#SpeakingOurMinds

A special series
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Foreword

The #SpeakingOurMinds series of articles was conceived and organised by mental health and human rights advocate Simon Katterl and was edited by Dr Ruth Armstrong.

It was published to coincide with Mental Health Week 2022 (October 8-15) as a vehicle to privilege the voices of lived experience.

The series was supported by Mental Health Carers Australia, Simon Katterl Consulting, Tandem, First Nations Co, and Mind Australia. The supporters respect the independence of the authors and the editors.

Readers are cautioned that these articles contain references to severe mental distress, human rights breaches, and suicide.

On Twitter, follow #SpeakingOurMinds.

For assistance:

Lifeline 13 11 14 www.lifeline.org.au
Suicide Call Back Service 1300 659 467 www.suicidecallbackservice.org.au
beyondblue 1300 224 636 www.beyondblue.org.au
13Yarn 13 92 76 13yarn.org.au
Kids Helpline 1800 551 800 kids helpline.com.au
Join us for a swim upstream this Mental Health Week

**Image Donna Elliott, Unsplash**

**Introduction by Croakey:** In your media consumption over the next week (October 8-15), you’re likely to encounter more than the usual amount of statistical information and expert opinion about the state of Australians’ mental health.

Initiatives like Mental Health Week create space for important conversations but too often, around policymaking and service provision tables as well as in the public discourse, vital perspectives are missing.

Below, mental health and human rights advocate, Simon Katterl, writes that only by listening to the voices of lived experience, will we be able to challenge the status quo and effect the dramatic changes needed to right our failing mental health systems.

Putting these words into action, Katterl has pitched, planned and expertly shepherded a series of articles for Croakey, featuring six authors who have experienced, or been a carer for those experiencing, mental health problems.

Be prepared: stories of lived experience can be heartbreaking and are often harrowing. The authors have not flinched from the truth in their telling, but as one author, Leilani Darwin, writes,

> “Lived and living experiences... need to to be elevated and embedded not just in future responses, but also in ensuring that all aspects of mental health reform, policies and practices are built on these experiences.”

The articles will roll out over the course of next week, so be sure to bookmark Speaking our minds for your Croakey reading, and follow along on Twitter #SpeakingOurMinds.
Simon Katterl writes:

David Foster Wallace – the American novelist – once told a parable of three fish:

“There are these two young fish swimming along and they happen to meet an older fish swimming the other way, who nods at them and says ‘Morning, boys. How’s the water?’ And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes, ‘What the hell is water?’”

For me, the story is a reminder of how the organising frameworks, cultures and ideologies we work within can shape our concerns, our experiences, and our realities.

The ideologies surrounding mental and emotional distress are that water too. Michel Foucault, talking about the birth of modern psychiatry in the preface to his 1961 book, History of Madness, reflected:

“The constitution of madness as mental illness, at the end of the eighteenth century, bears witness to a rupture in a dialogue, gives the separation as already enacted, and expels from the memory all those imperfect words, of no fixed syntax, spoken falteringly, in which the exchange between madness and reason was carried out. The language of psychiatry, which is a monologue by reason about madness, could only have come into existence in such a silence.”

Until very recently, discussions about mental and emotional distress have been about us (those of us with lived experience), and have occurred without us.

If ever there were leaders swimming upstream, it is leaders with lived experience – those with their own experiences of distress and mental health systems, and those who have been carers, family members and supporters.

Centring the voices of lived experience

Mental health week, in my view, risks becoming a ritual of ineffective and disorganised messages. A greater risk is that this disorganisation will function to reinforce the status quo, when our systems and communities need dramatic change.

Centring lived experience perspectives is one way to organise around that change. It is the reason why I approached Melissa Sweet and Ruth Armstrong from Croakey to ask that they work with myself and other lived experience authors to publish daily lived experience-perspective pieces during Mental Health Week.

With the support of socially conscious organisations (Mental Health Carers Australia, Tandem, First Nations Co, and Mind Australia) sponsoring the editing of this process (while maintaining the independence of both authors and Croakey), I’m proud to forecast six articles beginning Monday 10th of October. They are the views of the authors, but they have had wonderful support in particular from Ruth, but also the broader Croakey team.
Speaking our minds and calling for change

This quote, from Cassi Strauss:

“We are able to provide an authentic holistic approach to supporting someone through their mental health journey by being with them as opposed to doing things to or for them.”

Cassi Strauss will, on Monday, introduce us to her work as an emergency department peer practitioner. Peer work is a new and innovative approach to distress, particularly acute distress, which I hope continues to enjoy greater respect, leadership and pay equity within the mental health system.

On Tuesday, Kerry Hawkins writes about her experiences as a carer, amidst mental health systems that often hurt rather than help the people she loves. Kerry laments the lack of progress, while holding hope for the introduction of both consumer and carer mental health peaks at a national level.

While Cassi Strauss wrote about peer workers, Wanda Bennett introduces you to her twenty-two years of experience as a consumer consultant. Often caught between two worlds, consumer consultants work within mental health services, utilising their own lived experience of distress and using services, as well as their community-connection to others with similar experiences, to make improvements.

It is often a comprising role, with Wanda taking you into that lived professional reality.

You will also hear from Caroline Lambert, someone who wrestles with the “carer” identity. Gracefully taking us into this battle, Caroline shares the impossibility of living up to the “saintly” master-identity that some carers accept and others resist. Caroline reflects – with my full support – on the value of leaning into the “angry middle-aged witch” that some carers who advocate for a better system are cast as.

On Thursday Leilani Darwin, a Quandamooka woman, writes about the shame that First Nations people are forced to endure when they enter mental health systems in this colony. Despite her professional experiences working in the mental health system, her personal experiences as a family member and carer carry the same shame and disempowerment.

With humility and grace, Leilani asks government and officials to walk with her and her colleagues, to create a more inclusive and culturally safe mental health system.

As a late call-up off the bench, on Friday I will close out our perspectives, highlighting how our mental health system would benefit from dissolving the wall that separates staff safety from consumers’ human rights. To me, shared liberation is found in the abolition of the violent mental health system. That will require more mental health practitioners to stop, reflect, and help us swim up-stream.

If we do so, and we centre lived experience perspectives more broadly, better waters await.

*Simon Katterl has lived experience of mental health issues and has used predominantly private as well as community public mental health services. Simon’s work focuses on mental health laws, governance, regulation, and systems design.*

Published on Friday, October 7, 2022
Introduction by Croakey: As flagged earlier, this Mental Health Week Croakey is hosting the Speaking Our Minds series of articles, featuring powerful messages from writers with lived experience, about what needs to be done to improve our mental health and mental health services.

Cassi Strauss, who writes below, is one such person. Strauss works as a peer practitioner, creating a safe, non-judgemental and non-clinical space for people who are dealing with mental health problems and diagnoses.

It’s a role that she describes as both the most challenging and the easiest thing she has ever done, and one that she believes has the potential to be even more effective, if properly understood and supported.

On World Mental Health Day, could peer leadership be the game-changing reform we need?

Cassi Strauss writes:

Growing up in an era that did not allow space for children to express emotion or complain of physical ailments, it’s no surprise that, after a diagnosis of ovarian cancer at the age of 25, I went on to develop complex Post Traumatic Stress Disorder. With this came what I then thought was a sudden onset of anxiety and suicidal ideation.

However, with the support of a great therapist, I was able to recognise that many of my struggles came from unresolved childhood and teenage trauma – triggered by the recent health scare. The more of life I experienced, the more I recognised the things it was lacking, and the disconnect I was feeling grew.
I knew something had to change. I could no longer sit around waiting and accepting the things happening to me and my family. I decided I needed to understand us all better.

**Becoming a Peer Practitioner**

After four years of study I completed my bachelor of psychology and graduated in the midst of COVID. I was determined to use my experiences, my pain, and my knowledge, to help others to never end up in the helpless position I’d found myself in.

