# What will it take for peers to have an equal voice in key decision making?

# Dr Louise Byrne

Thank you, before I start – In Australia it's customary to begin meetings and presentations with an acknowledgment of the traditional custodians of the unceded lands on which we live and work.

It always reminds me of my First Nations family members, friends and colleagues and leads me to deeper connection with the country I stand upon.

My home is on Darumbal Country in Central Queensland, Australia, right on the border of Woppa Burra lands.

I first learned about spirituality walking alone in the Australian bush and I first learned about holding ground – being an outsider working to influence change, in First Nations led organisations.

So, I'm importing that custom - at least for today and would very much like to pay my respects to the First Nations people whose lands we meet upon.

My very limited understanding – and please forgive me if I get something wrong, I'm happy to be corrected, is that there are seven federally recognised tribes within Virginia and the area around Norfolk is recognised as Nansemond Nation tribal lands.

I promise to walk softly on these lands with respect for First Nations Elders past, present and those still emerging, with respect for all First Nations people, their ancestors and the spirits of this beautiful country.

I would also like to acknowledge everyone here today with significant lived and living experience and the peer frontiers who came before us, paving the roads upon which we

now walk. I'd like to pay particular respect to a dear friend, the late, great Anthony Stratford, who held many roles internationally including Expert Advisor to the World Health Organization, and former Board Director of NAPS. Anthony was a beautiful human being, a pioneer in peer research and forged bridges between our nations.

I work and speak from my personal lived and living experience of mental health, alcohol and other drugs, homelessness, suicide, domestic, family and other forms of violence, trauma, an acquired brain injury and physical disability including deafness.

I will use the terms Lived Experience and peer interchangeably this morning. In Australia 'Lived Experience' is a common term that encompasses people working in peer support roles but also designated roles in systemic advocacy, consulting, training and education, research, all levels of management – right up to Executive positions.

It's not always people's preferred term, but I am going to use it because it encompasses every type of designated job role - which is what I'm going to talk about, it's also easy to grasp – it explains itself. And! Because of a point I will reveal later…

But for now, a vision statement that was shared as part of a multi-disciplinary funding application, including Lived Experience leaders and allies from other professions, who unusually, truly did privilege peer perspectives and were committed to a radical vision.

Indulge me for a moment. Close your eyes. Picture This. You walk into a recovery service and from your first impressions of the physical environment, the way you are greeted, the interactions you have with staff, it's obvious every person working in this organisation is committed to finding ways to work with you to improve your emotional, spiritual and psychological life.
This is obvious in the tone of people's voice, in the language and the phrasing they use, in the way your whole self is considered and respected, and how that inspires you to feel like you matter.

And instead of feeling lost, frustrated or terrified, a tiny little kernel of hope alights within you because here are people who get it - who are going to ally with you, partner with you, respect your knowledge of yourself and be guided by that, who are going to contribute to your confidence and walk with you on a journey that is shared.

You can open your eyes now. What has happened in this multi-disciplinary organisation to create such a positive first impression?

The short answer is the embedding of peer perspectives values and principles from concept development through design, delivery and evaluation.

It is creating from the ground up, an organisation that truly understands and aligns with the person walking through the door.

And that is achieved by robust, proactive, lived experience workforce development and willingness to share power with peers at all levels of authority, in order to co-produce something transformationally different that can facilitate the type of best practice outcomes that keep us all working in this space. I find that persuasive.

I've had the honour and privilege of working in a vast range of peer job types and settings and been able to devote many years to understanding and advocating for our combined workforces. I've seen enormous shifts.

Today I want to share some of what I've observed, as well as what the research tells us about the remaining barriers to full equity for peers within the system. I'll also share what I see as key strategies to further enable a full seat at the tables of decision making for peers. I'm going to preface this talk by saying, much of my public messaging over the last decade and a half has focussed on how we move forward most effectively with allies, people from any other discipline background, non-peers. I've spent a lot of time gently challenging folks in other professions by myth-busting some of the misconceptions about our workforce and being firm but generally as positive as possible in that messaging.

I've chosen that focus because you catch more flies with honey and berating people rarely wins hearts and minds. I also believe, and research shows us, that there are great benefits –

including for our colleagues in other professions, in peer perspectives being more embedded and honoured throughout the system – when peers rise, we all win. However, I have also experienced a great deal of private disappointment and disillusionment over these years and sometimes, with a group of like-minded folk - I also believe it's important to acknowledge the enormous challenges we still face and to speak plainly. If you've noticed the balance of power is still overwhelmingly not including our priorities and perspectives, wave your arms in the air.

