15 Standing Up Against the Weight of History

The Importance of Lived Experience in the Mental Health Context

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Introduction

In Australia, the contemporary mental health system is driven by a centuries-old 'deficit narrative' that has created a bias towards a bio-medical, individualistic approach to understanding and responding to people experiencing mental ill-health. As a result, and despite new models of care, multiple inquiries and various attempts to deliver better supports for people with mental ill-health in Australia, many people affected by mental ill-health, trauma and emotional distress remain marginalised and continue to experience poor outcomes.

In this chapter, we will articulate how this persistent 'deficit' narrative positions people living with mental ill-health as 'other' – incapable, unreliable and even dangerous, requiring individual medical intervention and paternalistic laws to deliver on a promise of safety to the individual and community. We will then explore how this narrative remains embedded within aspects of the mental health system today, particularly in (a) mental health law, (b) the treatment of people with lived experience working in the system (as peer workers, advisors and consultants) and (c) the disregard of the social determinants of mental ill-health. For the purposes of this chapter, the 'mental health system' refers to the clinical and community sector that offers mental health services. Although this chapter examines the broader historical mistreatment of people experiencing mental ill-health across the world, we emphasise developments in our own national context in Australia, with reference to major federal and state governmental reports from the past half century. This includes the recent final report of the Royal Commission into Victoria's Mental Health System (2021) (Victorian Royal Commission), on which Professor Bernadette McSherry was a commissioner.

At the conclusion of this chapter, we briefly explore several strategies and points for further consideration in moving beyond the deficit narrative. First, to bring change, we argue for awareness of the ongoing influence of the conceptual history of mental ill-health, including the need to be clear about the values and social norms embedded within contemporary understandings of mental health. Second, we contend that the concept of 'allyship', that is mental health professionals reflecting on their role in upholding a system built on

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flawed foundations and working in partnership with people with lived experience as equals (as discussed later), has transformative potential. Finally, we argue that prioritisation and integration of lived experience perspectives in all aspects of the mental health system, including leadership, is the most effective way to challenge the flawed foundations of mental health policy and practice today.

We write from our experiences working in the mental health sector. The lead author (Jayakody) writes from a lived experience perspective with qualifications in law. The second author (Perera) writes from his experience as an occupational therapist with a public health background. We have each worked in the mental health sector for more than ten years in a variety of settings. We are interested in understanding and challenging the social norms that underpin the mental health system. Bernadette McSherry has insisted throughout her scholarship that law – and particularly mental health legislation – should be viewed in its social and policy context. We would like to extend this approach to include the history that shapes contemporary social and political conditions and link it with McSherry's continued emphasis on the inclusion of lived experience perspectives in research. (For discussion of the history of mental health law see also Arstein-Kerslake in Chapter 12 of this volume.)

Flawed Foundations

According to Davidson, Rakfeldt and Strauss (2010: 30), 'few subjects in medicine are so intimately connected with the history and philosophy of the human mind as insanity. There are still fewer, where there are so many errors to rectify, and so many prejudices to remove'.

The evolution of our understanding of mental ill-health is complex. We will briefly look at two conceptualisations of mental ill-health in Western culture throughout history: a supernatural paradigm and a medical paradigm. We will then examine how the stigma and discrimination experienced by people living with mental ill-health today is driven by these paradigms.

The largely pre-modern, supernatural framing conceptualised mental ill-health as a manifestation of something beyond our comprehension and is attributed to something beyond scientific understanding and the laws of nature. This conceptualisation was discussed in a 1993 report by the Australian Human Rights Commission (AHRC), titled *Report of the National Inquiry into the Human Rights of People with Mental Illness* (better known as the 'Burdekin Report' after its lead commissioner, Brian Burdekin). According to the Burdekin Report:

> Literature available from the Middle Ages in Europe indicates that with the spread of Christianity natural causes were lost sight of and madness was seen as a manifestation of possession by the devil or other evil spirits, heresy, or some other form of immorality.
>
> (AHRC 1993: 38)

Foerschner (2010: 1) summarises the conceptual evolution of mental ill-health in ancient civilisations, and notes that:

> In all of these ancient civilizations, mental illness was attributed to some supernatural force, generally a displeased deity. Most ill health, particularly mental ill health, was thought to be afflicted upon an individual or group of peoples as punishment for their trespasses.

As is well covered, the supernatural understanding of 'madness' gave way in the modern era to the 'medicalised paradigm'. By the 'medicalised paradigm', we mean the framing of mental ill-health as a predominantly biological condition – a 'chemical imbalance' requiring alteration, in which medical intervention is prioritised. This conceptual model takes an individualised approach without regard to the broader context of an individual, including social determinants such as housing, employment and relationships. According to Davidson, Rakfeldt and Strauss (2010: 24), in their examination of Philippe Pinel[1] the 18th and 19th century reformer, Pinel 'was establishing mental ill health to be ill health that belonged, like other illness, under the purview of medicine'.[2] He was also 'arguing that recovery was possible' (Davidson, Rakfeldt and Strauss 2010: 24). Pinel's framing of mental ill-health as a medical condition helped establish psychiatry as a discipline within medicine, and this has been firmly cemented in the second half of the 20th century with the rise of the pharmaceutical industry.