I took a part time job in youth residential care on top of my full time managerial role, to gain some experience.

From there I applied for a community mental health practitioner’s role, but instead was offered to interview for a new position that had not been advertised yet – peer practitioner.

I had never heard of this title before and had no idea what to expect. I began my time as a peer practitioner working alongside other newbie peer practitioners at the local hospital emergency department.

Peer work means different things to different people, but to me it means using my lived experiences to support other people to their own self-discovery. Much of my own recovery journey has extended from understanding myself better – why I feel what I feel, and how my reactions relate to those feelings.

**The value of lived experience**

As peer practitioners in the ED we were able to offer alternative crisis support to people presenting in distress, while also learning and developing our own peer practice. This was both the most challenging and the easiest thing I have ever done.

I found that my practice was always going to stem from my own lived experience, however I quickly discovered that my learnt judgemental opinions had no place here and I needed to be completely open minded if I was going to be authentic in my practice.

Before practising peer work, I had very strong opinions around drug use, specifically that there was no reason why people should become addicted. Early into my work and training, I came to recognise that, for some people, the impact of life experiences may mean their best coping mechanism becomes using drugs.

I am now able to support people with alcohol and drug use effectively by embracing empathy, understanding and zero judgment.

I have had the privilege of working across many different programs during my time as a peer practitioner. This has given me great insight to the amazing support lived experience brings to the mental health system.

Through our own lived experience, peer practitioners can look beyond someone’s diagnosis and see the whole person. We are able to provide people with authentic, holistic support throughout their mental health journey by being with them, as opposed to doing things to or for them.
We take the time to learn from and about the person we are supporting so that we can co-facilitate a recovery plan, and we strive to create a safe, non-clinical environment, where people can be supported to self-discovery.

The advantage of this non-clinical environment is that it removes barriers such as intrusive paperwork and assessments – both of which add no value to support provided, and are simply a check box exercise for organisational procedure.

As someone with their own lived experience, I know that people need understanding, not fixing. People want to be heard and to feel safe, especially when exploring subjects such as suicide.

Peer practitioners are able to create a safe space where people can explore what they need to, without fear of judgement or consequence. We know we are not perfect – we won’t always get things right – but you can be sure that we will take responsibility when we get it wrong and learn from the experience. There are no egos here. And we will ask your permission, every step of the way.

**Barriers to effective peer work**

Currently the benefits of lived experience in the mental health system are being hindered, whether intentionally or not. Through my professional experiences, I have seen how most system guidelines, policies or procedures don’t align with peer practice and values.

This includes the expectation of unnecessary incident reporting or intrusive and unwarranted welfare checks for people expressing suicidal thoughts or ideation. These systems have been created to protect liability of organisations and have lost sight of why they were implemented in the first place – to support people who want to be supported.

As someone with this lived experience, I can recognise that not everyone who has suicidal thoughts has the intention to end their life. This has been a common theme I have come across in my peer support work – people afraid to be honest due to fear of hospitalisation or other consequences.

These include having child services involved if they are a parent, being “dobbed on” to other support services, and unwanted welfare checks by police or ambulance.

**The need for understanding and inclusion**

Many non-peer mental health professionals don’t know or understand what it means to be a peer practitioner. The number of times I have introduced myself and been met with the blank stare or roll of the eyes – I have reverted to introducing myself as a community mental health practitioner in some professional settings to avoid the awkward conversation or explanation.

Alongside this is the myth that people with their own lived experience are damaged, broken and fragile. They couldn’t – so the myth goes – possibly be able to help themselves, let alone anybody else.

This could not be further from the truth, and this stigma and emphasis on tiptoeing around peer practitioners creates a huge barrier.

This is evident even in some of the peer work educational framework – where there is a massive emphasis on safe disclosure but nothing about how to utilise lived experience in a practical way. Without advice around this, peer practitioners are thrown into practice without all the tools they need to provide the best support possible.
A powerful tool

Of the many great outcomes achieved by people I’ve supported, one in particular has held a special place for me: supporting someone with a recent diagnosis of BPD (Borderline Personality Disorder) who was feeling lost and hopeless around their ability to manage their daily symptoms.

At the start of our support they were hyper focused on the diagnosis and all the barriers this created for them. As we would find out, many programs, organisations and mental health professionals will not support someone with BPD directly.

This is due to the lack of understanding around the diagnosis and the wide breadth of symptoms that can accompany BPD. This lack of awareness has created a stigma around BPD, felt immensely by people seeking support through long wait times and inappropriate support options.

I was able to be flexible in my role and create space for both self-discovery and education for others supporting this person. Together we explored the whole person and how their symptoms were affecting, and intertwined with, every part of their life – work, social, family etc.

Our collaborative care approach allowed a safe space for this person to explore their self-harm and suicidal ideation to a point where they began to feel somewhat safer with themselves, as their understanding of themselves had changed.

At the end of our support, we were both able to reflect on the growth we’d each experienced. We learnt a lot from each other and we were able to create some trust in the system again for this person. They were able to detach themselves from their diagnosis and recognise that they were a whole person outside of their BPD.

Seizing the opportunity to empower peer practice

This person’s story and my experience point to an opportunity.

The idea of peer work has become the flavour of the month, but organisations need to provide the right support and awareness across all service providers, for peer practitioners to ensure their impact is felt.

Without proper understanding and acceptance of the peer workforce, lived experience will not be utilised to its fullest effect but, if done correctly, peer work will be the way forward for mental health support, providing a trustworthy pathway for people to access the support they want.

*Cassi Strauss is a mother of three, and a peer practitioner for Mind Australia. She is currently completing her Masters in child and adolescent mental health

Published on Monday, October 10, 2022
Let’s talk about psychosis, and the families mental health reform forgot

Introduction by Croakey: Announcing a *Lancet Psychiatry Commission on Psychoses in Global Context* last year, the authors wrote:

“Psychoses affect more than 20 million people worldwide and are associated with substantial impoverishment, premature mortality, stigma, and human rights violations.”

The article paints a stark picture of poor outcomes in high income countries and a dearth of research to underpin our knowledge of the situation in low resource settings.

**Australian statistics** indicate that about five in a thousand people each year encounter the health system for psychosis yet, as Kerry Hawkins points out in the post below, it rarely features in public conversations about mental health.

Worse still, she writes, it is poorly understood, resulting in stigma for those affected, with consequent increased suffering.

In this, the third article of the Speaking Our Minds series, Hawkins writes from the lived experience of a carer for a family member with psychosis, making a compelling argument for the need to place lived experience at the centre of future research and planning.

Kerry Hawkins writes:
Fifteen years ago in the usual morning rush of getting young children to school whilst getting ready for work I received a phone call from a nurse with a Canadian accent politely asking if I could possibly pick up my family member from an inpatient ward in Canada, where he had been for two weeks since his most recent suicide attempt.

He had left Australia to escape his persecutors trying to kill him. We had not known where he was – in the world – for months as he was careful not to identify his location in case phone calls were being traced.

Prior to him fleeing Australia, I had of course made many futile and increasingly frantic attempts to obtain help from our private and primary mental health systems.

A gap in the mental health discourse

Australians talk a lot now about mental health: of anxiety, depression, eating disorders, and workplace and lifestyle stress. An unrelenting daily slew of sloganeering, apps and websites is fed to us on television, social media, shopping centres and train stations, telling us to talk about it.

But we don’t talk about psychosis. And we never seek out the opinions of people who hear menacing unrelenting voices, who have visions and other visceral experiences to the point where they lose their homes, jobs, and most agonisingly, their relationships with friends and families.

And if we do talk about it, the relentless living hell that is the experience of unsupported extreme psychological distress is usually explained as a brain disorder or disease mitigated by medication, instead of seeking experiential perspectives.

We don’t talk, either, of the failure of our monolithic medico-legal health system (by which, in some circumstances, people are compelled by law to undergo medical interventions, including involuntary commitment) that claims to be the solution to mental health problems, in case we discourage people from seeking help or talking about unusual and terrifying thoughts and feelings.

