focused recommendations on **clinical responsibilities to accurately maintain records**:



‘[R]eform laws so that people can be charged for writing the incorrect information, and that these rights are more easily enforced. I want better systems so that clinicians are made to do the right thing and are made responsible when they do the wrong thing.’

One expert recommended that laws should change so that **police are not first responders** to people experiencing mental health issues.

(c) ‘People need to be held accountable’ – improving transparency and oversight bodies

A number of lived experience experts argued for broad changes to improve transparency and accountability.

Specific solutions

- Improve complaints handling within services and the Mental Health Complaints Commissioner
- Ensure that people before the Mental Health Tribunal are not negatively impacted or restricted from self-representing due to antipsychotic medication

Improvements in the operation of monitoring and oversight bodies to **‘hold services to account’**, as well as processes to **improve transparency**. For example, one lived experience expert argued that mental health services and clinicians ‘need to be held accountable’ by changing the way that complaints are handled by the MHCC and services. Specifically, that they spend more time directly talking to psychiatrists and critically evaluating evidence in clinical notes.

One lived experience expert who had made several complaints asked the government to create a framework that prevents, rather than merely responds to, abuse:



‘put a system in place where it’s not possible to abuse someone like I have been abused. Why should I have to make a complaint after I’ve been abused?’

Another lived experience expert argued for reforms so that people can self-represent to, and be assessed by, the Tribunal without being under the influence of medications.

Another expert asked for the Royal Commission to examine ‘the close relationship between pharmaceutical companies and clinicians needs to be examined properly. There are conflicts of interests and cover-ups.’

(d) 'Compensation and justice' – establishing processes to compensate for damage and harm

Many of the lived experience experts who told their story to the Royal Commission also wanted **compensation for the harm** they had experienced.

Specific Solutions

- Compensation for physical and psychological harm received
- Compensation for damage to property

Many stories included a recommendation for compensation, including an argument for 'a scheme that gives compensation to victims of abuse by the mental health system. If someone has done something wrong, they should admit it and the victim should be compensated.'

Another expert recommended clearer rights to compensation for lost property (e.g. jewellery) that is lost by services or stolen in the units. This could be payable out of the hospital's insurance.

5. CONCLUDING MESSAGE

We conclude this report with a short message from one of the lived experience experts who participated in VLA's *Your story, your say* project. She asks – in her own words – that every person working at the Royal Commission connect with the stories of mental health consumers and their experiences as human beings, in order to fully understand the important work that needs to be done:



'Mental people are sane, but they need help. They need help like I need help. But I want it done with a better understanding. At the moment I am treated like a trash-heap.

C'mon, I am wanting help, but I am not getting it. I want proper help. But what I need, not what they need to give me.

They don't listen. They are scared of mental people. The mental person needs something from a sane person. They just need love. It is an environment of love.

Treat me like a human being first – no matter how hard it is. If you can do that, connect your head and your heart, the truth will come out of you. You will be proud of yourself and you will have a right to be.

***Will each individual at the Royal Commission ask themselves why they are doing this work?
Will each individual at the Royal Commission make changes from the heart?'***

APPENDIX 1: VICTORIA LEGAL AID, OUR CLIENTS AND CONSUMERS, AND MENTAL HEALTH

Victoria Legal Aid is a statutory agency responsible for providing information, advice, and assistance in response to a broad range of legal problems. Working alongside our partners in the private profession, community legal centres, and Aboriginal legal services, the following teams and programs provide legal advice and representation to people affected by mental health issues or who use mental health services:

- **Mental Health and Disability Law** – provides advice and representation to people with a mental health diagnosis or cognitive disability before the Mental Health Tribunal as well as matters under the Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (Vic).
- **Independent Mental Health Advocacy (IMHA)** – provides non-legal advocacy to people who are or are at risk of experiencing compulsory mental health treatment so that they can have as much say as possible about their assessment, treatment, and recovery.
- **Independent Family Advocacy and Support (IFAS)** – provides non-legal advocacy to parents and primary carers involved in the early stages of the child protection system.
- **Family, Youth and Children’s Law program** – provides help to children, young people and families to keep safe, resolve family disputes and achieve safe, workable and child-focused parenting and care arrangements, including services such as Family Dispute Resolution Service.
- **Criminal Law program** – provides support for people involved in the criminal justice system, including those with mental health issues that may be relevant to their offending or their experience of criminal justice processes. This includes the Therapeutic Courts team, who work with people in ARC, Drug Court and Neighbourhood Justice Centre.