The medical framing meant providing interventions to fix or correct the individual condition, with the aim of restoring them to what is deemed medically normal and acceptable. As the 21st century began, Peter Beresford, a British academic with lived experience, stated in an editorial in the *Journal of Mental Health* that 'it is difficult to think of any other area of medicine, let alone thought or practice more broadly, where prevailing understandings have remained so long glued to their nineteenth century origins' (Beresford 2002: 581). The first two decades of this current century have seen increasing recognition of the broad determinants of mental health such as social, economic and physical factors (World Health Organization 2014). However, this 'social model' understanding of mental ill-health arguably remains overshadowed by the centuries old, established medical paradigm.

Both these framings have created a deficit narrative, positioning people experiencing mental ill-health as either lacking something biologically (medical paradigm) or deviating from what is considered natural (supernatural paradigm). In the supernatural framing, where people were perceived to have sinned or otherwise displeased deities, individuals in many Western countries were required to confess and repent, creating immense shame and stigma. Families often hid relatives to avoid stigmatisation by association, while others were ostracised and shunned to the fringes of society and abandoned to fend for themselves. In extreme cases, where mental ill-health was perceived as witchcraft, they may have been subjected to torture to extract a 'confession' and murdered. Through the 15th to 17th centuries, more than 100,000 presumed 'witches' were burned at the stake in Europe (Farreras 2022). The narrative that a person had sinned also made it possible for society to disregard their experiences and views, and in cases where people experiencing mental ill-health were seen as being under demonic influence, they were regarded as particularly violent and unpredictable. This attitude persists into the contemporary era. As Beresford (2002: 581) notes:

> The increasing association of mental health service users with 'dangerousness' and the constant coupling of cruel and murderous activities with 'mental ill health', as though 'bad' is tantamount to mad, is a defining feature of early twenty-first century discussion.

Conceptualising mental-ill-health as a medical condition requiring intervention to correct biological causes such as a 'chemical imbalance' in the brain, framed the individual as having a fundamental impairment. The individual is seen as 'lacking', 'weak' and 'incapable' and needing to be 'cured', 'fixed' or 'taken care of' until they are restored to what is deemed normal or acceptable by medical authorities and society at large. This narrative attributes all explanation and blame to the individual themselves and ignores external factors and determinants that may be contributing to their mental health. People experiencing mental ill-health have been positioned as 'other' to and less than others, devaluing their human experience and fostering prejudice, stigma and discrimination.

As Mary O'Hagan, an international lived experience advocate, former Mental Health Commissioner in New Zealand, and current Executive Director Lived Experience at the Victorian Department of Health, has stated:

> People often say [discrimination] starts with fear, ignorance, misunderstanding, pity or malice. But these are just some of the clothes discrimination wears. Take off all the clothes and we are left with one thing; the devaluing of madness and the entwined assumptions that mad people are full of nonsense and incompetence.
>
> (New Zealand Ministry of Health 2003: 4)

The deficit narrative that underpinned the mental health system of the 19th century still pervades today's mental health systems, including in mental health law. Despite the social changes and greater recognition of human rights and dignity of people living with mental ill-health, they continue to be marginalised and denied the opportunities to lead meaningful, autonomous lives. The deficit narrative perceiving people living with mental ill-health as other – 'weak', 'incapable' and 'violent' – enables the mental health system to continue overlooking their needs and perspectives, creating a power imbalance that privileges the perspectives of professionals.

When the medical model was emerging in the 18th and 19th centuries, there were no groups with sufficient power and authority to challenge this deficit narrative. Doctors and the medical model were at the right place at the right time in history, and the medical model prevailed. Clinicians were put in charge of the asylums and have continued to have authority in the provision of care for people living with mental ill-health throughout the modern era. Credibility and authority remain with medical professionals, and the people living with the decisions they make are often shut out of making them. This dominance of the medical model also fails to consider the collective experiences of people living with mental ill-health, helping to create a view of social determinants of mental health as being beyond the scope of the mental health system. This has created a mental health system that is inherently biased towards a medicalised and individual approach, where the perspectives of people experiencing mental ill-health are marginalised. This marginalisation within service provision also extends outside those spaces, creating a bias against people experiencing mental ill-health being involved in critical areas such as funding, research and governance arrangements.

The mental health system needs to be fundamentally re-oriented to meet the needs of and empower people living with mental ill-health to take their place as full citizens in society. To do this, long-standing biases against people experiencing mental ill-health need to be recognised and actively challenged. There needs to be meaningful recognition of the perspectives and knowledge of people living with mental ill-health, and the growth of the lived experience workforce is an indication that this change is underway.

Whose Lived Experience Is It Anyway?