In fact, our mental health system has no idea how to respond effectively to psychosis.

This means we don’t talk about the cruelty families face when they are encouraged to seek help from unavailable services, or the shock experienced in going to a trusted institution for help and encountering ineffective and unresponsive services.

We don’t talk, either, about the guilt, horror, and helplessness families feel at being made complicit in coercive practices, or the despair of witnessing the slow, inevitable physical health decline of their family member as a result of their medications, the slow estrangement from their own family and friends, and above all overwhelming experience of powerlessness to do anything about it.

To love someone and witness this is a pain beyond description.
The toll on families

Families also live with the impossible reality of desperately trying to pivot between normal family roles – and appearing to everyone else to be a normal family – and the realities of negotiating the ruptures of psychological distress and the practical consequences imposed by the system of being a carer.

We don’t talk about the ripple effect on families’ physical and mental health. We have known for decades that the failure of our mental health system has led to prominent and enduring grief over relationship breakdowns, social isolation and poor quality of life for family members.

Many family members sacrifice their own careers and financially support their loved ones for decades, often drawing down on their superannuation to survive.

An unacknowledged workforce

A report released in 2017 identified that one of the consequences of this system failure is that family mental health carers are by far the largest mental health workforce in Australia, with over 240,000 family mental health carers measured in 2015 providing an annual replacement cost of $14.3 billion worth of care. Most of them don’t receive any carer payment; many of them don’t know of any supports.

Many more families are ‘hidden carers’, including child family members, culturally and linguistically diverse families, and Aboriginal and Torres Strait Islander family/kin.

Exploitative policy settings rely on families stepping in to support family members, often at great financial and personal cost. In doing so, they mask the ineffectiveness of the mental health system.

Gaps in policy and system design planning

Because they are then busy and poor, families are also shut out of opportunities to be heard and to influence policy and system design in appropriate ways alongside those most harmed by the system, their family members.

Ensuring child family member voices are integrated and their needs addressed also is also a neglected critical priority. Omitting the impacts on children of parental psychosis in policy and system design work, is both intellectually unimaginative and morally unacceptable.

This, despite the fact that our medico-legal mental health system manages to simultaneously breach Australia’s obligations under the United Nations Convention on the Rights of People with Disability (CRPD) whilst delivering people with psychosis a twenty-year shorter lifespan, lived with debilitating health conditions.

It also, as The Lancet puts it, leaves people with ‘poor social outcomes, [including] high levels of unemployment, poverty, and homelessness in the decades after the initial contact with mental health services.’

For many families, the introduction of the National Disability Insurance Scheme (NDIS) – an enactment of Australia’s ratification of the CRPD – has made things worse, adding yet another unresponsive government agency layer of negotiating non-existent, unreliable or ineffective services – and removed the paltry tokenistic support funding that had previously been available to families on the pretext that the NDIS would now relieve them of any caring duties.

The NDIS remains psychosocial disability-illiterate and incompetent and so has not lessened demand for family support services.
The narrow biomedical view leads to stigma

So unquestioning are we of the brain disease/disorder explanation of psychosis – and therefore the health system being the answer to it – that when we look at re-designing systems we often look only at the health system and how we can find system solutions within it.

For example, we look for technical fixes so that people don’t having to tell their story over and over, rather than asking hard questions about why people are having to return for the same reasons, a sure sign the service is ineffective.

Conversations about workforce centre unreflexively around how we can quickly grow more of the same workforce and how to reduce burnout, rather than considering that people clearly need different supports and different workforces.

And as others have noted, adhering to the brain disorder/progressive disease model of psychosis (rather than considering the contribution of other factors such as social adversity) has become an alibi cover for the effects of systemic neglect and lack of innovation in the sector.

It has also relegated families to para-clinical roles such as assisting with medication-adherence and repeated medication changes on the promise of the next one being more effective, appointments, and ‘symptom vigilance’.

It means families are more likely to acquiesce to, rather than challenge, poor outcomes, and to attribute relationship breakdowns to the ‘symptoms’ of a disease. The harm this does to relationships and recovery, particularly for child family members, is untold.

The brain dysfunction explanation is also behind the high and persistent levels of stigma and discrimination aimed at people with a lived experience of psychosis.

Stigma means we avert our eyes when we see people in the grips of paranoia or tormented by menacing, terrifying voices, and think it’s OK as a response to sedate them beyond sentience with life-shortening sedatives.

Stigma means it’s OK to put people on $20,000 a year support payments to survive and leave them in group hostels before dying twenty years ahead of the rest of the population.

Stigma means we can’t have honest discussions about risk approaches, and stigma means we don’t demand accountability of our systems.

Stigma means families don’t talk honestly with other families about their experiences in order to drive community demand for better outcomes.

And in a sickening policy twist of the ultimate act of structural stigma during the peak of the COVID pandemic, when all Australians were being reassured by Jobseeker and Jobkeeper payments, those already most impoverished, those most crippled by crushing poverty on disability or carer payments, were not given the same uplift payments as the rest of our community, further entrenching a sense of being unimportant.

Whose voices will we privilege?

Fifteen years on from that heart-jolting morning phone call, nothing has changed for families. Since then, our family has endured more terrifying suicide attempts, lengthy hospitalisations, and housing, employment and financial insecurity.
We have some work ahead of us. We must prioritise a strategically focused, outcomes directed and practical approach to research, led by people with a lived experience of enduring and high impact psychosis and their families.

Progress such as the establishment of a **national mental health consumer peak body and a national mental health carer peak body** will be critical first step, but for those of us for whom mental health reform forgot, the work needs to be done differently. Starting with whose voices are given platforms in the media.

*Kerry Hawkins is vice-president of Mental Health Carers Australia, a Director of Emerging Minds, a Trustee of Psychosis Australia, President of the Western Australian Association for Mental Health and a 2022 Churchill Fellowship award recipient. She works from a family lived experience perspective at a system reform level.*
Losing my naivety: reflecting on 22 years of consumer perspective work

Introduction by Croakey: Stand by for a masterclass in working in “consumer perspective” roles in mental health.

Consumer consultant Wanda Bennetts is the first person to admit that she started out pretty green, and maybe that’s just as well. But she has since used her lived experience to work with multiple mental health organisations, taking on various consumer perspective roles over twenty-two years.

Here, she reflects on what has been done well, what could have been done better, the multiple challenges for those working in consumer roles, and the sweet spots – where the opportunities lie to work with organisations to effect real change.

Bennetts writes in her personal capacity, rather than on behalf of any organisation, as part of Croakey’s Speaking Our Minds series of articles this Mental Health Week.
Wanda Bennetts writes:

I have struggled all my life with my mental health, but 1998 was the beginning of a few harrowing years in the clutches of both the private and the public mental health systems.

At one point, I didn’t feel I would survive and at that very darkest moment. I knew I had to take back control or life would no longer be worth living.

This experience was very personal, but it was the over medicalisation (seeing me as the problem and not the things that had happened to me), and the over prescription of drugs (that to this day have impacted negatively on my physical health) that concerned and confused me.

But, most of all, to my absolute horror I didn’t have the rights I assumed I had (aligned with other medical decisions) such the right to refuse treatment. The loss of this basic right as well as the coercion and fear of having my life controlled by the system have stayed with me and are the reasons I have done this work since the year 2000.

I decided to pursue work in mental health services with the hope that I could improve them. We often call working from such lived experience, working from a “consumer perspective”.

I thought it was as simple as letting people know how things could be done better. My naivety was both a blessing and an impediment in the early years of my work. A blessing because it helped me plunge into the work without a sense of blockages and obstacles in my way. An impediment in that I don’t think it allowed me to do “deep” work that truly “rocked the boat”.

Consumer perspective roles

“Consumer” can be a highly contested word, but the term was developed as a response to the passive role that “patients” have in healthcare systems.

