

Mental Health Lived Experience Peak Queensland

Submission to the Queensland Parliament Mental Health Select Committee

9 February 2022

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Summary of Recommendations

This submission is a co-creation between a Lived Experience Advisory Group (LEAG) of six, the MHLEPQ First Nations board member, MHLEPQ CEO and ConNetica Consulting. The process was five two hour zoom meetings a week apart. Between meetings submission iterations were developed and discussed with the group. Between meetings the consultants researched and provided context information for the LEAG to consider.

The issues discussed during the meetings changed as trust deepened amongst group members. Initial discussions focused on structural, funding and service issues, and then transitioned to the sharing of deeply personal experiences that highlighted the impact of power imbalances, trauma inducing experiences in care, lack of care options and social determinants. The shared information has been categorised and presented in this submission in three broad categories:

- Power Relations
- Cultural Blindness
- Social Determinants

Power Relations

Recommendation 1: Lived Experience at every table

First things first: reform of the mental health system should be led and co-designed with lived experience representatives. Lived experience is key to both defining the problems to be solved and developing solutions. Issues of power imbalances must specifically be considered in the establishment of any co-leadership processes.

Recommendation 2: Sustainable funding

Sustainable funding models over long periods of time should be developed. Longevity of services should be prioritised, and service user impact considered when defunding services. Longer term funding must factor in ongoing program evaluation, research, and development.

Recommendation 3: Local, community led, cross government approach

Develop and strengthen comprehensive place-based planning and implementation between all levels of government for locally driven and led interventions.

Recommendation 4: Dynamic systems planning

Develop and monitor sustainable funding models that use dynamic and complex planning methods and incorporate diverse sources of information, for example lived experience, expert knowledge, local contextual knowledge, and scientific knowledge. Such models will require investment in skilling, technology platforms and local or regional planning structures. The experiences of other jurisdictions (national and international) will support the transition and adoption.

Recommendation 5: Build the community services

Increased focus on preventing inpatient treatment. A community based mental health care system will require a significant shift of resources from hospital-based care (presently half of all funding). Funding models that sustain the focus on acute care, must be changed. Targets for growth in community based mental health services must be set and met.

Recommendation 6: Peer Workforce

A key strategy for changing the experience of mental health care, will be the development of a significant peer workforce. By 2030, 10% of all Queensland Health staff working in mental health services, should be peers.

Recommendation 7: Appoint Chief Peer Officer, Mental Health

To provide institutional support for the peer workforce and lived experience, Queensland establish the position of Executive Director of Lived Experience like the position created following the Mental Health Royal Commission in Victoria

*Cultural Blindness***Recommendation 8: Culturally Safe EDs and mental health units**

Scale up the 'Transforming EDs toward Cultural Safety' (TECS) project to all Emergency Departments and continue to ensure the EDs are culturally welcoming for First Nation's people. Adapt and apply the program for all authorized mental health services, inpatient units, community care units and step-up step down.

Recommendation 9: Remote Learning

Provide support to universities, TAFE and facilities to enable greater remote learning and suitable placement on country for First Nation's students to overcome the shortage of First Nations peer and clinical workers.

Recommendation 10: Build A First Nation's and Ethnically Diverse Peer Workforce

A comprehensive strategy is needed to achieve a culturally appropriate Peer Workforce, that reflects the community the services serve. Targets or quotas will be necessary to achieve real change this decade.

*Social Determinants***Recommendation 11: Impact Statements**

Ensure that all policy and program developed by government include consideration of the impacts on the mental health and wellbeing of people living with mental health conditions and the broader community. One mechanism would be to introduce across all government policy and program development and reviews, mental health impact statements that require all policy and funding decisions of government to consider the impacts on individual, family and community mental health and wellbeing.

Recommendation 12: Annual Statement to Parliament

Each year, on or about World Mental Health Day (October 10), a statement on the mental health and wellbeing of Queenslanders should be made to the Parliament. This should include the mental health status of the people, the access to and quality of care and the participation of people with a mental health condition in the community – socially, economically.

Recommendation 13: New funding models

New funding models must be developed according to the nature of the issue and contexts of communities. Comprehensive interventions considering justice, housing, education, employment issues should be favoured over narrow health program or service interventions. Place based, whole of government models must be applied to postcode 'hotspots' to tackle entrenched disadvantage.

Recommendation 14: A holistic approach

Adopt a holistic approach to social and emotional wellbeing that encompasses the broader societal impacts of intergenerational trauma, institutionalized racism and discrimination, unemployment, access to services, physical health, education. For example, end homelessness, during the first COVID wave and in the medium and longer term, those set out in the AHURI *Ending Homelessness* report.

Foreword from Chair

As members of the Queensland Parliament Mental Health Select Committee you will collectively have two choices in relation to this Inquiry. You can write a report to add to the long list of inquiries into Australia's mental health system going back 175 years **or** you can decide that your inquiry will be the first step in dealing with the systemic issues that have plagued the sector over time.

Every inquiry into the mental health system comes at a cost. It is re-traumatising for those of us who have been hurt by the system and feel compelled to provide submissions. It undermines the confidence in the system for those of us who rely on the system to care for their loved ones. It is demoralising for those of us working hard in the system to do our best to make the system work.

You can choose to fundamentally change the experience of care so that having a mental health condition in Queensland never means that you must give up your rights to be seen as an individual, your human rights and cultural rights. You can choose to guide the State towards a mental health system not driven by diagnosis and risk assessment but by the cultural, social and safety needs of its users. A system where safety and risk are seen from a client's perspective. You can choose to hear and embrace the voices of those who use the system – those who have been helped and supported by it, those who have been abused and diminished by it.

The Mental Health Lived Experience Peak Queensland (MHLEPQ) was established for the purpose of giving collective voice to users of the Queensland mental health system especially those who are marginalised and disadvantaged. We are a young organisation and still in our establishment phase. The opportunity to speak directly to you as our elected representatives, caused a great challenge to consult and hear from consumers on very short notice to write this submission. This report was prepared by a Lived Experience Advisory Group consisting of six individuals with very diverse experiences as users of the Queensland Mental Health System. It was coordinated by the MHLEPQ CEO and supported by the engaged consultants.

The voices we heard in this process were voices of praise for the many amazing people who make up the mental health system. We heard stories of love, recovery, and support. We also heard voices of pain. Pain from systemic abuse. Pain caused by a system with old fashioned demarcations and hierarchies between professions. We heard stories of abuse of power and human rights. We heard stories of cultural blindness hurting people.

This submission will ask you to consider three key issues:

- How do we support the whole person instead of just treating the illness?
- How do we treat people with respect and collaborate instead of encroaching on rights and asserting power?
- How do we understand the person and use inner strength instead of a one size fits all and culturally blind approach?

We urge you to see this opportunity as not only a matter of beds, funding, and services but as a start to creating a mental health system in Queensland that is humane, client focused, trauma and needs informed, all of community.

Peter Forday
Chair

Context

As close to half of Australians will experience a diagnosable mental health condition over a lifetime, the members of this committee may well have their own lived experience of poor mental health. Perhaps you have used the system yourself or perhaps you have cared for someone using the system.

As you read this submission, we ask you to picture your loved ones – family and friends and colleagues and constituents. Imagine how their lives would be impacted or have unfolded, if, when vulnerable and in need of mental health support, appropriate care was not forthcoming and perhaps even exacerbated their existing distress and condition.

We want you to imagine that someone you cared for said:

“My perception of the mental health system is that of a system made up for the purpose of protecting the system. The mental health system is broken, not the person.”

“Often First Nations Peoples requests for complementary, trusted, valued and proven traditional medicine and healing practices are resisted. We need to change this.”

“So often I am labelled as a person who is mentally ill and everything about me is seen through this narrow lens. All of who I am, my personal and social context, skills, experiences, hopes, and dreams are never seen, yet alone considered in treatment plans.”

“I experienced restraint, confinement, and coercive control. These experiences often led to more trauma, unbelievable debilitating side effects and incredible loss of quality of life.”

“I honestly believe that my healing journey had to encompass treatment for my mental health concerns, and treatment and healing for the trauma resulting from the treatment I received!”

“My role and value as a Peer Worker, with a living experience is often overlooked and diminished by clinicians. To make matters worse, there is an expectation on me to complete lots of paperwork and meet KPIs, rather than connect with the person in need of care.”

“The mental health system is causing moral injury to its users and workers. Workers often know what they are expected to do is causing harm. Treatment plans often avoid potential risk and this denied my ability to pursue a life I deemed best for me.”

“People who frequently visit an Emergency Department for mental health care are derogatively labelled “frequent flyers” or “attention seekers”. It is a paradox, the system says if you cannot keep yourself safe come to the hospital, but the clinician says after being in ED for ages “you can go home now” and in some cases “don't come back, you don't need care.”

While billions of dollars of funds continue to be allocated to mental health services, it is clear the system is ‘failing to serve’. There is anger amongst many of us reliant upon this system that our needs are not being met. We feel judged, unheard, stripped of our self-agency and too often we are treated as a “diagnosis to be fixed”, rather than a whole person in need of connection, care, and compassion. Our basic human rights are violated.

In addition, we are genuinely concerned for the well-being of those working in the mental health sector. We know caring professionals are burning out, with some reluctant to admit their own poor mental health, and at times are banned from the workforce because of their own mental health

conditions. Many of us, in the role of Peer Worker are also experiencing stress related to the demands of this role and the context in which we work.

We, those with lived experience of Queensland's mental health services and related services, want you to know that it is not all bad. There are many good things, there are many caring people and many stories of people finding meaningful and fulfilling lives through the system. We want you to see that as well. But most of all we want you to remember that at the heart of all the graphs and service plans you will experience in this inquiry you will find people just like us – who regrettably live, breathe and survive adversity on a daily basis.

Throughout this report text written in *green italics* is the direct voice of those with lived experience of the system.