Recognising the value of lived experience of people living with mental ill-health is radical. It challenges entrenched frameworks, ideas and biases that have prevailed for centuries, and requires a fundamental re-orientation of the mental health system. As Davidson, Rakfeldt and Strauss (2010: 2) note:

> these movements [including the lived experience workforce] indeed [are] a response to centuries of violence and bloodshed in which people with mental ill-health were stoned, burned at the stake, locked in cages, chained to posts and walls, confined to squalid and inhumane living conditions, insulin-shocked, hydro-shocked, electro-shocked and lobotomized.

The idea of 'lived experience' is currently experiencing a historical moment in mental health discourse and beyond. At the tabling of the final report of the Victorian Royal Commission, psychiatrist Patrick McGorry referred to the lived experience of clinicians.[3] Similarly, Australian political commentator Stan Grant in his 2022 'China Tonight' television programme referred to his own lived experience of living in China, while Pete Buttigieg, candidate for the US presidency in the 2020 Democratic presidential primary, referred to the importance of lived experience in the public policy agenda for people with disabilities (Abrams 2019).

So, whose lived experience matters? Don't we all have a lived experience? Commenting on the concept of lived experience in social policy research McIntosh and Wright (2019: 1) state:

> In our own research, we have found the idea of lived experience both intuitive and useful, but have become increasingly perplexed by its potential to seem vacuous or contradictory – what is any experience if it is not lived? . . . Emergent use of 'lived experience' in the social policy literature tends to pick it up as a free-floating notion, untethered from the theoretical and methodological contexts in which it originated, has been deployed and critiqued.

In 'Exploring the Conceptual History of Lived Experience', Rebecca Duke (2022: 11) notes that the notion of lived experience, at least in part, offers a counterpoint to positivism and 'the strictures of the scientific method with its emphasis on "objective" and unbiased observation and analysis'. Lived experience challenges the notion that 'knowledge, understanding and the conceptualisation of experience can only come about via positive affirmation of theories through strict scientific method' (Duke 2022: 11). Lived experience offers a counterpoint through the interpretation and analysis of knowledge gained by the direct experience of a condition.

In the mental health sector, 'lived experience' carries a specific meaning. It is used to recognise a voice and perspective (the 'consumer' perspective) that has been consistently overlooked and refers to the direct experience of people with lived/living experience of mental ill-health and or recovery. This diverse group is increasingly regarded as 'experts by experience'. Sometimes 'people with lived experience' can also refer to the experience of families, friends and carers that support someone experiencing mental ill-health. For the purposes of this chapter, we will be referring to lived/living experience of mental ill-health and or recovery (the consumer perspective) only.

Lived experience workers are those in designated lived experience positions and are required to primarily draw on their lived experience to inform their work. They must have the ability to use their personal experience to support others or to improve and change practices, policies and systems. When using lived experience at a system level, one must be able to 'contextualise their experience in the wider political, social and economic context' (Byrne et al. 2019: 10). This application of knowledge is sometimes referred to as 'lived experience expertise'. Lived experience expertise is increasingly and often informed by a body of knowledge known as Mad Studies. According to Beresford (2020: 1337):

> Mad studies are a field of scholarship, theory, and activism about the lived experiences, history, cultures, and politics about people who may identify as mad, mentally ill, psychiatric survivors, consumers, service users, patients, neurodiverse, and disabled.

Many clinicians have their own direct experience of lived/living experience of mental ill-health and recovery. They are invariably informed by that experience in addition to the expertise they hold in relation to their professional capacity and discipline. This is indeed valuable, but it is different to occupying a designated lived experience position where one draws on their lived experience as the primary source of knowledge to inform their work. Similarly, many lived experience workers have a background in other disciplines, but that expertise is secondary to their lived experience in the context of their work.

For example, the lead author (Jayakody) has a professional background in law, but primarily works from a lived experience perspective. As a person living with an enduring mental health condition, I have an intimate understanding of how mental ill-health pervades every aspect of one's life: distress, stigma, confusion and grief are all part of the experience. This is combined with the experience of finding peer support, navigating mental health services and treatments. A turning point in my journey was accidentally coming across a peer support network. There is a connection, a shared language and safety that peers offer. It helped me make sense of the distress as well as the experience of seeking support, and the stigma and discrimination experienced along the way. The peer support groups provided a much-needed sense of community and gave me hope that there are many creative ways of making this journey. These are the experiences I draw upon to inform my work. My knowledge is not scientific. Over the years I have learnt to translate these experiences into a broader policy context. For example, I am able to translate the helplessness experienced when seeking treatment and the lack of support for navigating treatments, to inform how power dynamics work at a systems level. (See also discussion of hopelessness in Cameron in the Foreword to this volume.) I am able to draw on the experience of differing responses from others when introducing myself as a lawyer or a lived experience worker, to articulate how stigma and power dynamics play out at a societal level. It is the art of bringing critical theory and a social justice lens to the personal experience. The personal becomes the political. My knowledge and skills as a lawyer enable me to complement and elevate my lived experience perspective; however, knowledge and skill as a lawyer are not my primary source of knowledge.