APPENDIX 2: OUR METHODOLOGY

About lived experience experts who participated in this project

We collected the stories of 34 people with experience of mental health issues or using mental health services. Our focus was to hear from people who have traditionally been hard-to-reach or excluded from conversations about mental health system reform, including:



In addition to these hard-to-reach groups, VLA, where possible, included stories from some experts with other experiences, such as of compulsory treatment.

VLA spoke with **3 Aboriginal lived experience experts** who shared their unique perspectives about the interaction of mental health services with their experiences of culture and spiritual healing. We encourage the Royal Commission to carefully take into account the stories of Aboriginal and Torres Strait Islander lived experience experts provided by the Victorian Aboriginal Community Controlled Health Organisation.

We identified lived experience experts through their relationships with non-legal advocates and lawyers across VLA's civil justice, criminal law and family, youth and children's law programs.

Our process for recording experts' stories

As part of this project, we obtained consent from lived experience experts to participate in the project and share their story and sought guidance and preparation for lived experience experts to tell their story in a safe way.

Most stories were captured through an in-depth interview, which was transcribed into a written story. Questions for the interview were discussed and agreed on in advance so that experts could best prepare for and safely direct their story.

Experts were given the opportunity to write the story themselves, however most preferred their project worker to write a first draft. Experts and project workers then worked together to revise in response to the expert's feedback. Project workers did not exercise editorial control over these stories, but did note that there were capacity limits on their ability to write stories. This meant time and word-limits were necessary where continued additions and changes to stories were being integrated by the project worker.

The project identified key trauma-informed processes for the interview and writing process. This included giving choice of interviewer, clear information in advance, enabling supporters to be present and checking in after interviews. This also included putting supports in place, including VLA's Employee Assistance Program, pro bono defamation advice, and warm referrals to VLA, IMHA and the MHCC where requested. These supports were monitored and updated to respond to changing circumstances during COVID-19.

Analysis of key themes from experts' stories

Preserving and maximising lived experience experts' choice and control over their stories was central to this project. For individuals, this meant supporting them to articulate their story and have the final say on content.

Writing the final report required VLA staff to interpret themes that emerged from all of the stories collectively. A working group worked collectively to identify themes from a representative sample of the stories.⁷ This group included VLA staff from within and outside the project team, as well as consumer advisers with qualitative research expertise.

From these stories, themes were identified and grouped, informing the themes identified in this report. The working group attempted to analyse story themes on face value rather than link them to their interpretations based on professional expertise. From this, a framework of codes was developed through which all stories were analysed, identifying which issues were more prevalent than others.

Lived experience experts' stories cannot be neatly removed from their context – our stories and experiences are complicated, messy and interconnected, and cannot be split into discrete themes or categories. However, this report is intended to group the issues and solutions which were raised by a number of lived experience experts, to assist the Royal Commission to identify common threads and priority issues identified by mental health consumers. There are a range of different ways to analyse, group and categorise themes which emerged from the stories. This report provides one framework, and this section briefly outlines the process for analysing the stories, as guided by consumer advisers.

In writing this report, VLA made a deliberate decision focus on a range of themes, rather than a single narrative, as this would not reflect, and risk oversimplifying, the unique and diverse experiences of lived experience experts.

Options for experts to choose how to share their story

Lived experience experts were given choice in how they wanted to participate, including:

- How they shared their story (e.g. written, audio, video)⁸
- Where they told their story – such as directly to the Royal Commission (privately), through a Witness Statement (privately or publicly), or as part of VLA's strategic advocacy (publicly), and
- Whether their personal details and identity were included or not.

The direct quotes used in this report have been included with the consent of lived experience experts. Project workers have removed the names of services from this report to preserve the anonymity of experts.

⁷ These stories were shared and analysed internally in line with consent provided by experts.

⁸ Stories were overwhelmingly shared in writing. However, some stories were shared via audio where the expert preferred, and by video where the expert wanted to be part of VLA's strategic advocacy.



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