There are many ways that you can work from a consumer perspective: roles include, policy, research, education, peer support, activism, and project work, with each of these requiring different skills.

Today I am mostly writing about the work of consumer consultant roles, but this may also apply to other types of roles.

[This article is written in my personal capacity and not on behalf of any organisation within which I have worked]
Consumer consultants work systemically, and try to use their experience of mental health service-use and their connection to the consumer community to improve services.

It is about facilitating the voices of those who use the services to design, deliver, and evaluate services at every level wherever possible. On a practical level, this can be to try and shape the following:

• How consumers can help influence the service model of care or advocacy
• How consumers can shape policies that determine how they can better have their views and preferences on treatment and their human rights respected
• How consumers can shape the organisation’s advocacy on mental health policy.

The extent to which this is done and the quality of the work varies, depending on how open organisations are to embracing consumer perspectives.

You can work within organisations or outside them, and both have challenges.

From the outside, the advocacy and activism is crucial to raise public awareness. However, most of the work I have chosen to do has been from within organisations that are inherently bureaucratic.

While every consumer worker and organisational context is different, in my twenty-two years in consumer perspective roles, I’ve also noticed that many things are the same.

I have worked in consumer consultant roles within clinical mental health services. These are services that use coercion and compulsory mental health treatment on people every day and this is allowed as we have mental health legislation that makes it possible.

My current work is with Victoria Legal Aid (VLA), an organisation that supports people to understand and exercise their rights when they are accessing mental health services or have other legal issues.

My work with Independent Mental Health Advocacy (IMHA), within VLA, aims to better embed consumer perspectives in their work. To do this I facilitate a consumer advisory group (called Speaking from Experience) which has people with lived experience of mental health issues and/or who have had compulsory mental health treatment.

Like anyone else, sometimes people working in mental health can look at issues through their narrow professional lens and lose sight of the person or people they are serving.

It is our role to give visibility to that on daily decisions the service makes – how it defines good practice, how it designs resources for consumers, and how it undertakes its public advocacy.

Victoria Legal Aid has done that in a good way. Though change is slow, the slowness has often been about wanting to get it right.

**Entering a workplace as a consumer worker**

I have often said that the work is limited only by time, money, resources and attitudes. But we do know that attitudes are the biggest enabler or barrier to good work.

As a consumer worker, when I first start a new role, I get a flurry of mixed feelings. At first, I have hope that there will be real change and that true co-production of services with consumers is possible.
On the other hand, I also know that the pace at which I expect change can be ambitious, and that I need to bring people along on the journey.

**Working within bureaucracies**

Organisational readiness is crucial, so it is important that the organisation has time to ask questions and explore any uncertainty and fears they have. It needs to be a space where it is okay to not know the answers. We explore that together.

It is interesting to notice that when organisations do get to the point where they are ready for change, they then see possibilities they never saw in the beginning – in fact possibilities that they may have even actively stifled or snubbed in the beginning.

Equally, there is also a risk that consumer consultants aren’t prepared for the role and may be “captured” or “co-opted” by the service they are meant to improve.

When I started out my consumer consultant roles, I wasn’t ready to know and hear what my more seasoned colleagues had experienced as that didn’t resonate with me at first. The work I did in the initial days was at a very superficial level.

This meant there was no resistance from the organisations, so they were happy. When I was warned or heard of the experiences of others, I understood it intellectually, but wasn’t really internalising it.

**Challenges for consumer consultants**

Consumer perspective work is about doing things differently – that is why the roles were envisaged in the first place. Although this is the exciting bit, it is also one of the most challenging bits. Organisations often don’t like to change the status quo and certainly struggle to give up their power, that they may also have trouble recognising and naming.

The status quo and the use of power to maintain it often means it can be hard to raise issues and challenges. After years of work in this environment, I have some reflections on the challenges.

We can face significant **compromises**. Of course, these are part of any work, but because this work is so closely linked to our (often harmful) experiences, it is particularly hard. When resistance to change is high in an organisation, there are times that I may need to let go. But doing this can feel like I’m letting people down or like I am selling out.

These compromises leave us open to **criticism** both within the organisation and within our own consumer community. My belief is that for mental health systems to change, our consumer perspective work needs to be done in all settings and ways. At times, I have been asked how I can work in these bureaucracies. For me this is just one way to make change.
The work raises questions of allegiances. When any worker goes into an organisation, their allegiance and duties are to that workplace. However, as consumer consultants are about facilitating the voices of those who use the service, it poses the question: who are you working for and whose voice should be privileged?

Organisations are often risk averse on many levels. However, risk is often only understood from the perspective of the organisation, not from the perspective of those who use the service. This is often grounded in paternalism, and can be a real barrier to change.

The slow pace of change is its own barrier. If we want to make meaningful change in real-time, things to address are prioritising consumer-perspective work, giving it authority in the organisation, and having enough consumer workers to do the work.

We usually don’t lead the services or set the agenda in those services. Consumer perspectives on important decisions can be seen as competing or conflicting with existing agendas, but when consumer perspectives are made central to all priorities, organisations understand and embrace these perspectives as enhancing.

In most of my roles over 22 years, I have been the only person in a consumer-designated role. With the Royal Commission into Victoria’s Mental Health System expanding the consumer workforce, there needs to be ways to connect consumer workers to their colleagues and their ideas.

This is also important for maintaining values and authenticity to the work and to guard against co-option of the consumer workforce. Co-option can be for well-meaning reasons such as services wanting you to feel part of a team, but once absorbed fully into a team it is easy to lose sight of the reason the roles were first developed. Critical to counter isolation and co-option are proactive efforts to ensure people are linked to their own consumer perspective discipline and history.

I don’t represent consumers and I don’t want other consumers to represent me. One of my high horse rants often follows being asked to be a consumer ‘representative’ when others are asked onto committees for their expertise (see further p 3).

There is a place for getting a representative view, but there are many ethical and practical considerations. There are many questions, including (but not limited to) who am I representing, was I voted into this role, how would I get their views, what about marginalised views? These and many more questions must be understood and worked through.

Money is an issue. These are often low paid roles. As a consumer worker, you may not have your own budget for activities, and may have to compete with other hospital activities for consumer perspective work.

Working in dedicated consumer roles is a discipline in its own right, that needs recognition. In all workplaces there may be people with lived experience in addition to their other roles. While this can be valuable, it is quite different and cannot be substituted for dedicated roles where someone is specifically tasked with using their lived experience (for an example of these distinctions, see this Position Paper). It’s a difficult conversation that can be personal and divisive, but it is an important one.

It can be exhausting playing the role of the annoying voice. I don’t want to be the annoying voice, but there are so many issues to be raised. One manager said to me “I give you a perfectly good explanation about why we can’t do something, and you just come back at it another way!”

If I stopped at every “perfectly good explanation”, I wouldn’t be doing my job! The other alternative is to “roll over” and then feel like a failure, like you have let people down who don’t have a voice at the table.
Ultimately, this work is about **human rights**. It’s about the human rights of people who are treated differently and **discriminated against** because of who they are and because they are caught up in a mental health system that greatly impacts on freedoms and can often **perpetuate trauma** that has occurred in their lives – the trauma that quite likely landed them in the system in the first place. Human rights are too important to be lost in all the other activity and bustle that gets its way.

**The things that would have helped me in guiding organisations**

Having done this work for more than twenty-two years, I wish I had done things in a much more aware way. For instance, I didn’t know anything about “organisational readiness” – a way of looking at whether organisations are in the right place to understand and commit to change based on the consumer perspective.

With that in mind, here are some considerations – based on my experiences as a consumer consultant – for organisations looking to work with consumers:

1. **Learn:** Learn about consumer perspective work so that you understand it and are ready for it. There can often be parallel processes in play where staff may feel powerless or feel that they cannot make a difference. Notice the power and acknowledge this as well. This all takes time and commitment, but the benefits are great. This work won’t flourish until the organisation is ready.