Introduction

This MHLEPQ submission is presented with a spirit of hope and optimism. Hope that this Parliamentary Review will result in a report leading to practical actions that ensure:

- Mental health is a human right for all Queensland citizens
- Mental health consumers are treated as individuals entitled to care that is appropriate to their unique needs, culture, and context
- The peer workforce is treated as equal and valued partners in the provision of care
- The voice of those with a lived and living experience of poor mental health is central to all aspects of the system – *nothing about us without us*, and
- Recommended solutions are broad and encompass the economic, social, environmental, and cultural determinants of mental health, services, and models of care.

While HOPE is not a strategy, our OPTIMISM is firmly based in the knowledge that our hopes will be actioned, mental health outcomes improved, and limited funds used more effectively to achieve mental health and wellbeing gains for all individuals and communities.

There is much to celebrate and commend in the mental health system. The broader efforts and focus on whole of government approaches outlined in the *Shifting Minds* strategy and the Fifth National Mental Health plan give room for optimism. We believe it is imperative to build on what is right and what is working, but that the gap between the intent of policy and the results, have been far too wide, for far too long.

Throughout the submission, the voice of us with living experiences of mental health and mental health services are included to give greater meaning and insight. We present our submission in 4 broad categories:

- history of mental health reform
- power relations
- cultural blindness, and
- social determinants.

Recommendations will be found under the relevant categories. These recommendations include actions that can be actioned immediately and longer-term strategic initiatives that call for 'big picture thinking' and new mechanisms to achieve transformation.

As you read this, we envisage you will acknowledge that fundamental change and improvements are essential and achievable within this decade. Our organisation is fully supportive and willing to be an active contributor to such change.

These improvements are dependent upon timing and champions. We submit our submission with the hope and optimism that at long last, this is the **RIGHT TIME** and **YOU ARE THE CHAMPIONS** to turn the recommendations in our submission into **ACTION**.

We hope you will commit to far reaching change to ensure our needs and human rights are not violated. We urge you to accept us as fellow Queenslanders, entitled to the same rights and protections as others in our community.

The Mental Health Lived Experience Peak Queensland

The Mental Health Lived Experience Peak Queensland (MHLEPQ) is a new initiative funded by the Mental Health, Alcohol and Other Drugs Branch, Department of Health. Our organisation was created in July 2021 and is currently in an auspice arrangement with the Queensland Mental Health Commission (QMHC). This auspice arrangement will be maintained while the peak establishes its organisational structures.

The MHLEPQ was established through a co-design process involving relevant organisations and individuals with lived experience of the mental health system. The organisation was established using the Stretch2Engage Framework championed by the QMHC.

The MHLEPQ was established to deliver the following objects:

- Provide policy advice and system advocacy for, and with, Consumers of all ages of the Queensland mental health system, in particular those who are marginalized and disadvantaged, based on the principles of equity, access, cultural-safety, recovery, and human rights.
- Work with the mental health system to empower and build capacity of experienced and emerging mental health Consumer representatives to participate in mental health sector improvement initiatives.
- Undertake projects in relation to supporting Consumer engagement and participation.
- Work collaboratively and/or in partnership with other agencies and organisations in the sector to improve the mental health and wellbeing of Consumers and the community.
- Support, demonstrate and foster Company practices and environments, at all levels, that are culturally safe, recovery-oriented, trauma-informed, and consumer-led.

A guiding principle of the MHLEPQ is that its activities are led by mental health service consumers with relevant lived experience. When the Queensland Health Minister Yvette D'ath announced the establishment of a parliamentary select committee to examine the mental health system for Queenslanders the MHLEPQ formed a Lived Experience Advisory Group (LEAG) to lead the preparation of a submission to this committee.

The LEAG's brief was to guide a submission from a lived experience perspective with special consideration of those in the community who are or should be mental health service consumers and who are marginalized and disadvantaged. The LEAG led the writing of this submission with specific regard to principles of equity, access, cultural-safety, recovery, and human rights. This submission was developed via a process of co-design with the LEAG, MHLEPQ CEO and ConNetica.

The Co-authors of this submission

This submission was developed via a process of co-creation between a Lived Experience Advisory Group consisting of:

Naraja Clay
Justin Geange

Tanja Kretschmann
Angela Davies

Melissa Pietzner
Rosiel Elwyn

and the MHLEPQ's First Nations Peoples representative David Wenitong, the MHLEPQ CEO Jorgen Gullestrup and ConNetica consultants John Mendoza and Marion Wands.

Information sharing and discussion was via five two-hour zoom meetings, regular emails, and SLACK message board discussions. Research was undertaken to provide further insight and evidence into the issues raised by the LEAG.

All participants are joint authors of the submission. Appendix 1 contains a full biography of each of the co-authors wishing to have their bio included.

The Mental Health System

The long road of mental health reform

"Those that fail to learn from history are doomed to repeat it." (Winston Churchill)

In 1846 Australia's first mental health inquiry was established to investigate reports of violence, corruption, and mismanagement of mental asylums. This was just over a decade after the opening of the first purpose built psychiatric institution. Like so many inquiries since, it was in response to growing recognition in the community of the abuses being perpetrated against the mentally ill. ^(1, 2)

Since then, literally hundreds of inquiries into the care of the mentally ill have been conducted. ⁽³⁾ Figure 1 provides a snapshot of the major inquiries since 1983. ⁽⁴⁾

The most recent inquiry completed by a Federal Parliamentary committee ⁽⁵⁾ in October 2021 said:

"Today, Australia is navigating a mental health, suicidality, and social and emotional wellbeing crisis. Exacerbated by successive natural disasters and the COVID-19 pandemic, this crisis has amplified social disadvantage, increased service demand and presentations of mental illness, and exposed the limitations of our mental health, suicide prevention and aftercare service systems."

Similar damning conclusions about a "broken system", 'of a system failing to provide the treatment and support those in need legitimately expect', of a "poorly planned and badly integrated system" have been repeated in every one of the most recent major inquiries into mental health.

While there are many mental health stories relating to hope, resilience and recovery, the dominant themes in all these reviews, and the media, detail people living with a mental health condition struggling to get access to affordable, safe, culturally welcoming, and effective care and the discrimination and exclusion they routinely experience. We know this from our firsthand living experiences.

Despite this scrutiny, there continues an un-bridgeable gap between the nation's capacity to provide care commensurate with community needs. You have an opportunity to change that.

Action matters

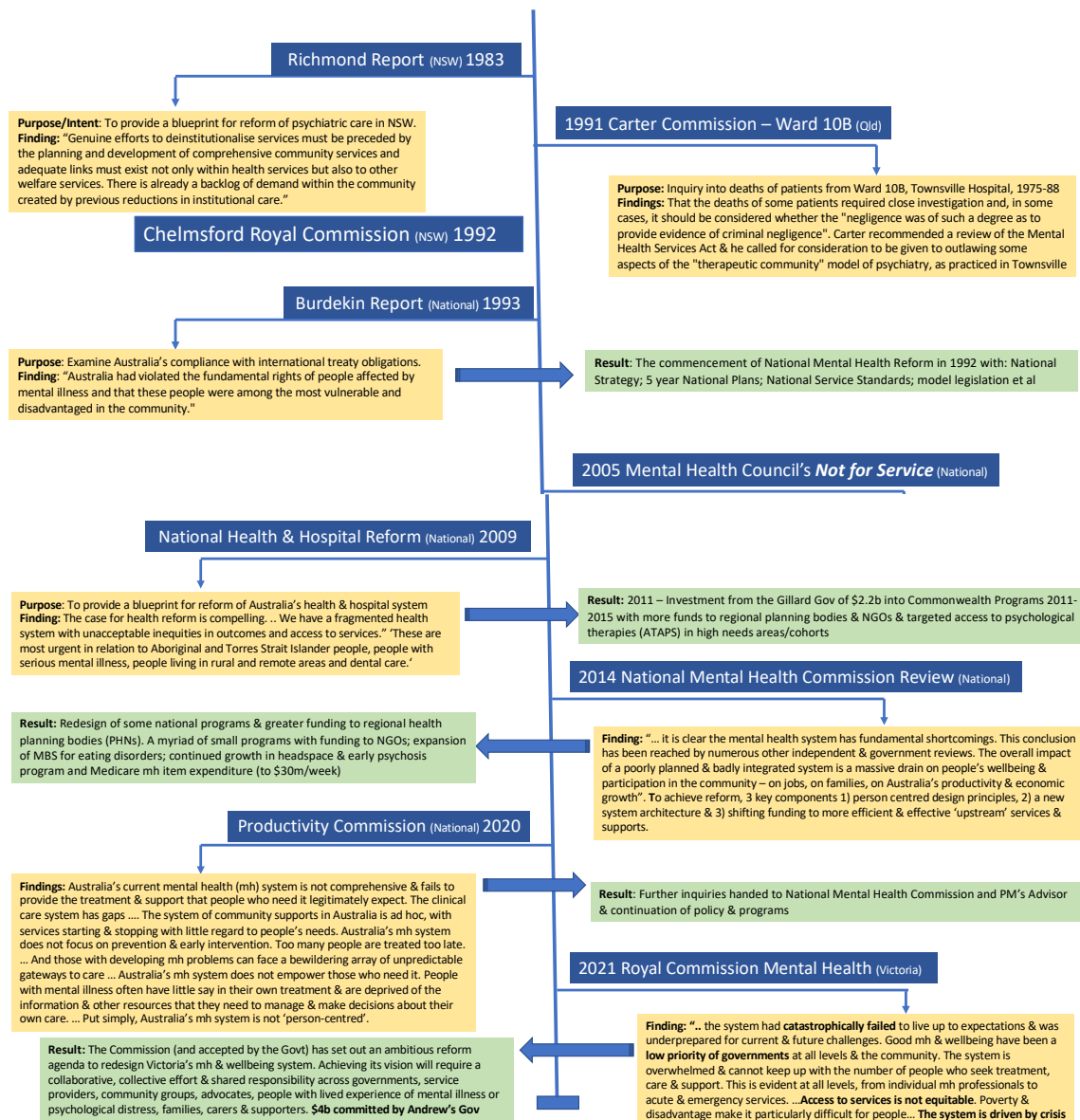
"There are good and insightful reports and recommendations. We just need to do it".