Increasingly, as noted earlier, in our work the phrase 'lived experience' is being used by clinicians to describe their professional experiences. This adoption of the term has been criticised, as this terminology was meant to elevate the marginalised voices of consumers, and its co-option by clinicians is sometimes referred to as the 'colonisation of Lived Experience'. Caution must be exercised with this type of critique, particularly in colonised nations such as Australia where there is a violent history of subjugation of Aboriginal and Torres Strait Islander people associated with the word 'colonisation'. The effect of colonisation is still being felt by Aboriginal and Torres Strait Islander people, and in our view 'colonisation' is inappropriate as an analogy or metaphor in this context, as the co-optation of emancipatory language like 'lived experience' is not comparable to colonisation of country and its ongoing impacts on Aboriginal and Torres Strait Islander people. Nevertheless, we do see it as inappropriate for clinicians to refer to their professional experience as a 'lived experience' perspective.

As evident through this short discussion, the term 'lived experience' in the mental health context is dynamic and can be contested, requiring a nuanced approach. Care must be taken not to create an oppositional 'us' and 'them' binary. It is important to remember that the locus of the discussion on lived experience is the attempt to recognise and elevate a perspective that has been consistently overlooked. In attempting to recognise this perspective and address power imbalances, (see also Katterl and Friel in Chapter 14 of this volume) care must be taken (a) not to deny the lived/living experience of mental ill-health and recovery experienced by clinicians, and (b) not dilute the lived experience perspective of persons with mental ill-health. The lived experience workforce, in requiring a person to primarily work from a lived experience perspective, ensures that that perspective remains prominent and offers a counterpoint to the established, dominant way of thinking.

The Evidence of Bias

'Structural and systemic bias' refers here to biases in the way structures, practices and policies are developed and maintained to deliver a particular outcome. The underinvestment in the mental health system by successive governments reflects the established bias against people experiencing mental ill-health, and their needs continue to be overlooked and marginalised. This view was supported by the Victorian Royal Commission noted previously, which described an 'overlooked and de-prioritised mental health system' in Victoria (Royal Commission into Victoria's Mental Health System 2021: Volume 1, 9). Underinvestment in Australia is consistent with reports from other OECD (2014) countries, in which spending on mental health services has reportedly grown in recent years but is not consistent with the level of need.

Continuous underinvestment has meant not only poor outcomes for people living with mental ill-health but enormous economic cost to society, according to the Productivity Commission (2020) inquiry into the economic impacts of mental ill-health.[4] There have been many reports that quantify the economic cost of mental ill-health, and in 2018–19 the Australian economic cost of mental ill-health and suicide was estimated to be up to AUD$70 billion (Productivity Commission 2020). These economic costs do little to convey the emotional and human cost to an individual and families and the ultimate toll it takes on society. The Productivity Commission (2020: 9) stated that 'not all of this cost is avoidable, but there is considerable scope for Australia to do better'. In commenting on Victoria's low monetary investment in mental health, Kevin Bell AM KC, former Justice of the Supreme Court of Victoria, noted:

> In human rights terms, this is a matter of obligation, not policy. Victoria is not like a developing nation where lack of resources is an explanation for under-investment in health.
>
> (Royal Commission into Victoria's Mental Health System 2021: Summary and Recommendations, 17)

Allan Fels, inaugural chair of Australia's National Mental Health Commission[5] and a commissioner of Victoria's Royal Commission alongside Bernadette McSherry, similarly stated:

> Mental health is still a fairly low priority for governments. From time to time, politicians talk about taking a big initiative, and momentarily, mental health is at the top of the policy pile. Then other matters intervene, and it falls back down. I've seen this happen time and again. Mental health is the poor cousin of health and social welfare and doesn't get priority when budgets are drawn up.
>
> (Fels 2019: 17)

What drives this underinvestment? Why does mental health remain a low priority for governments despite the enormous economic cost? As Bell clearly articulated, this is a matter of human rights and of obligation, yet Australia has continued to deprioritise mental health. Again, the historical precedent of shunning people experiencing mental ill-health to the fringes of society now continues in the form of underinvestment.

However, although increased investment is important, it does not necessarily translate to good outcomes if it does not adequately address the biases discussed previously, including the power imbalance in professional-consumer encounters, and with attention to the broader determinants of mental health. Change is in the wind, at least in Victoria. This longstanding tendency to underinvest in mental health is being addressed through a new Victorian mental health levy and a dedicated revenue mechanism for funding mental health services, as recommended by the Victorian Royal Commission. Guaranteeing investment through a special levy is one way of addressing this structural bias in mental health funding. However, systemic issues of power imbalance and bias need to be addressed if people living with mental ill-health are to truly benefit from this change. (See also Donnelly in Chapter 2 of this volume.)