All the way back in 1997, I got my first proper job working at a First Nation's led and run youth service. I hadn't heard of peer work back then – I lived in a regional area, 400 miles from a major city and about 40 years from the latest trends. I didn't have any qualifications, but I was and am the oldest of nearly 30 cousins and I learned to look after little people when I was still a very small person myself. And so, they gave me the job.

I didn't know what peer work was, but it made sense to me to connect with the kids as meaningfully as I could, so I drew from common experience. Over the years I would work many times with young people, particularly young folks described back then as 'at risk'.

I knew exactly what they were at risk of, I'd been there too. So, when it seemed appropriate, I shared stories from my life I suspected would resonate with them and unsurprisingly, built rapid rapport and trust.

When I was finally introduced to the idea of peer work - that become my immediate vocation. Nothing in my life had ever made as much sense and I was compelled to find a way to contribute. I finally talked the local state-run health and hospital service into creating the first paid peer role for my district in 2005, it was not an easy gig.

To say there was resistance would be something of an understatement.

Over the years I worked in many different types of peer roles, trained in Intentional Peer Support, and later moved into my first lived experience academic position in 2009. I'm now nearing the end of my second research fellowship and recently I've started consulting with

motivated organisations to assist them to implement our evidence-based strategies to build peer workforces that are well understood, accepted, respected and prioritised.

There have undeniably been huge gains across the decades – I was recently on the interview panel for an Executive Lived Experience role at one of Australia's largest not-for-profit mental health organisations.

I also helped inform that position description and design the interview questions, to ensure the person has strong roots in our collective, grass roots thinking and an emphasis on human rights, social justice and systems change. It was very gratifying.

We have seen an enormous upsurge in the number of peers employed internationally and a growing trickle of more senior roles that allow us greater authority and influence within organisations and the sector.

Earlier this year, the Australian federal government announced 7.5 million dollars to establish and operate two new independent national mental health lived experience peak bodies. One to represent those of us with first-hand, personal experience and the other for folks with an experience of supporting or walking beside those of us who find our lives disrupted by stress and distress.

Great. As long as the people they bring on understand the principles and practices of our community and they don't favour an 'easy option' – either peers who won't prove too challenging and/or those who don't have sufficient experience in peer roles and grounding in the collective thinking that informs our work. Based on a trend many of us have no doubt observed, we shall see.

Through those years I, like most of us, have faced seemingly insurmountable barriers at times, largely attitudinal, and been ground down by the constant need to fight to maintain the same slivers of ground. I applaud every one of us, here today and those who aren't, who chose to stay and work towards service and social change despite how emotionally challenging it can be to act as a change agent.

Raise your hand if you have faced discrimination and discrediting, having to constantly re-explain and justify our value, often to the same people time and time again.

We are still frequently excluded from decisions and barred from real influence. I'm not making these claims simply from my own experience and that of others I know - although that is of course a valid and valuable form of knowledge.

Nearly a decade ago now, the primary finding of my PhD thesis was that, regardless of setting, service type, role or level of authority, prejudicial attitudes – stigma and discrimination, towards us as a workforce was so prevalent, many of us no longer saw it.

It was and is, just part of the job for many of us.

Another key theme of the thesis was sacrifice. During analysis I remember curling up in a ball crying under my desk, after hours of reading participants describe having no social life, no romantic partner, limited ability to engage in hobbies or see family, inability to work full-time - with all the financial implications that brings to mind.

All of this, because the work was so draining, it took so much.

They were describing my life, but I hadn't seen it till others shared their stories.

I expect this may also be familiar to many people here today.

It is clearly and unquestionably, unreasonable and unlawful, for any job to include regular discrimination, inherent prejudice. It is also far beyond the emotional demands of most employment for people to be routinely unable to participate meaningfully in their own life because of their job role.

The impacts on us, particularly for those who've been around a long time or are advocating and working within multi-disciplinary environments are often excessive. No-one in their employment should face ingrained discrimination and constant discrediting. And yet we do.