The hundreds of mental health inquiries over the past 30 years have produced thousands of worthy recommendations that are rarely fully implemented and most often ignored until another inquiry repeats the same messages.

Inquiries come with a cost. They come with a monetary cost to the community. But they come with far greater human costs: for mental health staff working hard to get the system working, inquiries come at a cost to their morale; for carers of people with poor mental health inquiries can undermine trust in the system and create uncertainty; for people with lived experience of the system it is traumatising. Each time we are called upon to prepare submissions or when we hear reports in the media, we relive past traumatising experiences. ⁽⁶⁾

It is therefore of the utmost importance for this Queensland Parliamentary Inquiry, that it is worth that cost. There must be a return on our investment through real reform and actions.

FIGURE 1: FORTY YEARS - MAJOR MENTAL HEALTH INQUIRIES ⁽⁴⁾



Despite numerous roadmaps, blueprints and no less than five National Mental Health Plans, the indicators of mental health are either unchanged or worsening (see Table 1). Record numbers of Australians are seeking help and being medicated for mental health needs, and pressures on mental health services are at record highs, yet the health status and outcome indicators are not improving.

This can mean three things: the society we live is making more people unwell, or the approach we are taking to mental health is ineffective, or both.

In this submission, we set the case for tackling both: those factors driving the ever-increasing levels of distress and mental ill health and the reforms necessary to have a mental health service system that can more compassionately serve those in need, and in turn, the broader community.

“Planning for improved mental health outcomes need to reflect the complexity and interplay of related issues. Planning approaches therefore need to adopt complex and adaptive planning models that adjust to changing circumstances. Linear, rigid approaches are inappropriate.”

In part the lack of action, the cycle of crisis-inquiry-failed implementation, stems from the dysfunctional power relations within the system. This is the key issue we address in this submission.

TABLE 1: KEY MEASURES – MENTAL HEALTH REFORM: A ROAD TO SOMEWHERE? ⁽⁷⁾

Measure	1990s	2020s	Trend	Notes
Expenditure	\$1.579b (1992/3)	11.018b (2019/20)	Increased Cost	Per capita spending constant price \$185 to \$431
Life Expectancy	- 10.4 (Females) - 13.5 (males) (1985)	- 12.0 (females) - 15.9 (males) (2005)	No Significant Change	For people with psychosis the gap is largely unchanged for a century at 14-23 years.
Prevalence of mental illness (MI) Adults (18+ yrs) Children (4-17 yrs)	(1997) 18% 14%	(2020 estimated) 20% - 1 in 5 (12 mths) 13.9% - 1 in 7 (12 mths)	Prevalence Increasing slightly	In Qld there is an estimated 160,000 adults with severe MI, 260,000 with moderate MI & 470,000 with mild MI
Deaths by suicide Men Women Children (5-17yr) First Nations Peoples	2161 - 13.2/100,000 1735 - 21.2/100,000 426 - 5.1/1000,00 81 - 13, 0.5 for <14yrs & 68, 7.9 15-17yrs- Aver. 25/yr 1980s	3291 - 13.2/100,000 20.0/100,000 6.7/100,000 99 – 26, 0.8 for <14yrs & 73, 9.0 15-17yrs 165 – 24.2/100000	No Significant Change, except in First Nation’s people	This shows 1990 & 2017; the last year of complete data. Data on children (2010 & 2020) is not reported for all states. Deaths due to suicide for Indigenous pop’n is consistently 2.2 times the non-Indigenous pop’n.
Psychological distress	1.9% (1997)	3.4% (2011-12 ABS) 7.4% (2017 HILDA) 7.7% (2021 ABS)	Significantly increased	Adults reporting very high psychological distress.
Emergency Dept presentations	138,000 or 2.3% (2005)	310,000 or 3.8% of all ED presents (2020) Qld 4.1%	Sustained Increase	Annual growth in MH ED pres. higher than overall growth
Medicare subsidised MH services - % of pop’n accessing	6.2% (2010)	10.7% (2020)	Almost double in a decade	1.4m in 2010 to 2.7m people in 2020

GP encounters for mental health	2.1% (1990)	13% (2020-21)	Six fold increase	Percent of adults seeing GP Preliminary data from
Medication - MH meds. prescribed	NA	17.2% (4.4million in 2019/20)	Significant & sustained increase	Percentage of pop'n prescribed MH medication
Anti-depressant prescriptions	5.1m nationally (1991)	29.3m nationally (2020)		In 2020, this was 72.1% of all MH prescriptions
Specialist Housing Support (SHS) Services	23.8% (40,400) of all SHS clients (2012)	36.5% (88,300) of all SHS clients (64% for those 35-44yrs)	Significant increase	SHS clients with a current MH issue has increased each year from 2012 to 2020
Homeless	89,700 or 0.45% (2006)	116,000 or 0.5% (2016)	No significant change	Total pop'n of homeless
Employment Participation rates	29% (participation) (1998)	33.5% (participation) 25.7% (employed)	No significant change	People with a mental illness of working age. Note, improved participation but unemployment double general pop'n
Prison	46% on reception	40% on reception	No significant change	Australia's prison pop is growing; hence more people with MI are in prison.
Ex-Defence Persons suicide rates and homelessness	2002-4 Suicide, 30.4/100000 Homeless - NA	2014-16 Suicide, 33.2/100000 Homeless, 5.6% of all homeless	Increasing	The number of homeless veterans among total homeless population

Suicide & suicide prevention

"While suicide has been part of the human experience in most cultures, the biomedical world has managed to imprison suicide for more than a century" Tatz & Tatz, 2019 ⁽⁸⁾

It is important that this inquiry recognise suicide as distinct and separate from mental illness and the interconnected challenges and opportunities for suicide prevention and mental health. Suicide is not a mental illness or disorder but a behaviour. At times this behaviour is associated with mental illness but only a small number of suicides are caused by the illness itself. More often suicide amongst those with diagnosed mental illness are linked to the social consequences of the illness and resulting experiences of despair.

The MHLEPQ has had the benefit of seeing Suicide Prevention Australia's submission to this inquiry. We largely support this submission. We will limit our submission to the intersection between the mental health service system and suicidality to the extent where the system's interaction with the suicidal person can assist in illuminating improvements to the system of care.

It is noteworthy that Australia's suicide rates over the past 30 years have remained remarkably steady but have trended up since 2006. We also note that over this period a large range of initiatives have been rolled out nationally without having any noticeable impact on suicide rates. (see Figure 2).

A suicide presentation in the health system is a high-risk situation. More than fifty years of suicide research on over 4,000 risk factors has found "existing risk factors are weak and inaccurate predictors of suicidal thinking and behaviours" and that "predictive ability has not improved."⁽⁹⁾ The consensus internationally is that we must shift from a focus on risk and use of checklists to a focus on safety and safety planning and yet the focus in most Queensland Emergency Departments and inpatient units is on assessing the individual rather than planning and working with them. These are life and death situation where the use of outdated diagnostic tools can be fatal.

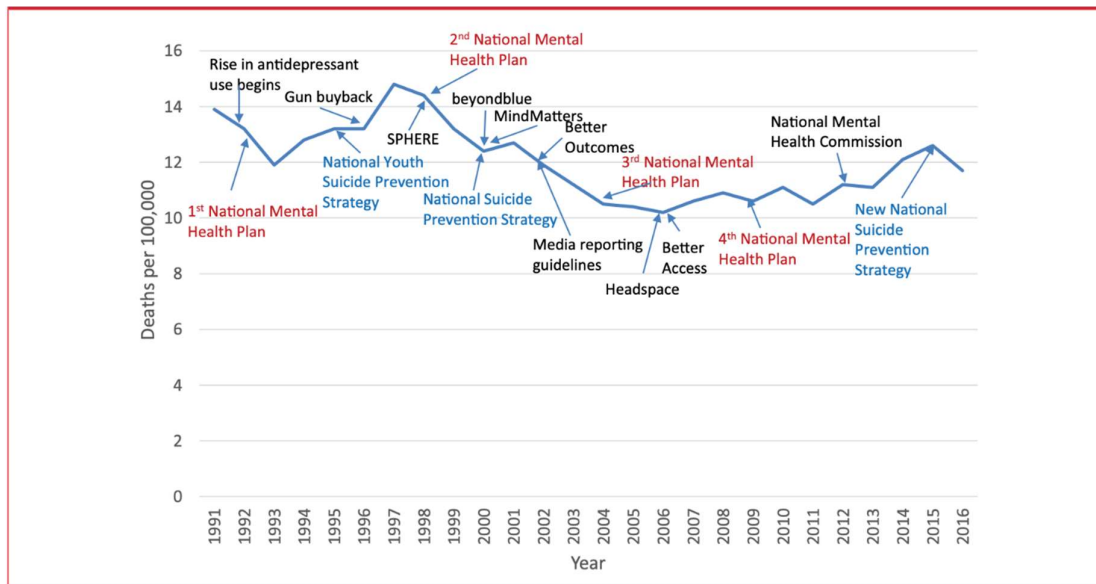


FIGURE 2: Australia's SUICIDE RATE SHOWING POINTS AT WHICH VARIOUS INTERVENTIONS & PLANS WERE INTRODUCED ⁽¹⁰⁾

As submitted by the QMHC, this is failing too many Queenslanders in crisis and having a devastating impact on families, friends, and workplaces. As we write this submission to you, several of us carry this grief of losing a loved one in our heart, to this flawed procedure

"The Police brought him to the ED. They'd intervened in his suicide attempt. Under the Act, he should have been assessed by the consultant psychiatrist, but a registrar did it. They had all of his records over 12 years, including his past admissions when he attempted to kill himself, but they assessed him as 'low risk'. He was released within 20 hours of the ED presentation and died 42 hours later. He was sent home alone, with a Valium script. The community team rang just after his death to do a so called 'welfare check'."