The Royal Commission into Victoria's Mental Health System (2021) also recommended that the Victorian Government establish a Mental Health and Wellbeing Cabinet Subcommittee chaired by the Victorian Premier (who is the head of the Victorian state government) to monitor outcomes to inform planning and policy decisions. The Victorian Royal Commission's intention was to keep mental health a priority by keeping it close to the locus of power and control in government. It remains to be seen if this policy structure will remain with successive governments, and history has demonstrated that attempts to prioritise mental health through reporting structures have not been sustained. For example, when the National Mental Health Commission was initially established, it reported directly to the Prime Minister of Australia (the head of the Australian federal government) and federal Cabinet, signalling the prioritisation of mental health. However, this Commission was moved to the Australian Department of Health after a few years and distanced from the centre of power (Fels 2019: 25).

The biases inherent in the practices and policies of the mental health system are best demonstrated through how the lived experience workforce is perceived. For the lead author (Jayakody), it has been all too common to hear disparaging comments about the workforce in over a decade of work. Examples include comments such as: 'this is a very complex role. It is not suitable for someone with a lived experience'; 'people with a lived experience should be given part-time jobs not full-time jobs'; 'peer workers have high turnover rates'; and 'peer workers become unwell'. The implication is clear, that lived experience workers are 'incapable' and 'unpredictable'. These and other such statements were and continue to be made in the presence of lived experience workers. In contrast, if such statements are made regarding race or gender, there is increasing recognition of the prejudice and fallacy of such statements. For example, statements such as 'you can't do this job because you are a woman' or 'this job is not suited to you because you are a migrant' are understood as prejudicial and unacceptable. Both authors are first generation migrants from Sri Lanka, and this is evident in our skin colour, yet these authors have rarely encountered outright racial prejudicial statements in a work setting. The racial prejudice is subtle. However, when the lead author (Jayakody) has clearly identified they have a lived experience and present as a lived experience worker, disparaging statements are made constantly. There have also been instances where the lead author has been told that they are not suited for full time work (because of their lived experience) and denied learning and development opportunities (because of their role as a lived experience worker). The statements about lived experience workers come from the assumption that people with lived experience are unreliable and incompetent because of their mental health challenges. These are the same views as those visible throughout history about people experiencing mental ill-health.

These statements rarely get challenged in today's mental health system. If such statements are challenged, it is invariably by lived experience workers themselves. The fact that such statements are deemed insignificant and not typically called out demonstrates the pervasiveness of the stigma and suggests that it often remains 'hidden' in plain sight. It is demonstrative of the entrenched power imbalances of a mental health system that continues to devalue lived experience perspectives. (See also Katterl and Friel in Chapter 14 of this volume.)

Without recognition of the prejudice, there is an inherent tendency to continue narratives that perpetuate stigma. The conversation is framed around the person's ill-health or deficit rather than the system failure. Examples of systemic problems include the lack of peer supervision, inadequate learning and development opportunities and working in isolation (that is, being the only lived experience worker in the team). Research suggests there is high burnout of lived experience workers (Byrne et al. 2019), which is often interpreted by the sector as the incapability of lived experience workers to cope. There is little regard for inadequate training and hostile working environments that indicate a lack of value in lived experience expertise. Instead, the narrative is simply that that *lived experience workers can't cope*.

This contrasts with the way other workers are described in the mental health system. For example, in 2019 Professor Gordon Parker AO, Scientia Professor of Psychiatry at the University of New South Wales and former Executive Director of the Black Dog Institute, spoke about the shortfalls of the New South Wales public mental health system and noted that junior psychiatrists are leaving the sector:

> I see so many young psychiatrists enter the public sector with a genuine commitment and wish to help those with serious psychiatric problems but who become profoundly disillusioned.
>
> (Aubusson 2019)

The narrative here is not about the capability of the individual; instead, it is about the failure of the system and environmental factors. Likewise, one news report in the *Sydney Morning Herald* reported the situation by noting that 'the "psychiatric breakdown of the public system" is driving away overburdened psychiatrists' (Aubusson 2019). Words like 'disillusioned' and 'overburdened' are used to describe psychiatrists leaving the system, while terms such as 'can't cope' and 'job is too complex' are often used to describe lived experience workers who leave the mental health system.

In a speech titled, 'This is Water', US novelist David Foster Wallace warns of the danger of pervasive phenomena that remain unacknowledged, sometimes described as the 'default setting'. Wallace (2005: 4) begins the speech with a parable to demonstrate his point:

> 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?'

The inability to recognise and call out false statements in the mental health system is reflective of a default setting that disregards and marginalises the experiences of people experiencing mental ill-health. This has resulted in practices and policies that are biased in favour of the medical framing of mental ill-health as a deficit in the individual.