I say all of this as a white woman who ended up in a heterosexual relationship, who has physical disabilities, but they're largely invisible - which of course means that the ways I am systemically silenced, discredited and kept from positions of influence is significantly less

than many others representing our community, as well as often-marginalised cultures, backgrounds and identifications. In other words, I clearly have it much easier than my colleagues who stand for intersectional issues and perspectives.

I've been asked many times over the years "What do you do for a living?"
When I explain it to people outside the service system, in about 30-60 seconds a light bulb comes on, "What a great idea" they say. "Of course it should be like that", "Why haven't I heard about this sooner" etc.

It takes no time or effort for the average person to understand that someone who has walked these journeys is by far the most knowledgeable about that type of journey and can provide - given the right employment conditions, by far the most relevant support.

And yet, here we are after decades of international advocacy, thinking, training, breakthroughs, expansion of our workforce and still, somehow, the mainstream service system largely fails to understand our fundamental value and the roles we can potentially play. How is that not wilful ignorance?

Personally, I never again want to hear "peer work has an emerging evidence base".
For a start, we have tons of evidence, and that argument has been outdated for years. It's literally my job to know this.
Secondly, talk to any person who has been impacted by the truth of someone else's story, of having someone walk beside them who really understood the struggles they were facing. There's your evidence.
It's prevarication what we're facing now, this resistance. It's stalling, it's denial, it is wilful ignorance.

Again, I say this as someone who has worked within the system for a long time and tried hard to rationalise and convince others. I say this as someone who has used the processes that prop up the status quo to advocate for our community, our key messages.

I say this as somebody who understood that being Dr Louise Byrne was going to give me a lot more credence than just being Louise. I say this as someone who on the surface has had a number of big wins, and you might imagine could be feeling pretty satisfied with the impact of my work.

What I see is that we can follow the established processes, translate our lived and living knowledge into the empirical evidence base required for credibility, we can create policies - even at a national level and have those policies signed off by all levels of government - as we did recently in Australia for the National Lived Experience (Peer) Workforce Development Guidelines, which is described by government as a key action of mental health reform. And then, the majority of the system is more than capable of ignoring the key messages and continuing to undervalue, exclude and minimise our contribution.

So, these days, I say to funders and policy makers - don't talk to me about co-production. Lived Experience leadership is what we need. We can't have co-production when our power roles are still so completely unequal. How can you co-produce with someone or with a community that you frequently undermine, coerce and try to discredit. How can we co-produce when we're not trusted to have the knowledge to contribute meaningfully?

We, collectively, have advocated with our whole hearts and minds. We have humbled ourselves, held out our hats, bitten our tongues and said far less than we mean. We have taken whatever scraps they would give us from the tables of influence, and we have made of it the best we can.

Then – and I'm hearing this a lot lately, they tell us peers are getting too much power.

Too much power. Because there is a fraction of funding now attributed to our workforce. Even though the guidelines of that funding often prohibits us from doing our work properly and gets in the way of the best benefits we have to offer.

Because we finally have a voice at the Big Table, however emergent, that's considered too much power. Because the system - and I'm not pointing to individuals today. Or even necessarily individual organisations. I've had the privilege now of consulting with some organisations that have truly embraced and invested in multi-layered strategies emerging from *our* evidence base, to genuinely position Lived Experience at the centre of everything they do. Good work. The path to that investment can be windy, but we're all learning and growing and change is challenging.

So, while there are of course individuals and organisations who perpetuate the attitudes and behaviours that create barriers to our most meaningful contribution. I'm talking today about the powers that be – setting the agenda, allocating the dollars, driving conventional behaviour and decision-making - the 'hive mind' many people employed to uphold the system often share, particularly when what *we're* suggesting seems too risky.

What I think of as a type of illogical mob mentality, an inability to trust our wisdom simply because it's different. And that persists due to a lack of investment in systemic education and re-education about the value and necessity of our workforce and the unique knowledge we bring.

For the last 9 years I've worked a lot in conjunction with various government agencies and mental health commissions - major funders, and it has repeatedly broken my spirit and injured my faith in the possibility of real change.

I see the final frontier for us is to infiltrate that level of the system and it will not be easy. There are several key barriers I see for us at that level.

The continuation of the existing power base is a primary driver of centralised systems in general. I'd go so far as to claim the system broadly has no intention of sharing power with us, regardless of what we're being told.

As you're probably aware, Goffman's theories around stigma, particularly perceived stigma, centre around the idea of social deviancy. This is of course at odds with the desire for predictability and control.