From our lived experiences, the focus of the mental health service system is to assess and treat, rather than collaborate and support. The view was that in the health system suicidality is treated as a risk to the system more so than as a risk to the person experiencing suicidality.

"My suicidality is not really a threat to me as over the years, I have developed management skills around it. For me it is a relief to know from past experience, that I am more than capable of killing myself. With that knowledge, I am able to withstand significant crisis and difficult times by cutting my time into chunks – staying safe for another day, to see how the crisis pan out, knowing that I have options. It is relief to me to be able to embrace my suicidal thoughts and acknowledge that for me it is an option, but that just now my focus needs to be on the other options I have."

Rather than focusing on the inability of the individual to manage impulses (i.e. risk assessment conducted on the individual due to their inabilities and deficits) we need to focus on safety and what the person requires to stay safe and include them as an equal party in that planning. ⁽¹¹⁾

While people in crisis, need alternative pathways to care, we recognise that hospital EDs will continue to be important settings in the prevention of suicide, particularly as we build those alternatives. This submission supports Suicide Prevention Australia's call for the establishment of several levels of safe spaces readily available to the community to focus on strength-based support and safety. We support an increased use of community based and locally led suicide prevention networks.

Power Relations

“The mental health system is one of power over the powerless. Psychiatric diagnoses are based more on ‘agreed opinion’ rather than ‘objective reason’, and mental health laws similarly are not really based on ‘reason’ but on agreement amongst the powerful.”

“The power imbalance between the clinical and non-clinical workers, Peer Workers and consumers is palpable and it gets in the way of holistic care.”

Dysfunctional and at times destructive power relations manifest in numerous ways in the mental health service system – not just in the relations between consumers and treating clinicians. Different clinical groups jostle for positions in a hierarchy where psychiatrists are seen to be at the top, after all they have the prescribed powers under the Mental Health Act. Demarcations between different services such as the public mental health services, primary care providers (i.e. GPs, psychologist and psychiatrists) and the community services push responsibility to each other and jostle for power. The funding system and funding bodies drive inefficiencies and unhelpful competition within the system. It is in the context of this breadth of dysfunction that we would like you to understand the power imbalance experienced by the users of the mental health system.

At the core of power relations, manifestations between consumers and their clinicians and other providers, is the failure to uphold service users’ human rights. Until this changes, we will continue to see and hear too often that the mental health system is damaging service users and those working in the system.

“I feel my power was taken from me. “

“The system is broken. It is dysfunctional and destructive to those who use it and those who work in it.”

“I was blown away by the way the nurses treat one another and the upward bullying from below to senior nurses ... I have seen appalling behaviour that goes unchallenged. There are people working in the system who should be sacked but know how to navigate to retain their positions.”

Human Rights

Australia is a signatory to the United Nations Principles for the *Protection of Persons with Mental illness and for the Improvement of Mental Health Care* ⁽¹²⁾ which were adopted by the United Nations General Assembly in 1991 and more recently the UN *Convention on the Rights of People with Disability (CRPD)*. ⁽¹³⁾ These conventions stipulate that every person with a mental illness has the same basic rights as every other person, including the right to the best possible health care, to protection from exploitation, abuse and degrading treatment, the right to live and work, as far as possible in the community, and to be recognised as a person before the law.

For First Nations peoples, a human rights approach for mental health recognises the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP). ⁽¹⁴⁾ The Australian Human Rights Commission has set out four key principles arising from the rights contained in the *UNDRIP*, namely:

- safety and dignity
- self-determination
- respect for and protection of culture
- equality and non-discrimination.

“Decisions made based on paternalistic medical model of care limits our rights to access culture as part of a holistic approach to treatment and care.”

Members of the LEAG shared incidences where they personally or others they knew were:

- not informed of their rights in hospital
- forcibly sedated and placed in seclusion with nothing more than a plastic cup of water
- held down on the floor by several people while having charcoal forced down their throat
- transferred to hospital in police vans, not ambulances, when not a threat to others
- treated less favourably because they were forensic inpatients
- wrongfully shackled in hospital
- denied all privacy during inpatient consultations, and
- placed in locked wards, even though they had voluntarily admitted themselves to hospital.

“I find it interesting the way that restrictive and coercive treatment impact on the ongoing relationship with access to and experience of care. Due to the restrictive and coercive treatment inherent in care in the public sector - it genuinely took me over 15 years before I learned that care didn't need to be combative! It wasn't until I was given dignity of risk and grace to fall within the system that I learnt to be a partner in care. The system sets us (consumers and workers) up for greater restrictive practice. It takes a lot of unlearning to have a healthy relationship with the healthcare setting.”

“I honestly believe that my healing journey has not only had to encompass treatment for my mental health concerns, but also treatment and healing of the trauma of treatment!”

“I still chronically avoid healthcare (both medical and mental health) and refuse to call ambulances when I need them, which has sometimes led to serious consequences. I don't call because I'm afraid of more restraint and confinement. It truly damages my willingness to engage and trust mental health facilities. It takes a long time to heal and re-establish that sense of feeling safe enough to seek help because access to care has resulted in further vulnerability, trauma, and loss of autonomy.”

These experiences, and many others including sexual and physical assaults in mental health units, are repeated in the recent findings of the Victorian Royal Commission on Mental Health and in the hearings underway with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.⁽¹⁵⁾ These are not new developments. A systematic review of 32 audit reports focussing on mental health services by statutory authorities and similar bodies undertaken in Australia between 2006 and 2013, found the audits reported human rights concerns among crisis and inpatient services and denial of equitable access to supported accommodation.⁽¹⁶⁾

Across Australia, restrictive practices remain commonplace. Such practices are a measure of a system in crisis only responding to people in crisis, rather than earlier in the onset of an episode of severe ill-health or progression of the person's condition. Restrictive practices contribute to traumatic consumer experiences and act as a barrier to engagement in therapy.

There is strong international and some national evidence that such practices as restraint and seclusion can not only be reduced but eliminated from mental health care settings.⁽¹⁷⁾ Sadly, we know of local efforts where restraint and seclusion have been eliminated, only to see these practices return when there is a change in senior mental health staff.¹

¹ This is a reference to leadership at Nambour Hospital in 2017-18 by a senior clinician who has since retired.

The Power of Lived Experience

Involving people with lived experience in the defining of the problem as well as considering possible solutions will create different outcomes. For this to work there needs to be a genuine equalisation of power between those with lived experience and those in the professions and bureaucracies in that process. The results of this Inquiry do not just involve deciding what should be done, but equally importantly, how it should be done and who should be involved in every aspect of the reforms.

A seat at every table for people with a lived experience

"We want a seat at the table, we want to be seen and heard. We need to be afforded the respect that we have insight into our illness and know what does and does not work in relation to our recovery. All stakeholders, need to accept the risk that goes with consumers adopting their preferred method of care."

Our experiences exemplify 'care being done to us, rather than with us'. Feeling powerless, having our context, our insights, our expressed needs, and treatment preferences ignored are all too frequent experiences. Biomedical models of care are mostly prescribed and, in some cases, enforced.

"Psychiatrists have presented themselves experts in "madness". They claim to be able to prevent, diagnose and treat mental illness but as a profession they can't provide any definitive explanations for the "illnesses" they define. I'm not saying psychiatrists don't have a place in the mental health system, but I'd appreciate them engaging in some honest reflection on what they can actually deliver."

"There is no way that a group of men should ever have been allowed to sit in a room without me being present and make decisions about what I, as a woman, "just needed to do" to escape the abusive situation I was in. I'm not an idiot. If it had been safe for me "just" to do those things, I would have done them."

Dignity of Risk and the Consequences of Do No Harm:

"In the health system we talk about doing no harm and this usually means nothing will be done until it is clear no harm will occur. Those in positions of power, never seem to stop and consider the harm of not doing anything."

Paternalistic views about people with poor mental health, including that we are impaired and therefore incapable of understanding our own needs results in our dignity of risk being violated. As noted earlier, giving a consumer greater agency can be the key to recovery which may include "falling".

The implications of avoiding 'dignity of risk' are illustrated in this comment:

"---- an individual, who although no longer in need of inpatient services and wanting to return to his way of living, was not discharged, as he had no stable accommodation. He stayed in hospital for 12 months, until suitable accommodation, as deemed by the clinicians was available. There was no consideration of the impact of the 'harm' caused by staying away from his supports and effectively institutionalised for 1 year."

We are not broken

"I learnt through the diagnosis I was given and how I was treated in the mental health system, 'not to trust my judgement or myself'. I was constantly told that my perceptions of

the world were impaired and that I was the problem. These experiences left me vulnerable to abuse."

"The concept of broken is from the medical paradigm we have a broken leg, liver and this is what is causing the symptoms. With my experience of illness, I have been led to believe that I am broken, not functioning correctly rather than acknowledging that my experience is part of the full spectrum of human conditions – I don't see this as broken as I am still here, I am still getting around. A lot of things in the system are broken, but the person is not."

Being described as 'broken', implies being impaired, defective, lacking insight and personal wisdom about one's situation and recovery goals. Such language continues to reinforce the power imbalance between consumers and clinicians and the reluctance to give consumers more agency in their preferred recovery plans.

"Psychosocial education has helped me to understand that I am not broken. I live in a broken environment, that does not recognise the invaluable contribution I can make to my community if given the right support."

"Honour the person and their whole experiences – don't shame or hide them. Let the person bring their mental illness out of the shadows, as their experience has meaning and maybe they are sensitive to their situation for a reason."

"Sit with the person, help them identify their unique strengths and not pigeon whole them."

"Accept me for who I am – don't simply label me as sick, try to shut me down because I am different or tell me how I should feel, act and what I can do to recover. Ask me for my insights, walk with me and together we can plan what is right for me."