The default setting of marginalising the lived experience-perspective was evident in the way the Victorian Government established the organisation, Mental Health Reform Victoria. Mental Health Reform Victoria was established in 2020 in response to the interim report recommendations of the Victorian Royal Commission. The Victorian Government appointed a chief executive officer and a 'Senior Advisor, Clinical' upon the establishment of Mental Health Reform Victoria. However, there was no lived experience appointee at the time of this organisational establishment. Lived Experience Advisors were employed only *after* Mental Health Reform Victoria was set up, and they were not employed at an executive level. This setting up of Mental Health Reform Victoria with the absence of a lived experience appointee was ironic, as it was in the same interim report in which the Victorian Royal Commission was unequivocal on the value of lived experience. Two of the ten recommendations in the interim report were about recognising and promoting the lived experience perspective (Royal Commission into Victoria's Mental Health System 2019).

It is interesting to note that in the final report of the Victorian Royal Commission, the commissioners were more explicit in their recommendations; for example, they recommended a requirement to have 'Lived Experience Commissioners' at the new Mental Health Commission and 'Lived Experience Members' in the regional boards (Royal Commission into Victoria's Mental Health System 2021). The Commission evidently saw enforcement of obligations on the mental health system concerning lived experience leadership as one crucial way to combat structural bias. Without an obligation, the mental health system so easily reverts backs to its 'default setting': the centuries old habit of dismissing and marginalising the experiences of people living with mental ill-health.

A Narrow View: Expanding the Frame From the Individual to Society

Bias in favour of the medical framing has also meant that the responsibility for addressing the broad determinants of mental ill-health and distress is placed outside the scope of the mental health system. Often there is little intersection between the mental health system and other systems that address social determinants. Some mental health practitioners view their role as alleviating the distress of an individual through individual treatment and therapy – addressing broader determinates is not considered within their remit. This is a narrow view that is the result of the medical and individualistic approach. Rather, a mental health system which takes into consideration broad determinants and addresses them is required.

Australia's *Mental Health and Suicide Prevention Plan – Final Report*, produced by a House of Representatives Select Committee on Mental Health

Suicide Prevention (2021: 280), concluded that 'evidence to the inquiry suggests clinical interventions, in the absence of broader measures to address social determinants of health, cannot resolve growing mental health concerns in Australia'. It also described the mental health system as operating in 'a palliative' manner (House of Representatives Select Committee on Mental Health Suicide Prevention 2021: 281). This approach, once again, reflects the strong bias towards a medicalised model where mental ill-health is constructed primarily as a biological deficit of the individual for which outcomes relate to reduction in symptoms and distress. Positive outcomes are more than the reduction of symptoms – it is about enabling people to live an autonomous, meaningful life with or without symptoms and distress. This cannot be achieved without explicitly addressing the broader determinants. It is well established that mental ill-health is interlinked with factors such as housing, education, finances and community connections (World Health Organization 2014). The mental health system must address this at the macro level. This includes creating services, roles and incentives to address broad determinants as a core function of the mental health system alongside mental health responses such as treatment and wellbeing supports.

The lead author's (Jayakody) experience of being a tribunal member at the Mental Health Tribunal in Victoria provides an insight into the dynamics of the mental health system. People who are subject to compulsory treatment often say what they want is to 'get on with my life', 'I want to get a job' and 'I want to spend time with friends'. The response from the treating team invariably is that the person is not ready or has not progressed far enough in their recovery journey to begin addressing these needs. The focus of the supports is on addressing the deficits of the person rather than addressing the other contributing factors. There are also many instances of people on compulsory treatment orders being discharged from hospital into temporary accommodation such as motels. This is a prime example of a mental health system operating in a palliative manner. In this example, housing is a critical factor in achieving a good outcome and must be part of the mental health service response. Unfortunately, services are not centred on addressing such determinants.

Another example is the second author's (Perera) experience of working with a young person who was experiencing mental ill-health. The young person had accessed two different mental health services over the past year. Although the services sought to address the young person's distress through medical and psychological interventions, what was also helpful was a referral to a financial counselling service that assisted with longstanding financial difficulties. This addressed an underlying contributor to their distress.

An effective mental health system should be required to address such broader determinants. Provision of, or referral to, legal, housing or financial services may meet these needs. For these services to be considered a critical element, the system needs to be built on a different foundation that not only conceptualises mental ill-health as intrinsically linked to social and economic determinants, but also addresses these determinants by providing holistic support that enables full and effective participation in society.

The Productivity Commission (2020) observed that housing, employment services and services that help the person integrate into the community can be as or more important than health care in supporting a person's recovery. Out of the five priority reforms identified by the Productivity Commission, only one related to improving people's experience with mental health care. The other four acknowledged the broader determinants as they related to prevention, experiences beyond the health system, workplaces (called out in addition to the other services beyond the health system), and incentives and accountability for improved outcomes. The Productivity Commission (2020: Volume 1, 7) described barriers that lead to poor outcomes as:

> [A] narrow view of people seeking treatment and support – mental health services are often based on an incomplete picture of what people are seeking, failing to look beyond the symptoms being presented to work out what help an individual needs to recover and remain well in the longer term, and how to deliver that help most effectively.