Hoffman describes the 'situation of the individual who is disqualified from full social acceptance'. He's describing people like you and me, who in the eyes of the status quo, are fundamentally less credible and are our views undesirable. It is the business of the system to ensure our deviant ideas don't gain too much credibility or influence. Peers can't have too much power.


This underpins what I consider our next biggest obstacle – risk aversion.

We all know it, right?

What *we* define as necessary growth is often labelled as risk by the system, and the system is *terrified* of risk – regardless of the potential rewards.

In Intentional Peer Support I remember learning that when our processes and reactions are informed by fear, everything we do is tainted by that fear. And of course, if you for example - don't let a toddler practice walking in the lounge room for fear of falling and hitting their head, you end up with one mighty passive and incapable toddler. You inhibit their natural growth and the building of necessary ability to function independently. There are parallels.


Additionally, the type of thinking, the types of brains that are successful in our outdated education system and then attracted to working in organisations that hold power, often think, perceive and behave very differently than we collectively do as a community.

Even when there is the desire to engage meaningfully with us, with few exceptions, understanding of how different our views and approach is from current practice, falls short.

The power of the existing system is so prevalent, and privilege so ingrained, the way the system engages with us is damaging to us, and any changes we *can* make are still falling

dramatically short of our collective goals and the logical need within our communities for human centred, heart-based services that build connection and contribute to hope.

There is essentially no accountability for policy makers and funders at this point and instead, an almost worshipful and often illogical prioritisation of convoluted existing processes, that leads to massive procrastination on the part of funders, leaves *ridiculously* short time frames for *us* to respond to funding bids, and if successful – to complete projects.

All of this against a backdrop of us already being stretched to the limit but feeling unable to let opportunities go by – even for the sake of our well-being – because if peers don't lead it, it'll go to someone who distorts our concepts and misses the point.

All this said, I still believe we as a community, as a philosophy and a new way of thinking can transform what's possible.

I have stayed in this work because I couldn't imagine spending my time and energy on anything else. I've been driven, it's a fire that almost burnt me up - over, and over again. It's a need to contribute that has significantly impacted my health, relationships, my quality of life, and like many of the other addictions I've faced, I can't stay away, I can't stop. Because the need is too great, and *I* know all too well, as so many of us do, what it is to have your life destroyed by a system that is meant to help. To have your concept of self, distorted by the beliefs of a system that frequently and fundamentally misunderstands and misinterprets the needs of vulnerable human beings. I have stayed, and I have fought, because I believe in us.

What needs to shift, in my opinion, is what counts as valid evidence, what is considered valuable knowledge and how to apply that knowledge in practice.

For millennia, formal, more traditionally 'masculine' forms of knowledge have been increasingly promoted. To the point where nearly all advanced education now happens in

the hallowed halls of the academy – regardless of how effective or otherwise that education may be.

It is a widely accepted truism these days that many degrees are not worth the paper they're printed on. And yet, it is this formal, formalised knowledge that still dominates.

What *we* bring is a different kind of knowing. An emotionally earned and built, experiential knowledge. A school of hard knocks knowledge. A more traditionally 'feminine' and therefore historically less valued form of knowledge.

It is a common-sense, practical and grounded knowing, that allows us to see what other forms of knowledge miss, and to do what other professions are less able to do – bridge that gap and 'be with' someone in their distress, their confusion, their trauma.

I'm the first person to acknowledge there's no such thing as a concrete reality. Even day to day I can see my perspective of the same situation shifting and changing. As a person and as a researcher I don't prescribe to the idea of objective truth, or one set reality.

But *my* truth and the truth of many others within our community is that the system is broken, and it will remain so, unless and until *we* have the leadership that is logical and allows us to create something radically different and new, which responds to the real needs of actual human beings within our communities. And that can only happen when our knowledge base is respected and accepted as necessary.

So how do we get there? Well, I'm one person so I don't have all the answers. Others will provide many strategies and ideas I've never considered. I recently saw on the NAPS LinkedIn page the campaign for the 'PEER Support Act' to - amongst other things, have peer specialists recognised as a distinct occupation. Exactly. That's part of it.

Despite all the disappointments over the years, I still believe in *us* collectively. And yes, I know we're not homogenous, we have different views, we have multiple perspectives. We have competition amongst ourselves, disagreement.

Sometimes unfortunately, we have parallel violence. I'm not immune.