Power Relations that Reinforce the Status Quo

Funding and Innovation

Too often we and others in need have accessed services, only to be turned away because we did not fit the rigid funding criteria. The cycle of start/stop funding, with narrow parameters, a lack of focus on prevention and early intervention and community sector initiatives are deeply problematic for:

- Consumers - the results are breakdowns in trust and therapeutic relationships, and more complexity in navigating care; all compromising self-agency and recovery.
- Service providers - attracting and retaining quality staff, developing and maturing service offerings, pathways and partnerships within and across the sector are constant challenges and compromises to the quality of care.
- Public sector services - the constant reinvesting in new service agreements and educating staff about what community programs and services are available to enable them to transition consumers from hospital and back to community.

This funding approach is failing all the players and we need to move to new models of funding and accountability.

"Stagnant funding does not enable us to apply contemporary evidence. We need a more agile approach to funding and service provision and those initiatives that prove to be working need to be continued."

“The only part of the mental health system that is stable, is the hospital bit. Everything else is like a shanty town that gets blown over with every change of decision maker. Hence we have a hospital centric, acute and crisis system. Funding is simply perpetuating the crisis.”

“By the time we get the evidence there is often no funding to do what we know best. It is like putting all foundations down, with no intention to do the building.”

“The cycle of START/STOP funding results in people becoming reluctant and or refusing to engage in mental health services. Often their participation requires significant trust and courage on their behalf. When their needs are still existent, but the service is stopped they feel personally neglected and invisible, neither contributes to good mental health.”

Planning for improved mental health outcomes needs to reflect the complexity and interplay of related issues. Planning approaches need to adopt complex and adaptive planning models that adjust to changing circumstances. The linear, rigid approaches applied over the past few decades are clearly failing to build what so many mental health plans have articulated.

We recommend the adoption of agile business practices in which innovative ideas are quickly implemented, ‘failure is quick’, and practice is then reviewed, and action continued.

Power of the Bureaucracy

“Mental health initiatives need to be driven and led by local communities whose members develop the capability to consult widely, interpret data, research best practice and design and implement solutions that address the needs of the mainstream and those often marginalised. These placed based approaches ensure solutions are “fit for purpose”, valued and supported by community. To ensure that “fit”, it is not surprising that they cannot be centrally led by bureaucracy based in George and Charlotte Streets.”

System reform includes the all-of-government approach to mental health called for in *Shifting Minds*. Departmental controlled, siloed funding is ineffective. Planning and co-designing mental health services must be informed by a deeper knowledge of the local and regional diversity. This has been shown as the way forward in many communities around the world and to an extent here. ⁽¹⁸⁾

“Funding needs to be long term and cross sector so that all community related activities that are fundamental to good mental health, such as justice, housing, education, jobs, and inclusivity are aligned and complementary”.

“Imagine the outcomes if required levels of community mental health care were available and social determinants influenced the breadth and depth of service provision.”

Both the National Mental Health Commission in its 2014 National Review and more recently the Productivity Commission have recommended a stronger focus on localised community based mental health services. The Productivity Commission encouraged enhanced cooperation between local Primary Health Networks and state-based health services districts.

Place based approaches have been ‘piloted’ many times in Australia, and they invariably produce positive outcomes for modest investments. ⁽¹⁹⁾ However, they are rarely sustained and the dominant siloed funding models soon re-assert. Disadvantaged communities that overcome adversity often take many years to do so. Investment in their citizens’ capacity to work together towards a higher quality of life is the smart investment. ⁽²⁰⁾

The *Shifting Minds* strategy articulates many of these points, but a sense of urgency is needed, particularly in the shadow of Covid-19. Communities need to regain a sense of purpose and control.

“The Thomson Institute on the Sunshine Coast is leading a community wide Suicide Alliance and it is rewarding to see the community, local organisations and individuals coming together to be educated about how to jointly reduce suicide in their region.”

The Power of Peer Workforce

“Access to the Peer Workforce was a profound experience for me. I learnt that I was not ‘broken’ or ‘defective’, but that my mental and emotional ‘messiness’ was human, and that I could live a rich, meaningful, and contributing life with my mental health concerns.”

“Peer work is where I’ve found the best support.”

Peer workers include all workers in mental health services who are trained, employed, and supervised to openly use their lived experience of mental distress and recovery, in a role that requires lived experience. LEAG members were unanimous in their valuing of peer workers.

“Connecting with the Lived Experience Workforce supported me to shed the shame (and individual/ societal/ institutional stigma) that I carried.”

“Simply put: peer workers send a message that this place is safe, there are people around who have gone through similar things, and you like they can get through this. When people feel safe, they are more willing to share ‘what has happened to them’ and their ‘needs’. Getting to know this means care can be better tailored to the individual’s unique context.”

The presence of First Nations People peer workers is especially advantageous, as many find health care settings confronting and not culturally safe.

“Our people better understand our mob’s context and circumstances. The level of trust we can build with our people means they are more willing to tell us their needs and concerns.”

Through the *Shifting Minds* and earlier State mental health strategies, Queensland led the nation in the engagement, employment, and empowerment of peer workers in mental health services.

“It must be noted that while Queensland initially led this initiative, the commitment to effectively engage this workforce in the mental health sector has waned.”

We need more peer workers in the public sector and there is almost no peer workforce engaged by the private care sector. The role of Peer Workers is often overlooked by clinicians, with an adherence to a biomedical model.

“It is difficult for peer workers with a lived experience to fulfill our ultimate contribution to a person’s recovery when our role and value is ignored and or diminished by clinicians.”

“A lack of funding means it is hard for us to provide what is needed, as we need to fulfill bureaucratic demands and meet set KPIs, rather than focus on spending time with consumers.”

“Being ignored and not able to do our job can create moral injury for us (Peer Workers) as we know the potential impact of our role on consumers.”

“We want greater recognition of this role as a ‘key worker’ in the mental health system”.

“Let the psychiatrist do the medical diagnosis and the Peer Workers do the relationship and trust building and the social diagnosis. Considering both ... will improve the quality and appropriateness of care.”

There was also frustration that non-peer workers were teaching others how to become Peer Workers. This was deemed ludicrous:

“We don’t have a plumber teach a nurse how to do their job, so why do we allow non-Peer Workers to tell us and teach others how to do our job.”

The power of connecting – compassion and humanity is key

Security guards are employed in most mental health wards and EDs and are called on to physically restrain people. Interestingly, they can and do frequently deescalated heightened tensions by authentically connecting and communicating with consumers.

“The people who work as security guards often build much better and stronger relations with the mental health inpatients. This is because they often share life experiences and can easily talk about cars, motorbikes, horses, and football. I see a big shift when security guards interact with the people.”

“They do not interact with the person with a need to make a diagnosis or complete a medical related task. They have not read the person’s file notes. They interact with a desire to create a ‘connection’. They do not have preconceived ideas about the person.”

“Security officers are employed to do ‘hard’ things to people - such as restraining and guarding and for many they find this task extremely traumatic, and many choose to stop this work as a result”.

These experiences and insights further demonstrate the importance of non-judgmental acceptance and finding common ground that enables trust to build and communication to flow. Compassion, connection, and conversation need to be the hallmarks of all service provision.

Mental Health Workers and Moral Injury

While it has already been noted that peer workers, and security guards experience moral injury, this condition is also likely to impact clinicians and other workers in the sector. They are under resourced to address the growing need for mental health services. Often, due to time pressures they have no choice but to make a diagnosis based on a brief assessment and then a ‘quick huddle meeting’ with other clinicians where dozens of case notes are reviewed. As reported in the Guardian:

“My first experiences as a clinician are of stepping into service systems in crisis, ... Deprived of resources and beset by fatigue, no amount of individual responsibility can bear the weight of structural failure” (Rhys Kierkegaard, The Guardian, 7/1/2022)

As consumers we know that clinicians often experience distress as a result of their inability to give people adequate care and knowing and seeing the impact of this on people. Many are traumatised by repeatedly having to apply restrictive practices due to the overwhelming pressures on hospital flow (pressure on ED wait times etc), the shortages of beds and other care setting options and the poor build or design of the facilities. This observation has also been made by the Australasian College of Emergency Medicine.⁽²¹⁾

“When I tell clinicians the negative impact of their care on my health and healing, I can see how this is negatively impacting them. They too are experiencing moral injury from the nature of work in the mental health system”.

Power Relations: Recommendations

Recommendation 1: Lived Experience at every table

First things first: reform of the mental health system should be led and co-designed with lived experience representatives. Lived experience is key to both defining the problems to be solved and developing solutions. Issues of power imbalances must specifically be considered in the establishment of any co-leadership processes.

Recommendation 2: Sustainable funding

Sustainable funding models over long periods of time should be developed. Longevity of services should be prioritised, and service user impact considered when defunding services. Longer term funding must factor in ongoing program evaluation, research, and development.

Recommendation 3: Local, community led, cross government approach

Develop and strengthen comprehensive place-based planning and implementation between all levels of government for locally driven and led interventions.

Recommendation 4: Dynamic systems planning

Develop and monitor sustainable funding models that use dynamic and complex planning methods and incorporate diverse sources of information, for example lived experience, expert knowledge, local contextual knowledge and scientific knowledge. Such models will require investment in skilling, technology platforms and local or regional planning structures. The experiences of other jurisdictions (national and international) will support the transition and adoption.

Recommendation 5: Build the community services

Increased focus on preventing inpatient treatment. A community based mental health care system will require a significant shift of resources from hospital-based care (presently half of all funding). Funding models that sustain the focus on acute care, must be changed. Targets for growth in community based mental health services must be set and met.

Recommendation 6: Peer Workforce

A key strategy for changing the experience of mental health care, will be the development of a significant peer workforce. By 2030, 10% of all Queensland Health staff working in mental health services, should be peers.

Recommendation 7: Appoint Chief Peer Officer, Mental Health

To provide institutional support for the peer workforce and lived experience, Queensland establish the position of Executive Director of Lived Experience like the position created following the Mental Health Royal Commission in Victoria

Cultural blindness

“Deep seated and institutionalised racism prevents our mob being employed and moving up the career ladder. We need more of our mob in positions of power and influence, so that the needs of First Nations Peoples are better understood and actioned.”