2. **Grow:** The best way to get started is to sow the fertile soil. Start with things that create a win all around, no matter how small they may be. Start with the achievable things so confidence grows, and people feel safe to move forward.

3. **Reflect:** Ask yourself – Is what we do as an organisation good enough for me and my family? If not, it is not good enough for any consumer, so support us to support you to find better ways. There is such valuable knowledge in first-hand experience. It can lead to practical and transformative ways to improve your service. That knowledge is unique to people who have used your services, but you need to ask.

Over the years, I have tried to model what I want to see. And I don’t get that right anywhere near as often as I would like. Would I do things differently if I had my time again? Absolutely. This is a lifelong journey and although head banging at times, this is the work I always want to do.

My dream – and this is a personal opinion – is that we no longer have mental health legislation that permits compulsory mental health treatment, and that services are what people want them to be.

Ultimately, I hope that the consumer voice becomes so centred that my role becomes redundant.

*Wanda Bennetts has worked in mental health consumer perspective roles for multiple organisations over twenty-two years. She currently works as a Senior Consumer Consultant for Independent Mental Health Advocacy, Victoria, but this article is written in her personal capacity.*
From time slips to visceral disquiet: the experience of mental health caring

Introduction by Croakey: As we continue the Speaking our Minds series this Mental Health Week, in the post below a carer comes clean.

Drawing from her own experience as a long haul carer for someone with mental distress, as well as submissions to 2019 Royal Commission into Victoria’s mental health system, Dr Caroline Lambert walks us through some of the “intricate, the peculiar, [and] the dark spaces” of her lived reality.

This is much more than an intellectual exercise: Lambert notes that many of the stressors on carers result from societal injustices, broken systems, inadequate resources, lack of support and compassion, and sheer neglect.

Lambert’s words beg the question: could fairer, better societies and systems lessen the burden of “visceral disquiet” that mental health carers are currently forced to carry?

**Readers are warned that this post contains references to suicidal ideation**
Caroline Lambert writes:

As my first decade of supporting a young person who “thinks all the thoughts”, and who feels deeply, quietly clicks over, I reflect on the contractions and contrasts; the dualities, the multiplicities, and the messiness of the experiences of those supporting someone with mental distress.

The experience of supporting someone is sometimes portrayed as an act of altruistic, selfless benevolence – which is an unforgiving portrayal that fails to capture the complex nature of the individual and the relationship: I am no self-sacrificing saint with endless reserves of support and solicitude.

This one-dimensional depiction does no favours in representing the diverse and intersectional identity and experience of carers, nor to consumers, whose relationships with that person or persons, may be characterised by violence, misery, or suffering.

Messiness of the caring experience

Society often demands neat, polished packageable narratives of caring, but “mental health” carers know that this sanitised version of “caring” is often not the reality. I get the appeal – I just know it’s a lie.

I suspect that the portrayal of one dimensional, benign carers is more palatable for mental health services to engage with – or to ignore. There is a payoff in perpetuating the myth of “carers walking alongside consumers” on their yellow brick road to recovery.

This photoshopped narrative allows for denial of responsibility by government and services – for continuing to inadequately fund innovative community programs for service users and sufficient carer resources.

Carers are rarely encouraged to explore the intricate, the peculiar, or the dark spaces of our experiences. I wonder if this is a hermeneutical injustice of kinds.

Perhaps then we can begin to explore the intricate spaces, in those moments where we hold two (or more) opposing truths?

The monotony and volatility of time

My therapist once told me that time was definitive, concrete and predictable. I remain unconvinced.

Many carers speak to the rubbery nature of time – the hours that feel like days, and the months that feel like a decade. When you are housing the person you support, and the world around you has shrunk to just those within the household, each hour can feel endless – particularly if you are attending to someone who experiencing suicidal ideation or self-harming.

As one woman in her submission to the 2019 Royal Commission into Victoria’s mental health system noted about supporting her brother,

“I sat by his bed for many, many hours just letting him know I was there”.

Dr Caroline Lambert
So many carers have done and are doing just that. Watching. Waiting. Attending. Singing. Wondering. Particularly during that stretch of time between 3am and dawn.

This black hole of time can sometimes feel like the longest stretch for carers – a fraught time when many of us feel at “peak vulnerability” for haplessness and loneliness.

As a carer, the experience of time can, paradoxically – feel both tedious and volatile. I wonder if this contributes to our hypervigilance – even in the most monotonous of times, we can feel heedful and sharp eyed. Never quite trusting the quiet moments.

The weight and the gift of caring

The weight of providing long-term care, is captured throughout the final report of the recent Royal Commission into Victoria’s Mental Health System, in which families spoke of caring as placing, ‘a soul-destroying burden on families...’.

In Tandem’s submission, one carer notes,

“Families are at the end of their tether with this broken system.”

We know that it is not the person with psychic distress who is the burden on carers, rather it is the absence of safe, compassionate, accessible support. Without adequate supports our rights to education opportunities, employment, stable housing and social participation are eroded.

For me, the gift comes in moments of accidental reciprocity. I have gained clarity – from reimagining my own priorities and the collective priorities of our family – leaning into a newly created space to explore my own history of neurodiversity and mental distress, and reaffirming both the value and precarity of life.

I have learnt that sometimes carers have no choice but to sit with obverse truths – to experience the clash of despair and grief; joy and gratitude.

The “doing whatever you can to keep the person you support alive” – but also understanding the pull of a different world.

Carers are not often permitted to publicly consider the peculiar or bleak spaces that supporting someone can take you to, but in those moments when the person you support is experiencing relentless psychic pain, and no relief can be found, I confess to wondering about the arrogance of imposing a sometimes-wicked and unjust world on someone who no longer wants to be here.

I will always argue that people should have the right to do what they need to do, but I also recognise the inconsistencies and contradictions inherent in my position – knowing that I have and would do almost anything to ensure that the person I support stays earthside.

It is no secret that caring for someone – or for many people – can contribute to our own feelings of mental distress. Another carer in a submission to the Royal Commission writes,

“Six days ago I buried my husband. He couldn’t take any more stress. He had a massive heart attack. I have developed heart problems on top of extreme anxiety on a daily basis.”

As carers, our relationships and functioning within the family can become ruptured. This stress and rupture is not a product of an illness or disease – this is the product of societal structures and systems that are not responsive, compassionate, fair, equitable or just.
Even in the context of widespread system reforms within the State of Victoria I still hear carers saying, “nothing is changing,” and that the reforms have yet to make real change in their own lives – or in the lives of the people they support. One carer writes,

“My life has literally been in a state of depression so much, that at times it would be easier to simply not be on earth. This is not an option but sounds easier than constantly dealing with my lot.”

The wickedness of the world around us continues.

**The feelings and doing versus the embodied experience of caring**

Legislation and regulations recognise that caring is as an action, a behaviour or a doing if you will. The breadth and depth of “doing” in our role of carers is extraordinary.

We are often advocates, supporters, cleaners, cooks, drivers, friends, financial and legal managers and facilitators, and entertainers. Many of us also push back on the roles ascribed to us by the medical system – we do not want to be the medicators, the weighers, the measurers, or the regime regulators.

Sometimes the feelings associated with caring are recognised by mental health services, by government, by researchers and society at large – albeit in narrow and tightly bounded ways. However, the embodied way that carers experience caring is rarely explored – unless it is couched in medicalised ways of assessment – through our blood pressure, diabetes rates or rates of stroke.

While I understand that this kind of framing of the care experience matters, what characterises my own caring experience can best be described as a “visceral disquiet,” which I would identify as a deep instinctive, inward feeling of unease and impact.

The gut-wrenching moments of needing help for the person I support – but not finding any, the gnawing worry of years of school refusal, or of a loved one sleeping rough. Visceral disquiet ruffles my spirit when I wonder if the savagery of today’s world will be too much to bear for the person that I support.

This “visceral disquiet” is the opposite experience of an ‘embodiment’ which signifies a feeling of safety, a fit or a snugness. If there was an opposite for the Danish word of hygge – then this, is it.