Reflecting on the evolution of mental ill-health and the resulting power dynamics, these findings are unsurprising, despite well-established evidence of the relationship between broad social determinants and mental ill-health.

Bias in the Law

Contemporary mental health law is likewise driven by the historical prejudices noted previously. (See also Arstein-Kerslake in Chapter 12 of this volume.) The law is rooted in a deficit narrative that suggests a person with mental ill-health is incapable and dangerous.

Mental health law gives medical professionals power to detain and restrain people experiencing mental ill-health, thus restricting their liberty and undermining their autonomy in a manner that would be illegal in other circumstances. This is justified on the basis of treatment and a promise of safety for the individual and the community. The law is driven by a deficit and medicalised narrative that drives a 'we know best' approach. The root of paternalism is based on 'parens patriae'. As Gooding (2014: 7) articulates:

> The 'parens patriae' power, translating literally as parent of the country, justifies detaining and/or treating a person compulsorily in his or her best interests on the basis of the person not being able to look after his or her own interests.

In contemporary times, 'parens patriae' is typically identified with family law whereby the state acts as the parent of any child or individual needing protection. The assumption behind this paternalistic approach is that people experiencing mental ill-health are, in similar fashion to a child, incapable of making informed decisions about their own life. This then gives authority for the medical professionals to step into the role of 'parent' – to make decisions for people experiencing mental ill-health, and to restrict individual liberty and undermine autonomy, thus disregarding the views of the individual. The role of procedural safeguard mechanisms, like the Mental Health Tribunal in Victoria, is to confirm or reject the role of the medical professionals in their role as the 'parent'.

With increased recognition of human rights, mental health law has been somewhat reoriented to promote the person's autonomy and self-determination, but the entrenched power imbalances against those interests remain. Under Victoria's new *Mental Health and Wellbeing Act 2022* (which will come into effect in September 2023), recommended by the aforementioned Victorian Royal Commission, there is no obligation on the Mental Health Tribunal to provide a 'Statement of Reasons' for its decisions. A 'Statement of Reasons', as the name suggests, is a formal note that articulates why the tribunal made a particular decision. The burden of seeking such a statement is on the individual. In 2020–21, only 238 Statements of Reasons were requested in comparison to the 8,212 Treatment Orders made during that period (Mental Health Tribunal 2021). An agency that exercises power by restricting individual liberty must be held accountable. Instead of creating an obligation on the Mental Health Tribunal, it is framed as a right of the individual. This, in our view, is deeply unjust. Statements of Reasons for decisions will be resource intensive; however, they will create transparency and accountability. Notably, there are other adjudicative bodies in Victoria where there is also no obligation to provide a written Statement of Reasons. For example, the Magistrates Court where the majority of criminal cases are heard, or certain matters before the Victorian Civil and Administrative Tribunal, such as those cases on the Residential Tenancies List and the Guardianship List. However, unlike residential tenancies, mental health legislation involves a significant loss of liberty as it permits people to be detained in hospital and treated with psychiatric drugs without their consent, and unlike the criminal law this occurs where they have not been found guilty of any crime. The lack of a Statement of Reasons for the Guardianship List, however, is objectionable for the same reasons as it is in the mental health context. Further, persons subject to treatment orders may not understand why they are being detained and a Statement of Reasons could help them reflect on their recovery journey and understand what occurred at a later date. Published Statements of Reasons will also create (non-binding) legal precedents and will add to mental health law jurisprudence.

As noted earlier, the prejudicial belief that people experiencing mental ill-health are violent and dangerous also underpins mental health law. The compulsory treatment criteria under the *Mental Health and Wellbeing Act 2022* (Vic) includes the requirement that involuntary intervention is required to prevent a serious deterioration in the person's mental health or physical health, or serious harm to the person or to another person (section 143).[6] The premise here is that detention will keep the individual and the community safe, and the continuation of the narrative that people experiencing mental ill-health are violent justifies their detention for the good of others.

The promise of safety is very much driven by the public discourse reflecting the prejudicial values of our society. Safety of people experiencing mental ill-health, workers and the community are often deemed paramount, even if this involves trauma to persons with mental ill-health. For example, when the Victorian Government announced its intention to work towards ending restraint and seclusion within a decade, (see also Chesterman in Chapter 5 and Freckelton in Chapter 6 of this volume) the immediate response from the Victorian branch of the Australian Medical Association (AMA) was to ridicule and dismiss the idea:

> The plan is right up there with pink elephants flying.
>
> How are we meant to manage these people if we can't use medical and chemical restraint?
>
> The safety of healthcare workers needs to be paramount when changing laws dealing with unpredictable and sometimes psychotic patients, but that has not been done in this case.
>
> (Illanbey 2022)

This response emphasises the paramount importance of the safety of health care workers, and there is no mention of the safety of the person with mental ill-health. The AMA branch also uses dehumanising language referring to 'these people' rather than recognising that persons are in distress and are in need of compassionate care. We contrast the AMA's response with the response by Forensicare (2022):[7]

> We do not agree with recent commentary that reducing or eliminating restrictive practices will increase risks to the community and health care workers. However, we recognise the elimination of restrictive interventions is a challenge and will require substantial investment and change across our mental health and wellbeing systems.