What is culturally appropriate

There is not a lack of knowledge of what is required to create culturally welcoming and safe health care. Elements of culturally safe care identified by De Silva et al ⁽²²⁾ were inter-related and included:

- personable two-way communication grounded in culturally safe work practices,
- a well-resourced Indigenous health workforce,
- trusting relationships and
- supportive health care systems that are responsive to Indigenous Peoples’ cultural knowledge, beliefs, and values.

The Gayaa Dhuwi (Proud Spirit) Declaration ⁽²³⁾ of 2015 and the more recent National Strategic Framework (2017-2023) set out the approach to improve Aboriginal and Torres Strait mental health and suicide prevention services and outcomes⁽²⁴⁾:

“Aboriginal and Torres Strait Islander leadership, engagement and partnership in the planning, delivery, evaluation, and measurement of services and programs is critical in fostering greater trust, connectivity, culturally appropriate care and effective outcomes.”

This is welcome, but there must be clear actions taken by every jurisdiction, specific funding and clear accountability and reporting to see these intentions materialise. Much needed and far-reaching social change must be led by First Nations Peoples and jointly co-designed, implemented and evaluated with First Nations Peoples. This will ensure the dominant paradigm of ‘doing things to, rather than with’ First Nations Peoples is avoided.

Our discussions for this submission revealed that institutions and individuals within and external to the mental health system are often racist, sometimes unknowingly. Those on the receiving end of racism face enormous challenges to fulfil their potential, have their human rights respected, and their needs understood and met.

Given the high psychological distress experienced by First Nations Peoples, and those from other minority cultures, it is essential that Queensland takes assertive action to STOP RACISM and DISCRIMINATION. Such actions must look beyond the mental health system and challenge existing power bases.

The impact of the current child protection system also negatively impacts the wellbeing of First Nations Peoples.

“There are now more First Nations children being removed from their families than during the Stolen Generation. This is having a disastrous impact upon our mob’s wellbeing and mental health. Lack of available and appropriate workers and legislation in this sector further compounds the deleterious implications of children being removed.”

The importance of early childhood and the impacts of neglect and trauma in the trajectory of mental health and suicide into adulthood is becoming increasingly clear. This is reflected in the focus on early childhood in the *Shifting Minds* strategy. But this is contradictory to the high rates of removal

of First Nations children, and the lack of kinship care and appropriately trained staff to support the cultural development and care for children removed from their home.

Treatment plans must look broadly at a person's life context to best facilitate sustainable mental health improvements.

Recovering from mental illness needs to be seen more broadly. Treatment plans need to include broader initiatives that facilitate the meeting of basic needs such as purpose, contribution, shelter, food security and belonging. Underpinning these needs include a person's access to employment pathways (paid and voluntary), education, affordable and secure housing, health care, legal services, strong community connections and a sense of belonging.

Increasing employment opportunities would be enhanced by:

"Actively encouraging, supporting, and promoting First Nations Peoples led enterprises that create employment opportunities for our mob. With employment comes purpose and financial independence"

The First Nation's workforce

"We need more of our mob employed and present in the hospitals and the legal system. Our people must see others like them. This will help make them to feel safe and more willing to use these services and discuss their needs and circumstances. At a deeper level, it will show that these systems are there for us too and that we have the right to access services."

Service organisations have created self-imposed requirements that exclude First Nations Peoples from applying and gaining employment. For example, having to have a specified qualification, fails to appreciate the difficulties First Nations Peoples experience to attain formal qualifications, and therefore the likelihood that although they do not have the needed qualification, but do have the relevant experience they will not be eligible to apply.

Difficulties often experienced when undertaking tertiary study included:

- leaving country, family and other community supports which are key to social and emotional wellbeing
- having to engage with academic institutions often means being exposed to further colonial violence and impacts on social and emotional wellbeing.

"We need: 1) more opportunities for First Nations Peoples to complete formal qualification on their country; 2) Aboriginal services to become Registered Training Organisations and or to formalise partnerships with vocational and tertiary education institutions; 3 Academic institutions and the people within them to provide culturally safe learning environments."

Culturally welcoming

The *Queensland Human Rights Act* (section 28) provides that First Nations Australians are not to be denied the right to their cultural heritage, including traditional knowledge and spiritual practices. The act also provided a right not to be subjected to forces assimilation or destruction of their culture. However, this is exactly the experience that many First Nations people have when they interact with the mental health system.

"It is essential to not make assumptions about someone's cultural background and resulting care expectations. Every individual must be seen and heard so that their unique context and needs are understood and addressed."

"Our people better understand our mob's context and circumstances. The level of trust we can build with our people means they are more willing to tell us their needs and concerns. We need clinicians to better respect and utilise our advice about a First Nations Person's needs."

"Too often our thoughts and recommendations are disregarded and people seeking support don't get it and those that may not need to be admitted are admitted. We need to be seen more as legitimate workforce and not mere support workers who can be disregarded if our ideas do not comply with the dominant western medicine regime."

"Allowing a First Nations Peer Worker to build a relationship with these individuals is likely to result in better understanding and being able to meet a person's needs."

The Queensland Health 'Transforming EDs toward Cultural Safety' (TECS) project in 2019-20 aimed to create culturally safe EDs that reduce the barriers to Aboriginal and Torres Strait Islander patients engaging with hospital-based emergency care. It was trialled in Cairns and Gladstone and while final results are not yet available, the trial has resulted in both length of stay and representation rates to the ED been halved at Cairns ED.⁽²⁵⁾

We believe there is an urgent need for the learning from this work to be applied to all EDs across the state and trialled and then scaled for all inpatient mental health services to ensure Aboriginal and Torres Strait Islander peoples have access to culturally welcoming and capable care. The following provides insight into the value of traditional healing practices and the roadblocks to such care.

"An Aboriginal man from a remote First Nations community was brought to the Inpatient unit on a Treatment Authority (TA). His brother was a traditional healer from his community and sought to conduct a traditional healing and smoking ceremony as part of the healing journey for his brother. This was met with considerable opposition from the hospital's clinicians as it did not comply with the western medicine regime or Occupational Health and Safety standards, and they were concerned the person would "abscond" and not return to hospital.

"After lengthy discussions between the family and clinicians it was finally agreed that the traditional healing and smoking ceremony could proceed for the man and his family, off the hospital precinct. It was immensely spiritually healing for the man and his family. He did return to the hospital and abide with other treatment regimes."

A LEAG member also shared a story of a pregnant, depressed, and psychotic patient with an Indian heritage, who was admitted to the inpatient unit:

"She was not eating, and the clinical team thought she was trying to harm the baby. It was not until I as the Peer Worker asked if the clinicians considered if the food was appropriate. After several discussions it was agreed that the woman's husband could bring the woman food from home. She started eating this food immediately and within 3 days she was allowed to go home. The initial diagnosis was so dangerous as this could have continued to be a statement about her as a mother - it was so wrong!"

Making environments and services culturally welcoming needs to extend to people from all minority groups, including LGBTIQ+. Our mental health workforce must mirror the community it serves. That will greatly enhance the capacity to welcome and care for all.

Cultural Blindness: Recommendations

Recommendation 8: Culturally Safe EDs and mental health units

Scale up the 'Transforming EDs toward Cultural Safety' (TECS) project to all Emergency Departments and continue to ensure the EDs are culturally welcoming for First Nation's people. Adapt and apply the program for all authorized mental health services, inpatient units, community care units and step up step down.

Recommendation 9: Remote Learning

Provide support to universities, TAFE and facilities to enable greater remote learning and suitable placement on country for First Nation's students to overcome the shortage of First Nations peer and clinical workers.

Recommendation 10: Build A First Nation's and Ethnically Diverse Peer Workforce

A comprehensive strategy is needed to achieve a culturally appropriate Peer Workforce, that reflects the community the services serve. Targets or quotas will be necessary to achieve real change this decade.

Social Determinants

"We know that things like a lack of housing, lack of compassion, lack of food, poverty, bullying, abuse and domestic violence have a massive impact upon someone's wellbeing. We know from our experience, that these experiences make it much worse for people living with a mental illness".

Almost all the reviews into mental health in Australia, have focused on examining the system of care. Only recently has there been some effort to examine what is driving the ever-increasing demand for services. This 'gap' is akin to trying to reduce road trauma by only focusing on emergency medicine.

"Accessing the food bank was very difficult for me. It was only open during office hours and I was reliant upon public transport, which meant a four-hour round trip. Often I didn't have the money for the trip. I don't have a driver's licence, not because I don't want to but because I would have had to be in a car for lessons with my abusers. I couldn't afford private lessons or a car."

We know from our own lived experiences and from those the MHLEPQ represents, that social problems have a habit of accumulating and multiplying. Precarious employment, unsafe workplaces, periods of unemployment, unstable housing arrangements and debt all lead to psychological and financial stress, which in turn erodes our self-esteem, strains our relationships, and increases any mental health problems we may have.

"Social determinants of health play a key part in wellness, and this is where we all have a responsibility and opportunity to make a difference. Creating a better environment for the places we live, learn, work and play benefits everyone."

Similarly, our built environment, diminishing access to greens spaces and nature, and unsafe places and streets, all discourage us from getting out of the house to exercise or socialise. The effects of our environment are compounded for many by ongoing drought, increasingly frequent extreme

weather events and reduced viability of rural towns and regional centres. We note that the States suicide prevention strategy *Every Life* includes architecture and urban design as having a role in suicide prevention. We suggest that this role also is relevant to mental health more generally. ⁽²⁶⁾

None of this is new knowledge. The evidence on the relationship between social determinants and mental ill-health evidence dates back to the 1950s and shows the impact on an our own, our family and our community's mental health. ⁽²⁷⁾

We, like you, can see clear geographic concentrations of social disadvantage across our cities, regions, and state, with particular postcodes standing out as 'hot spots'. 'Lowering the heat' in these postcodes requires a sustained whole-of-government, whole-of-community approach.