* Dr Caroline Lambert is Director of Family, Carer Research at Tandem Carers and is a proudly neurodivergent academic who is based at RMIT university. Caroline has lived and living experience of supporting someone who thinks and feels deeply.
Keeping our loved ones alive: the compounding effects of racism and exclusion on mental health care

Introduction by Croakey: Seeking care and finding harm, feeling unsafe in the mental health system, falling into despair that much needed help will not be forthcoming: these are some of the lived experiences of the people who have written for our ongoing Speaking Our Minds series, and their loved ones.

The post below, from Quandamooka woman Leilani Darwin, is no exception. But for Leilani and her daughter, the failings of the mental health system have cut even deeper, with an overlay of racism and exclusion.

As someone whose work involves educating mainstream health services about culturally informed practice, Darwin knows things have to change. She calls again here for leadership, solidarity and action.

**Readers are warned that this post contains references to suicide**

Leilani Darwin writes:

When you are somebody who happens to work nationally across both the mental health and suicide prevention sectors you would hope that finding help would be possible. What if I told you that it is, in fact, the complete opposite?
Despite my knowledge and connections, my own experience with seeking help has been far from a positive process. In fact, it has been a damaging, frustrating, painful space that has left me and my loved one completely broken by the system.

Why is this of relevance? Quite frankly because, if these are my experiences, then it completely overwhelms me to imagine what it is like for everyday Australians, and what it is like for other First Nations People, who have additional challenges and barriers to overcome.

**Racism and exclusion in healthcare are real**

You see, the reality is that we do experience racism, and we are judged and treated differently to others in the healthcare system. These are both my personal experiences, and the experiences that others from across the country have bravely shared with me, backed by research findings from well-established authors.

Earlier this year, following a change in our nation’s leadership, I wrote a piece as part of the CEO update for Mental Health Australia. In that update I reflected that We (the First Nations People of Australia) have seen many things progress positively for our people.

This includes progress towards constitutional reform and recognition, removal of mandated cashless debit cards, forecasted improvements in access to affordable childcare for our young people, and many other positive reform activities.

The addition of Social and Emotional Wellbeing to the Close the Gap Strategy will provide a clear pathway to accountability of how we address and respond to mental distress and our service/support pathways.

However, exclusion still exists across the system.

For decades we have seen non-Indigenous service providers continue to be funded to provide mental health and suicide prevention supports and programs, often with the clear exclusion of self-determined and culturally safe and appropriate responses.

In both my professional and personal lives, I’ve experienced many conversations that have not just had a clear power imbalance, but have also embodied a very paternalistic, arrogant approach. Ultimately, the lack of cultural pathways and considerations of both safety and treatment options, remains in a desperate state of chaos.

**The human impacts of systemic failure**

In recent times I’ve been supporting my teenage daughter, and I can recall key moments when the systemic failings reflected in our experiences broke her.

Early on, her encounter with a doctor in the emergency department saw her in tears, unwilling to continue engaging and being shamed for her experiences and expressions.

I also felt exclusion and shame when I was questioned about my ability to keep my daughter safe, after I queried the lack of response or support for someone who was clearly suicidal and wanted to die, yet was sent home with the full responsibility on her family to keep her alive and safe.

During the times of hospitalisations and external support I was not once offered support for my own mental health and wellbeing despite being clearly distressed, and at a loss as to what I could do to keep her safe.
When a young person who has yet to be diagnosed mental illness, trauma and suicidality is told on several occasions that certain actions and supports will be provided, and then those things are not forthcoming, it damages any ongoing engagement.

And at other times, when that young person seeks help from a phone service, only to be hung up on when they are hyperventilating and unable to respond, this results in a genuine belief that help seeking will be met by no help, and that there is no hope of ever getting the right help and support, or of things getting better.

**Compounding impacts**

These experiences are not uncommon, but they have compounding impacts on Indigenous peoples. Some non-Indigenous people are quick to say that happens to everyone. However, in those statements there is an explicit non-valuing of how and why as First Nations people our experiences are different.

For example, when you discover your child has had a suicide attempt and a severe allergic reaction, you weigh everything up and know that it’s quicker for you to drive them to the emergency department than to call an ambulance.

Upon arrival in a packed waiting room, your daughter is directed to sit on the weight determining chair, and almost falls to the ground. The staff’s response is to berate and criticise you for not calling emergency services, who could have administered early healthcare interventions.

I’m not saying that I don’t understand this perspective because I know how overworked and under resourced our hospital and health systems are. What I’m saying is that not only was it shameful for me, but that when I looked down and saw the Aboriginal designed shirt I was wearing, it hit differently.

It also wasn’t helpful that time was being wasted to school me on what I should have done, while my child was about to pass out in the emergency waiting room.

The lack of empathy shown to my daughter and I continued, and I also observed another Aboriginal person who had clearly had an attempt being spoken down to with such an air of disdain and inconvenience that it took everything in me not to speak up on their behalf – but you see that wasn’t my role, nor was it going to address the underlying issues, or help my daughter to receive appropriate care.

With these examples being only a few of the many I and others have experienced, it’s an important time for us all to reflect on what is that we can do to make the system and services better so that others don’t have to have similar experiences.

**Building lived experiences into mental health reform**

During COVID our communities brought to light the struggles and challenges with mental illness and the stigma around accessing support. We are yet to see or understand what the true impacts have been and the ongoing effects of this global pandemic.

I’m asking for us all to come together to ensure that the lived and living experiences of everyone are elevated and embedded not just in future responses, but also in ensuring that all aspects of mental health reform, policies and practices are built on these experiences.

We need Federal Health Minister Mark Butler and Shadow Minister Emma McBride to commit to working with us and walking alongside us.
For this is one thing that I am certain of: if we don’t immediately address the barriers, challenges and lack of culturally led and appropriate systems responses and pathways, then our future generations will continue to be negatively impacted.

The lack of support and understanding is further exacerbated by our experiences of powerlessness and injustice, in ultimately just tirelessly working to keep our loved ones alive. I can’t and won’t stand by with idle hands and mind when we know the solutions to address the barriers and challenges.

“A Quandamooka woman living in Brisbane, Leilani Darwin is the CEO and Founder of First Nations Co. She is well known within the sector for her work and leadership in Suicide Prevention and Mental Health, and is a powerful advocate for Aboriginal and Torres Strait Islander led, culturally informed practices within mainstream services. Her work has been built from her own lived experience of losing many loved ones to suicide, and her own mental ill health. At ten years of age she had already experienced complex trauma including living with a mum who suffered from mental illness, regularly self harmed and ultimately died by suicide. A survivor of several suicide attempts, living with depression, anxiety and suicidality does at times pose challenges to Leilani. However, it is also one of the main motivators for her to get up, show up and stand up for her people so that they don’t have to experience what her and her family have gone through.
Don’t stop believing – pink elephants can fly!

Introduction by Croakey: Should a health care intervention ever involve a violation of human rights?

And how can we enshrine human rights in the care of people with severe mental illness, while making sure that all patients and staff are safe?

These questions have recently been the subject of much discussion, especially following the recommendation of the Royal Commission into the Victorian Mental Health System to:

“act immediately to reduce the use of seclusion and restraint in mental health and wellbeing service delivery, with the aim to eliminate these practices within 10 years.” (Recommendation 54)

Below, mental health and human rights advocate, Simon Katterl, asks us to consider if we have the framing of this debate all wrong. What if we take a step back and ask ourselves if the “impossible” is not the imperative.

This is the last lived experience perspective article in Croakey’s Speaking Our Minds series, however, Katterl, who has worked tirelessly to help bring you these valuable insights, will return in a post next week, to reflect on what has been learned.
Simon Katterl writes:

There have been many sliding doors moments for me. I often reflect that when I have called for help, such as when I’ve been suicidal, help is what I’ve received. My mum, friends and mental health professionals have acted as my supports, while ensuring every step on this journey was my supported choice.