But each of us contribute to a practical, real-world understanding of what service use or inability to access services feels like, and what is needed.

Even if at times we push against each other - and we do - at least the views we are variously representing authentically come from our experiential knowledge.

Anyone here see the Monty Python movie 'Life of Brian'? You'll probably know where I'm going with this…

For those who don't, in the film there are two rebel groups opposing Roman occupation. The Judean People's Front and the People's Front of Judea. They are both very small and as you may have guessed from their names – have fairly similar views. And yet! They spend more time opposing each other than the colonisers. In a poignant scene from the movie, one group member is trying to argue for a unified front. This is a British film so I'll do my best with the accents…

Brian: We mustn't fight each other! Surely we should be united against the common enemy!

Everyone: The Judean People's Front?!

Brian: No, no! The Romans!

Everyone: Oh, yeah. Yeah. Yeah. Yes.

Francis: Yeah. He's right. We can argue afterwards.

We can and will continue to disagree, it's part of the health of this movement – to think critically and constantly evolve. But we can also have shared vision at least on some points, and if we seek opportunities to publicly agree, present a united front and argue those common points, we move towards critical mass.

For wide-scale acceptance of our lived expertise as a valued form of knowledge, we will *need* our collective influence.

I believe one way to enhance this is being recognised more broadly as our own discipline, with our unique values, principles and practices better understood by the wider system.

To promote our knowledge base and increase respect and acceptance for what we uniquely bring, we need discrete spaces to explore, define, test and refine our understandings of what we do and what informs us. Without influence or interference from other, more influential professions. We need the time and opportunity to articulate our value - our existing and potential contributions, in ways that make sense to *us*, and reflect the principles and practices we uphold.

It's our combined and increasingly sophisticated understanding of our discipline that still provides me with hope and belief for change. When we can and do come together to devote time and resources to the promotion of our knowledge base, as we are here today - we find ways to unlock doors that have been closed to us.

So, I recommend advocating for large and small opportunities to do this as a matter of *great priority*.

We need peers within organisations to have time to yarn with each other, we also need formal research centres that allow us to leverage the processes of the existing system and establish our type of knowledge as credible in the eyes of the establishment, without sacrificing our independence or our uniqueness.

By extension, I believe if we are more insistent and consistent in both clarifying our knowledge base and pushing against established beliefs about what is valuable knowledge, it will be another small part of moving towards systems change.

Regardless of the remaining barriers, we've survived this long, with longer odds, less allies and no power or influence whatsoever. So, I think it's safe to say - we're not going away, we won't fade into the background, and collectively we will continue to push the system for what is actually needed - total re-envisaging of the very concepts of mental health, addiction, support, help, and a complete reversal in where power currently resides, who is considered expert, and whose voice is being heard.

We who have already persevered through so much, will continue to push for what we know is really needed, a paradigm shift - a revolution…

If you feel inclined I'd like you to raise your voices with me now.

*Song Lyrics shown on powerpoint: 'Talking Bout a Revolution' by Tracy Chapman.*
*Louise plays Baritone ukulele and sings.*

Don't you know, they're talking bout a revolution? It sounds like a whisper
Don't you know, they're talking bout a revolution? It sounds like a whisper

While they're, standing in the welfare lines
Crying at the doorsteps of those armies of salvation
Wasting time in the unemployment lines
Sitting around, waiting for a promotion

Don't you know, they're talking bout a revolution? It sounds like a whisper
Don't you know, they're talking bout a revolution? It sounds like a whisper

Poor people gonna rise up and get their share
Poor people gonna rise up and take what's theirs

Don't you know you better run, run, run, run, run, run, run, run, run, run, run, run
oh, I said you better run, run, run, run, run, run, run, run, run, run, run, run
Finally the tables are starting to turn, talkin' 'bout a revolution
Finally the tables are starting to turn, talkin' 'bout a revolution
Talkin' 'bout a revolution

I've been standing in the welfare lines, crying at the doorsteps of those armies of salvation
Wasting time in the unemployment lines, sitting around waiting for a promotion

Don't you know, they're talking bout a revolution? It sounds like a whisper

And finally the tables are starting to turn, talkin' 'bout a revolution

Yes, finally the tables are starting to turn, talkin' 'bout a revolution

Talkin' 'bout a revolution

Talkin' 'bout a revolution

Talkin' 'bout a revolution