The impact of the COVID pandemic did not feature strongly in our consultations for this submission. However, we are now collectively bearing witness to what has been described as an 'emotional pandemic', concurrent to the virus and 'psychological contagions' borne of myth and suspicion that create greater stress, anxiety and more aberrate behaviours and social division. ⁽²⁸⁾

Social distancing, isolation and quarantine have been used for millennia to control infectious diseases. For many people living with severe mental illnesses, they have reported no real change – they live with isolation and loneliness on a daily basis. But for the general population, recent data is giving us a sense of the scale of the impact of these public health measures. ⁽²⁹⁾

“(there is) ... not enough action to ensure every person has a roof over their head, food on the table, a basic income which matches the cost of living, and a good quality of life.”

During our discussions it was pointed out that massive impacts on homelessness were made temporarily during the first COVID wave. Hotels were used as makeshift accommodation to allow homeless people to comply with lockdown provisions. The COVID pandemic thus provided an opportunity to realise that having the problem of homelessness is a choice we make collectively and not a destiny.

Having a home is the first stage to connecting with services and through that develop a more stable existence.

We draw the Inquiry's attention to *Ending Homelessness* from AHURI (2020) which sets out succinctly what needs to change:

A fundamental system change ... is proposed that would focus on prevention and early intervention rather than be a largely crisis response; ensure every person is quickly provided with appropriate assistance via a 'duty to assist' protocol; incorporate a Housing First response for people experiencing homelessness so that they can move as quickly as possible into needs and age appropriate long-term housing options; actively involve existing homelessness services in reshaping the sector to deliver agreed outcomes for, and on behalf of, governments; and develop long-term plans for an adequate supply of social and affordable housing. ⁽³⁰⁾

This change is informed by the ending of homelessness in Finland over the past two decades and the significant progress for people with mental health conditions made in many regions across North America with the Housing First initiative. ⁽³¹⁾ We must learn and apply these lessons here.

Access to meaning employment was raised by several participants from the perspective of the benefits of having access to meaningful work:

“Our mob need jobs and there are often no jobs available. I represented a client in a remote community and in sentencing he was told that he should just get a job. I was disappointed and dismayed by this complete lack of understanding of the employment situation in this community and within regional and remote communities. There are often no employment opportunities in a lot of our First Nations communities and those that are there are mostly filled by white fellas.”

“I did a lot of volunteer work in my community, it was okay if I couldn’t make it in for the day or left early, there was no pressure to perform. I used volunteering to retrain myself to cope with the responsibility of a job, and I did it at my own unique pace as I was in charge of my employment.”

“It is important to actively encourage, support and promote First Nations Peoples led enterprises that create employment opportunities for our mob. With employment comes purpose and financial independence.”

We believe this Inquiry must recognise that the levels of mental distress among communities need to be understood not only in terms of individual pathology but also as a response to relative deprivation and social injustice.⁽³²⁾ Disadvantage starts before birth and accumulates throughout life.

For many years, policy makers have spoken of the need to invest in ‘social capital’, ‘community development’ and ‘strengthening community’. The message here is simple but powerful: communities have an inherent potential to achieve great things for themselves and for others, and they should be resourced to do so.⁽³³⁾

Strengthening communities involves increasing social inclusion and participation, improving neighbourhood environments, tackling bullying and discrimination in all settings, safe work and public places, and access to basic services like childcare and self-help/support networks. It involves accepting that communities best understand their own needs and are best positioned to come together to resolve problems and challenges.

Our recommendations are not the last word on how we must put in place both the mechanisms to assess the impact of policy and program initiatives on mental health and wellbeing of individuals and communities, and how we can improve the translation of mental health policy into real actions, real outcomes.

Social Determinants: Recommendations

Recommendation 11: Impact Statements

Ensure that all policy and program developed by government include consideration of the impacts on the mental health and wellbeing of people living with mental health conditions and the broader community. One mechanism would be to introduce across all government policy and program development and reviews, mental health impact statements that require all policy and funding decisions of government to consider the impacts on individual, family and community mental health and wellbeing.

Recommendation 12: Annual Statement to Parliament

Each year, on or about World Mental Health Day (October 10), a statement on the mental health and wellbeing of Queenslanders should be made to the Parliament. This should include the mental health status of the people, the access to and quality of care and the participation of people with a mental health condition in the community – socially, economically.

Recommendation 13: New funding models

New funding models must be developed according to the nature of the issue and contexts of communities. Comprehensive interventions considering justice, housing, education, employment issues should be favoured over narrow health program or service interventions. Place based, whole of government models must be applied to postcode 'hotspots' to tackle entrenched disadvantage.

Recommendation 14: A holistic approach

Adopt a holistic approach to social and emotional wellbeing that encompasses the broader societal impacts of intergenerational trauma, institutionalized racism and discrimination, unemployment, access to services, physical health, education. For example, end homelessness, during the first COVID wave and in the medium and longer term, those set out in the AHURI *Ending Homelessness* report.

Conclusion

If you always do what you have always done, you will always get what you've always got.
Henry Ford

There is a universal consensus among stakeholders in the mental health services system, that there is a need for significant and sustained real increases in funding. Even where we see effective models of care developed from strong evidence, positive outcomes are not sustained while the gap between demand and capacity remains.

However, simply pumping more money, even a lot more, into the dysfunctional service system, will not achieve the transformation required. More money will neither address the power imbalances nor the failures of implementation and the continuing neglect of human rights so clearly evident from the hundreds of inquiries and thousands of recommendations made over the past three decades. More money into mental health services will not, in itself, lower the heat in postcode hotspots or lessen the drivers of distress and poor mental health.

There is much in the current *Shifting Minds* strategy that we support in relation to structural reforms and priorities for investment, but a real sense of urgency is needed with more robust whole-of-government, whole-of-community structures and accountability. The Covid-19 pandemic has simply amplified the need for communities to regain a sense of purpose and control.

We can have a society that is caring and respectful for all, including those of us with a mental health condition. We can end the neglect, trauma and abuse experienced by too many citizens in mental health care, we can end restrictive practices in mental health care and build a community based mental health care system, we can find meaningful employment for people with poor mental health, we can end homelessness, and build stronger communities. Time is up for doing more of the same; time is up for more inquiries; we must move to action and new ways of addressing the mental health and wellbeing of all Queenslanders.

If not us and if not you, then who?

Glossary & Definitions

Terms	Definition
ABS	Australian Bureau of Statistics
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health & Welfare
Coercion & coercive practices	<p>“coercion”: forceful action, involuntary treatment, or threats undertaken in the course of providing treatment or addressing perceived harm that a person poses to his/her own self or others due to a mental health condition.</p> <p>“Coercive practices”: include formal detention, treatment without consent (or “compulsory treatment”), seclusion & restraint, incl. use of mechanical devices, person-to-person restraint, or psychotropic drugs for the primary purpose of controlling movement (“chemical restraint”).</p>
Ecosystem (in mental health)	Refers to: 1) all the components of the care system (health, mental health & non-health, hospital & community based), 2) the population & 3) the social, economic & environmental factors influencing their mental health & wellbeing & the interplay between all these elements.
ED	Emergency Department
Inquiry	In this submission ‘inquiry’ includes Royal Commissions, Parliamentary inquiries, and reviews.
Homeless	A person has experienced homelessness when they do not have suitable accommodation alternatives & if their current living arrangement: is in a dwelling that is inadequate; or has no tenure, or their initial tenure is short & not extendable; or does not allow them to have control of, & access to, space for social relations.
LEAG	Lived Experience Advisory Group
Lived / Living experience (LE)	People with LE identify either as someone who is living with (or has lived with) mental health conditions or psychological distress, or someone who is caring for or otherwise supporting (or has cared for or otherwise supported) a person who is living with (or has lived with) a mental health condition or psychological distress. People with LE are sometimes referred to as ‘consumers’ or ‘carers’.
MHLEPQ	Mental Health Lived Experience Queensland Limited
Mental illness	<p>The Qld Mental Health Act defines mental illness as a condition characterised by a clinically significant disturbance of thought, mood, perception or memory (s 10). However, people with lived experience can have varying ways of understanding the experiences that are often called ‘mental illness’. Mental illness can be described using terms such as ‘neurodiversity’, ‘emotional distress’, ‘trauma’ & ‘mental health challenges’.</p> <p>In this document mental illness is used interchangeably with having a mental health condition as many people with lived experience finds the term mental illness an offensive description of their experience</p>
NMHC	National Mental Health Commission
Psychological distress	One measure of poor mental health, which can be described as feelings of tiredness, anxiety, nervousness, hopelessness, depression & sadness.
QMHC	Queensland Mental Health Commission
Self-harm	The various methods by which individuals injure themselves, such as self-cutting, self-battering, taking overdoses or exhibiting deliberate recklessness.
Social determinants of Health (SDH)	Non-medical factors that influence health outcomes. SDH are the conditions in which people are born, grow, work, live & age & the wider set of forces & systems shaping the conditions of daily life. These include economic policies, social policies & norms, & political systems.
Stigma	Stigma refers to the social disapproval of individuals or groups due to a discredited characteristic that distinguishes them from others. Stigma has been ‘mapped’ as a problem of knowledge (ignorance), attitudes (prejudice) & behaviours (discrimination).
Systems thinking & approaches	An approach to problem solving that views “problems” as part of a wider, dynamic system; much more than a reaction to present outcomes or events. It demands a deeper understanding of the linkages, relationships, interactions & behaviours among elements of an entire system.
Suicidal thinking or behaviours (STB)	A complex process that can range from suicidal thoughts, through planning of suicide, to attempting suicide and ending in suicide. Suicidal behaviour is the consequence of interacting biological, genetic, psychological, social, environmental, and situational factors

Appendix 1 - Contributing Authors

(Alphabetic Listing. Not all contributing authors choose to provide a short biography)

Naraja Clay

Preferred Name: Naraja Clay

Pronouns: She/ Her

Work/ Community Roles: I have advised Local, State and Federal Governments in relation to youth mental health and its various intersections since 2015. I have worked with headspace National Youth Mental Health Foundation since 2017. I began as a member of the headspace Youth National Reference Group. I now Chair the headspace National Aboriginal and Torres Strait Islander Advisory Group and am a Youth Advisor to headspace Board. I am a member of the Queensland Mental Health Commission – Mental Health and Drug Advisory Council. I have held a range of roles within Non-Government Organisations, Not-For-Profits and Governmental Organisations. In roles that advocate for views, wishes and rights of vulnerable Queenslanders. I am now a non-clinical suicide prevention peer worker in Meanjin.