However, I know that there are others who, instead of help, have received profound harm. They have entered the system seeking help, often following their own trauma, but in the end, they’ve been left more hurt by the trauma of their involuntary mental health treatment.

A last resort

Victoria’s mental health system has made small steps towards improving these experiences. They are investing in new approaches to mental and emotional support, have introduced new mental health laws (though their changes are minor), and are replacing ineffective regulators that have failed to protect human rights.

Compulsory treatment is said now to be used only as a ‘last resort’, and seclusion (aka solitary confinement) and restraint (physical, mechanical and chemical) are aimed to be eliminated by 2031.

Even if these measures are taken, they fall well-short of international human rights standards as well as the expectations of many people who use the mental health system.

Not far enough for some, too far for others.

‘Idealistic, and right up there with pink elephants flying’. That’s how the Victorian Branch President of the Australian Medical Association described the Victorian Governments efforts to implement a key recommendation of the 2019 Royal Commission into Victoria’s Mental Health System – to eliminate seclusion and restraint.

The President went on to ask “How are we meant to manage these people if we can’t use medical or chemical restraints?”, and suggested that lives would be put at risk by the effort to move away from these practices.

I found this response deeply unhelpful and it reinforced my sadness about the cultures underpinning parts of our mental health system. It highlights that some perceive staff occupational health and safety to be mutually exclusive with the human rights of people already detained within mental health units.

Staff do experience significant occupational health and safety risks in the mental health system. There are reports of assaults in addition to verbal abuse and threats. This sits within the context of a system that has been chronically underfunded for decades, with staff stress levels and burnout high.

The evidence suggests – as does the Victorian AMA president’s comments – that the mental health sector believes that seclusion and restraint are necessary to manage conflict. It’s a belief that is particularly strong in Australia, with evidence suggesting that nurses do it in response to their own sense of fear and to ensure safety for others.
Overcoming a false binary

The logical outcome of these conversations is that the public views it a choice between consumers’ human rights and the staff’s occupational health and safety. While I believe that we need to privilege and consider far more deeply the implications of violating human rights as opposed to regulating work conditions, I also think this is a false binary.

Initiatives like Safewards promote another way. Originally developed in the UK in 2014, Victoria implemented a program of activities to reduce containment (of consumers) and create safety for all (including staff).

The program – which includes taking an organisation-wide approach to implementing language and culture change, less restrictive responses to conflict, and opportunities for mutual recognition and expectations – was independently evaluated as being effective for reducing seclusion events and reducing conflict between staff and consumers using the service.

Speaking about Safewards, mental health nurse and Centre for Mental Health Nursing head, a/Professor Bridget Hamilton tells me that:

“Safewards tells us that there is considerable hope for changing the conflict status quo in any ward; the model and the interventions make the most of anticipating flashpoints that can lead to escalation, and resetting environments and relationships that are welcoming and welcomed. Harm for patients and nurses is not the only option” (personal communication)

Harm to patients and nurses is indeed not the only option (and shouldn’t be an option). In 2017, colleagues Felicity Gray, Cath Roper and Piers Gooding were commissioned by the United Nations Rapporteur on the Rights of Persons with Disabilities to review alternatives to coercion, revealing hundreds of successful efforts to reduce coercive practices across mental health environments.

Winds of change

There is a gradual recognition within psychiatry of the need to change. The World Psychiatric Association has now pushed for psychiatrists and mental health systems to vigorously pursue alternatives to coercive mental health care.

Similar and more ambitious initiatives have been developed by the World Health Organization’s Quality Rights initiatives, which will drive a global shift away from force. There is a growing recognition, as was articulated by the Lancet Psychiatry Commission that the ‘use of compulsion needs to be seen as a system failure’.

However, at the same time, views from the profession in Australia are more conservative. While acknowledging that seclusion and restraint does harm, the Royal Australian and New Zealand College of Psychiatry fall short of full elimination and have disagreed with more substantive law reform.

This sits within a broader division within the health system and profession. On the one hand some clinicians believe a human rights-based approach unnecessarily impinges on clinical decision-making. On the other hand some put the profession within the purview of human rights norms, including the need to eliminate rights-breaching practices (see also the other doctor who commented on the proposed reforms in Victoria — a psychiatrist who supported elimination).
The Victorian AMA President’s incursion into the debate reflects this tension between different visions of clinical practice and the mental health system. The place of, and relation between, safety and human rights is central to these competing visions.

**Building a safe, human rights-based system**

A future mental health system built on safety, will be one built on human rights. That’s not where we are at. The current mental health system is violent, predominantly towards the people who are forced to use it. My experience as an advocate taught me this. My opportunity to participate in research reinforced it. Our laws, rules and culture sanction this violence.

The only pathway to safety for all in the mental health system is to recognise and eliminate the violence inherent to the system. We can do that, but it requires greater introspection from parts of the mental health system. If we do this well, one day we’ll all marvel at the pink elephants flying.

*Simon Katterl has lived experience of mental health issues and has used predominantly private as well as community public mental health services. Simon’s work focuses on mental health laws, governance, regulation, and systems design.*
Revelatory and resonant: fill your cup with the voices of lived experience

Image Ephraim Mayrena, Unsplash.

Introduction by Croakey: If you missed any of the six articles we published last week to coincide with Mental Health Week, be sure to take some time in the near future to dip into the Speaking Our Minds series, to read perspectives on the mental health system from people with lived experience of using it.

Below, Simon Katterl, who approached Croakey with the idea to privilege these voices and shepherded the series to publication, reflects on what he has learned from the stories and insights of the five unique writers featured in the series.

He also reminds us that public conversations are shaped as much by the people whose perspectives are missing as by those who get to speak.

Croakey looks forward to hosting more of these conversations, with a range of diverse voices, in the future.
Simon Katterl writes:

I’m often left depleted by this work – having the same conversations with the same (or different) people, maintaining the same systems...

New Zealand-based consumer/survivor advocate and friend, Mary O’Hagan, often reminds us of ‘the power of incumbency’ – the ability of systems to self-reinforce and maintain themselves.

I know these feelings of depletion, like my other experiences of distress and despair, are transitory. There are cycles of fear, distress, despair, optimism, thrill and hope that come with complex work that sails so close to your own experience and identity.

Rather than deplete my cup, this year, Mental Health Week helped fill it.

Working on the #SpeakingOurMinds project with the Croakey team as well as the expert writers, has been a privilege. I’ve learnt more – as I trust you have – about each of the writers and their unique contribution to our community and to changing mental health systems.

Lived experience and agents of change

Cassi Strauss’s article about working as a peer practitioner pointed us towards a way out of a narrowly defined mental health system that focuses just on assessment and treatment.

Others have been pointing and pushing us in that direction for twenty-two years, including Wanda Bennetts, whose article on consumer perspective work in mental health and legal settings illustrated the complex algorithms for generating change in institutional settings.

As I read Leilani Darwin’s article about racism in the system, I was reminded about how far we have to go, but how generous the spirit is, of First Nations leaders to walk with us as we learn.

Both Kerry Hawkins’ and Caroline Lambert’s articles embody the powerful change that carers want in the system, but also the toll that calls for change-making have had on them.

If you haven’t read the articles in this series, I encourage you to do so. I can’t stress enough the importance of all of the supportive organisations, as well as the work from Ruth, Melissa, Alison and Mitchell from Croakey.

Raising all voices

As I write, I’m conscious of the voices who have still been absent in the commentary surrounding mental health week.

Disabled and chronically ill people’s mental health seems invisible in public policy decisions to move to “post-COVID”. The uncritical releasing of all restrictions risks making their lives more nasty, brutish and short.
In a podcast earlier this year I spoke to two women, Jenny and Sarah (pseudonyms), about their experiences within Victoria’s prison settings. They described an institution of absolute surveillance and control, so spare a thought for Australians whose mental health is known to be worse than that of the non-incarcerated population but often ranks lowest in our public consciousness.

In Victoria, where changes to bail laws following multiple homicides in 2017 have made it more difficult for those arrested to obtain bail, First Nations women have been disproportionately impacted. These laws are driven in part, from my view, by mental health stigma.

Family violence survivors need to be part of conversations about mental health too.

Tess Moodie, who runs a victim-survivor media-advocacy and public awareness program (and is themself a victim-survivor), approached organisers of a Mental Health Week event in Tasmania to offer the voices of victim-survivor advocates. However, they say the organisers suggested that a family violence, rather than a mental health event, would be more appropriate.

I approached Tess after seeing their tweet, and understandably frustrated, they reminded us that, “despite the high rates of Post-Traumatic Stress Disorder (PTSD) experienced by victim-survivors, family violence is often viewed as a social issue and the mental health issues it creates is often not in plain sight due to shame and fear the victim-survivor may experience.”

It’s disappointing, they said, that “despite family violence being a major cause of anxiety and depression, conversations and awareness about it during Mental Health Week have taken a back row.” We can do better.

When we include the voices of lived experience, we are better for it as a community.

**Listening to lived experience for a better future**

Last Saturday I cried, laughed, and hugged my friends as I watched Honor Eastly’s live depiction of No Feeling is Final – her groundbreaking 2018 podcast on mental health and the system.

She repeatedly told the audience “how fucking hard” it was to explain her experiences, which makes sense, because she explained it in new and real ways that many of us with lived experience have struggled to find words for.

Seeing her and her wonderful team of her partner, friends and co-conspirators fills me with hope.

All the people mentioned here highlight injustice and opportunities. The injustices facing people with lived experience of distress from all different walks of life. And opportunities, that if we centre these voices, in positions of power and influence, they will help us create a healthier and more caring future.
 Revelatory and resonant: fill your cup with the voices of lived experience  
#SpeakingOurMinds

*Simon Katterl has lived experience of mental health issues and has used predominantly private as well as community public mental health services. Simon’s work focuses on mental health laws, governance, regulation, and systems design.

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For assistance:


Suicide Call Back Service 1300 659 467 [www.suicidecallbackservice.org.au](http://www.suicidecallbackservice.org.au)

beyondblue 1300 224 636 [www.beyondblue.org.au](http://www.beyondblue.org.au)

13Yarn 13 92 76 [13yarn.org.au](http://13yarn.org.au)


QLife 1800 184 527 [https://qlife.org.au/](https://qlife.org.au/)


You can view Croakey’s coverage of the series here.

Twitter wrap

As well as publishing the series of articles at Croakey.org, the #SpeakingOurMinds project involved a sustained presence across social media platforms, especially Twitter.

![Twitter wrap](image)

See the full Tweetbinder report here.

From Twitter

Croakey News Retweeted
Simon Katterer @SimonKatterer - Oct 7
Proud to forecast the authors from @CroakeyNews's #SpeakingOurMinds series for #MentalHealthWeek next week.
Read on and stay tuned!

Ping: @imhavic @mindaust @tandemcarers @LalaniDarwin @bulyresearch @kerryhawkins @DrRuthAtLarge @AlisonSBarrett

croakey.org

Join us for a swim upstream this Mental Health Week
Introduction by Croakey: In your media consumption over the next week (October 8-15), you’re likely to encounter more than the

Prof Victoria J Palmer (she/her) @VictoriaPalmer

A compelling account from @kerryhawkins and so important to recognise, as this piece shares, “Many more families are ‘hidden carers’, including child family members, culturally and linguistically diverse families, and Aboriginal and Torres Strait Islander family/kin.”

Croakey News @CroakeyNews - 3h
“Explosive policy settings rely on families stepping in to support family members, often at great financial & personal cost. In doing so, they mask the ineffectiveness of the mental health system”- Kerry Hawkins in the #SpeakingOurMinds series
croakey.org/lets-talk-about...

#SpeakingOurMinds

“Explosive policy settings rely on families stepping in to support family members, often at great financial and personal cost. In doing so, they mask the ineffectiveness of the mental health system”

Kerry Hawkins - VP of Mental Health Carers Australia & 2022 Churchill Fellowship award recipient
You can view Croakey’s coverage of the series [here](https://example.com).

Mind Peer Practitioner Cassi Strauss discusses her work as an Emergency Department Peer Practitioner in [CroakeyNews](https://example.com). This Mental Health Week Mind celebrates the valued experience in mental health recovery.

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@DrRuthAllarge · Oct 14

What if we don’t have to choose between human rights and “safety”? In this article in the [CroakeyNews #SpeakingOurMinds series](https://example.com), we ask you to take a good hard look at the assumptions underpinning the current MH care system & end the violence.

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@CroakeyNews · Oct 19

From time slips to visceral disquiet: the experience of mental health c... introduction by Croakey. As we continue the [Speaking our Minds series](https://example.com), in the post below a carer comes.

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@timheffernan · Oct 19

‘powerlessness and injustice’. thanks for your powerful words [Leilani Darwin](https://example.com).

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@CroakeyNews · Oct 19

Keeping our loved ones alive: the compounding effects of racism and exclusion on mental health care [Croakey.org](https://example.com)/keeping-our-l... #publichealth

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@SANEAustralia

People living with #psychosis are stigmatized & disregarded. Great article from @CroakeyNews #SpeakingOurMind series.

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@SANEAustralia · Oct 19

Let’s talk about psychosis, and the families mental health reform forgot.

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@Croakey.org · Oct 19

It’s not just about access to services, it’s about how you use those services. SANE Australia discuss the personal experience of [SANE Australia](https://example.com) in [Croakey.org](https://example.com).

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@Croakey.org · Oct 19

The lived experience of a peer practitioner. Introduction by Croakey. As flagged earlier, this Mental Health Week Croakey is hosting the Speaking Our Minds series of articles.
It's my turn to share, systemically racist experiences and quite frankly no help for my daughter, not uncommon experiences @SBSRadio @AMSANTaust @ssplencerthomas @NACCHOAustralia @cbpatsisp @GayaaDhuwi @coaltion_peaks @NMHC @Qld_MHC @AUMentalHealth @mindaustralia

You can view Croakey's coverage of the series here.

Thanks to @CroakeyNews for the opportunity to write this personal reflection of #MentalHealth - caring. #reform

This, from @bullyresearch as part of @CroakeyNews #SpeakingOurMinds series. On the messy, monotonous, hypervigilant, multitasking, conflicted and uncomfortable world of a mental health carer croakey.org/from-time-slip...

Everything written here by @kerryhawkins feels like she's writing about my family. The decades-long push & pull of trying to navigate institutions & services without subjecting dad to coercive & inappropriate ~care~ as well as the ruptures to family life often bc of services

croakey.org/lets-talk-abou...

#SpeakingOurMinds

"Exploitative policy settings rely on families stepping in to support family members, often at great financial and personal cost. In doing so, they mask the ineffectiveness of the mental health system"* Kerry Hawkins in the #SpeakingOurMinds series croakey.org/lets-talk-abou...

Truth speaking @kerryhawkins and then we bare the soul responsibility for keeping them alive. It begins believe the magnitude of the pain that brings.

croakey.org

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Simon Katterl @SimonKatterl · 7h
“We don’t talk, either, of the failure of our monolithic medico-legal health system that claims to be the solution to mental health problems.”

Another article as part of #MentalHealthWeek’s #SpeakingOurMinds series, this time from @karryhawks!

Article: croakey.org/lets-talk-abou...

Karry Hawkins - VP of Mental Health Carers Australia & 2022 Churchill Fellowship award recipient

Replying to @SimonKatterl @karryhawksins and 8 others

This is such a fabulous article, and so spot on!! Thank you @karryhawksins, @SimonKatterl and @CroakeyNews - it's wonderful to have #MentalHealthWeek coverage of real substance.

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Layout and design by Mitchell Ward