Lived Experience: I live with a diagnosis of Complex PTSD which includes a wide range of other mental illnesses and chronic health conditions. I have lived with the symptoms of C-PTSD for over a decade. This diagnosis is a result of experiencing prolonged adversity and trauma throughout my childhood. Prior to a diagnosis, I experienced several anxiety disorders and major depressive episodes. I have had several inpatient stays since I was 14, they have ranged from helpful to traumatic. I now receive adequate support and care from community based specialist services.

Key Learning from my Lived Experience: Key learnings from my lived experience is related to exposure to adversity and trauma during childhood, can predict a range of socio-economic concerns later in life. Young people who experience toxic stress, often go on to experience brain developmental changes that effect behaviour. Young people are often criminalised for symptoms of toxic stress instead of receiving the care and support they need.

The bulk of the advocacy work I do, is to support organisational and governmental change that positively effects access and safety of services delivered to young people.

Something I am proud of: Despite the experiences I have had, I have participated in incredible opportunities to advocate for young people, particularly First Nations young people.

I am engaged in meaningful work that is based around my passion to see appropriate and accessible support for young people who experience adversity and trauma.

In 2021 I attended the United Nations 14th Session of the Conference of State Parties to the Convention on the Rights of Persons with Disabilities.

Angela Davies

Preferred Name: Most people call me Ange or Angela.

Pronouns: I'm not sure my individual experiences with gender, or my understanding of gender, is reducible to a few short words. I'm just a person who most people know as Ange, Angela or Angie.

Lived Experience: I've experienced periods of mental ill-health and periods of wellness/healing. I've experienced mental distress, both as a result of symptoms and being labelled mentally ill. My journey has included using various in-patient and community mental health services.

Key Learning from my LE: My experiences have given me a strong sense of social responsibility. I want to make a difference for myself and for other people. My experiences have taught me the importance of being humble,

inquisitive, authentic and kind. I still have a lot to learn about myself, about self-acceptance, and about relationships with others.

Work / Community Roles: I work in a public mental health service as a Consumer Consultant/Senior Peer Coordinator. I've had quite a few different work roles.

Something I am proud of: My determination; the way I think; my ability to write; and the bond I have with my dog.

Rosiel Elwyn

Pronouns: They/Them/She/Her

Work / Community Roles: Lived Experience Community Member of the Beyond Blue Steering Committee EB2020; consumer consultant for the Brisbane North Hospital and Health Service; Lived Experience Researcher for RMIT "Equally Well and Health Talk" project; Lived Experience Researcher for the NSW Suicide Prevention Initiative Evaluation Project: Safe Havens; PhD student researching longitudinal risk factors and neurobiology of adolescent eating disorders; Master of Psychology graduate; member of the Lived Experience panel of Suicide Prevention Australia. In my community, I have worked as a peer support worker for 12 years at acute mental health wards in three Queensland hospitals and at three community mental health support centres and respite sites in Brisbane and the Sunshine Coast for a non-profit organisation. During my placement as a Master of Psychology student, I also supported older adults at aged care residential facilities. I am a Lived Experience speaker, guest lecturer, and consultant, and frequently speak at universities and hospitals to professional health workers and students on topics such as: responding compassionately to mental health crises (suicidality, psychosis, eating disorders, self-injury, trauma); supporting individuals with specialised care needs (autism and neurodivergence, LGBTIQ+, disability care, cultural sensitivity); understanding trauma responses and understanding psychosis; and iatrogenic harm and making reparations after incidents where harm has occurred in the process of care, including taking steps for self-care when working in mental health.

Lived Experience: I experienced early adversities and traumas, and developed anorexia nervosa, repetitive self-harming in childhood, and first survived suicide in childhood. I developed psychosis in my early teens after experiencing an escalation in abuse, neglect and violence at home, bullying, and identity-based marginalisation as an autistic LGBTIQ+ person. I was repeatedly cycled through the hospital system throughout my teenage years and adulthood, which compounded my traumas through the use of restraint, confinement, and coercive control. I also received continual messages of hopelessness and pathology, including that I would be dependent on the system forever, and should not pursue a career in mental health work as I would 'harm other people'. I resisted these messages until I successfully completed my degree from hospital. I was forcibly put on powerful neuroleptics, which led to severe side effects I was not informed about, including blood poisoning and organ failure in one instance, as well as tardive dyskinesia and akathisia, which increased my suicidality. I experienced instances of compassionate care and peer support as healing and going off medication led to regaining my quality of life and regaining my liberty.

Key Learning from my LE: Healing and recovery cannot occur in unsafe environments or isolation. Mental health care needs to be holistic and look at the meanings and history of our experiences. When mental health care compartmentalises our experiences and attempts to treat them separately, we become disconnected and dissociated from the meaning of our crises. We cannot learn from them and meet our needs in order to heal. When we feel safe, connected to others, and recognised as whole human beings that are respected and worthy of human rights and dignity, we can move from a place of traumatic physiological and emotional threat responses that are focused on our survival into a place of growth. It is there we can create a sanctuary to learn about ourselves and create new meaning for our lives.

Something I am proud of I am part of a small group of researchers and mental health advocates with Lived Experience who have established the International Mad Studies Journal (The IMSJ) and am part of the editorial board. The IMSJ will be the first academic journal that is Lived Experience-led, and centres the experience, history, politics, and discourses of psychiatric patients/survivors, consumers, ex-patients, people who are disabled or have been labelled mentally ill. Academia and academic journals often exclude the voices, critique and knowledge of people with Lived Experience, or filter and co-opt our experiences through research lenses

as ‘participants’, which can lead to misconceptualisations of them that become perpetually reproduced into dominant psychiatric discourse. Opportunities for Lived Experience-led and authentic co-production, co-design and accepted publication as first-person authors of autoethnographic work remains in the margins. The IMSJ is an attempt at ethical redress of this power imbalance, to create a space where Lived Experience knowledge can be featured and valued in mental health academic literature.

Justin Geange

Pronouns: He/Him

Work / Community Roles: I work as a field officer for suicide prevention Charity Mates in Construction. In my community I have volunteered as a community ambassador for RUOK for just under 8 years, I am currently the Chair of the Queensland and Northern Territory Suicide Prevention Australia committee, and I was also on the 2021 Mental Health week committee representing mates in construction. I am a recipient of the 2019 Suicide Prevention LIFE Award as an individual in the Communities Matter category and I also won the 2021 RUOK day Barbara Hockey Conversation Champion award, both for my work in the mental health and suicide prevention sectors.

Lived Experience: As a teenager I was treated for Manic Depression, surviving multiple suicide attempts and hospitalisations between the ages of 13 and 17, then again having episodes and further attempts in my 40's where I was diagnosed with bipolar type two. I daily use said lived experience to help me support other people presently experiencing varying levels of crisis.

Key Learning from my LE: I have learnt compassion and empathy, for every person is unique and therefore every person's experiences are unique. We hold our own perspectives based on circumstances and said experiences, and I have learnt to leave my judgement at the gate, doing my best to practice kindness because you just never know what someone may be going through in their life right now.

Something I am proud of: I started a degree of social science in 2012 and through year after year of mental ill health episodes I finally completed both a Diploma of Psychology and a Bachelor of Social Science in Humanities in 2020, 8 long years after I began. Educationally I have always struggled, so therefore, I am incredibly proud of my perseverance and achievement of this particular goal.

Tanya Kretschmann

Melissa Pietzner

Pronouns: She/Her

Work / Community Roles:

I was a member of the QLD Mental Health Commission peak project steering committee who created the Mental Health Lived Experience Peak QLD. I sit on various committees in Mental Health Alcohol & Other Drugs Branch and the Mental Health Alcohol & Other Drugs Quality Assurance Committee. I am a member of the Mental Health Review Tribunal reference group and was previously a volunteer with Mackay HHS community health reference group.

Lived Experience: I was diagnosed with Bipolar 1 when I had my first mental health episode at the age of twenty-two. I lost my grandmother to suicide when I was a child and I have a parent with Bipolar 2. I am their carer. Twenty-three years later and I've had nine hospitalisations across two countries, a lot of therapy and an endless list of medication regimes. Each mental health episode unravelled in a similar way. My mood would yo-yo between depression and hypomania, mania crept in and on some occasions tipped over into psychosis. I've experienced hospitalisation, ITO's, MHRT hearings and ECT. Some episodes were several years apart and some several months apart.

Key Learnings from my LE: I could not begin to heal until I accepted my illness. This was difficult. Because of stigma acceptance can be misconstrued to mean accepting the label 'mentally ill'. Where almost everything I

do gets understood in reference to my illness. I can't change the past. I had to let go of my grief for the time lost to periods of illness. I accept it will remain a feature of my past and will impact my future. Psychosocial education has helped me to understand that I am not broken. I live in a broken environment. It does not recognise the invaluable contribution I can make to my community if given the right support. Social determinants of health play a key part in wellness and this is where we all have a responsibility and opportunity to make a difference. Creating a better environment for the places we live, learn, work and play benefits everyone.

Something I am proud of: Being part of the design, implementation and operation of the Crisis Support Space in Mackay. Because of this project people in my community now receive more appropriate care when presenting to the ED in mental health distress.

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