This latter response is not driven by a narrative of paternalism or prejudice but underpinned by a belief that people experiencing mental ill-health deserve and can be provided with care in a compassionate and humane way. They also acknowledge that the change can be challenging and requires substantial investment to reduce the systemic issues which are related to use of restrictive practices.

When the approach to ensure safety for all is driven by the paternalistic narrative, the default position is to respond through restriction of liberty, as one seemingly would towards a child. Instead, if the mental health system is driven by a different narrative wherein this is a person in distress needing support, the instinctive and default response would be to ask how services can provide compassionate and humane care that will alleviate distress and ensure the safety of all. Such an approach would reduce the need for the high rates of compulsory treatment in Victoria.

The change can only be driven by different social norms and a different narrative. As the Royal Commission into Victoria's Mental Health System (2019: Summary, 5) stated in its Interim Report:

> As Victorians, we all bear some responsibility for the system's failings. Inclusive, tolerant, and supportive communities play a vital role in nurturing good mental health and wellbeing, yet it is evident that stigma and discrimination persist.

Moving Forward With Allyship

There needs to be a renewed awareness of the ongoing influence of the conceptual history of mental ill-health in contemporary times. As individuals and as a collective, we must begin to question the fundamental values that drive the discourse on mental health and how people living with mental ill-health are perceived. It is only with this kind of examination that we can begin to change the discourse on mental health and challenge the flawed foundation of the mental health system. This could include, for example, challenging the statements that are made about lived experience workers, questioning the public discourse on the association of mental ill-health and violence, and examining the broader social determinants of ill-health rather than exclusively responding to the deficit of the individual. These types of actions have been pursued in decades of sustained activism by people with lived experience. However, given the historical context noted previously and entrenched power imbalances, true transformation can only be achieved through allyship.

Allyship requires individuals to question their own role in upholding a system built upon such flawed foundations. Allyship does not mean 'helping' people with lived experience – individuals cannot be 'guided by an altruistic urge to save or fix people' (Nixon 2019: 5). People who maintain authority through sustained bias and marginalisation must be open to being challenged and sitting with this discomfort, rather than be defensive and becoming ashamed of that power. This can be confronting, and it requires humility. Margaret Grigg, CEO of Forensicare, recently talked about this discomfort (at a workshop for the Consumers Leading in Governance Program on 17 May 2022 in Melbourne, Victoria). She said, 'it is very difficult to sit and be told that what I was taught as best practice actually harmed people'.

Allyship is about services and policymakers working in partnership with people with lived experience to reflect, challenge and dismantle the existing foundations to ensure the mental health system works from a different starting point. It is about recognising people with lived experience as a valued and equal partner. This requires more than expanding the lived experience workforce – it is about integrating lived experience expertise at leadership levels such as in governance, regulation and funding decisions. Conscious effort is required to prioritise lived experience expertise in the way the system operates. Prioritisation of lived experience does not mean creating a new hierarchy or merely flipping the existing power imbalances in the mental health system, but is about making a conscious and consistent effort to integrate lived experience expertise in the system. Without this prioritisation, history has shown that lived experience expertise will continue to be marginalised.

Conclusion

The science fiction writer Ursula Le Guin once said that 'all privileged lives are based on injustice' (Freedman 2008: 127). In the mental health context, the system is biased against lived experience perspectives and it privileges the medicalised and individualised interpretation of mental ill-health with little regard to social determinants. Legal frameworks are paternalistic and reinforce societal fears based on several fallacies about distress and mental ill-health. Mainstream public discourse continues the centuries-old narrative that people experiencing mental ill-health are illogical, incompetent and dangerous. What would it take us to reorientate ourselves? Do we have the courage?

Notes

1 Philippe Pinel (1745–1826) was a French physician who is sometimes regarded as the father of psychiatry. Pinel was remarkably ahead of his time as he did not view mental ill-health as a bestial or demonic condition. His approach was influenced by the experience of losing a close friend to mental ill-health.

2 It is worth noting that Pinel's thinking was that recovery from mental ill-health was brought about primarily by psychological, rather than physical, means.

3 The final report of the Royal Commission into Victoria's Mental Health System was tabled in a special sitting of the Victorian Parliament on 2 March 2021.

4 The Productivity Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians.

5 Australia's National Mental Health Commission is a federal government agency that gives independent policy advice and evidence to the Australian Government on ways to improve Australia's mental health and suicide prevention system.

6 Note that the Victorian Government announced in 2022 an independent inquiry to review the compulsory treatment criteria with the view to reducing rates of compulsory treatment orders. The panel is chaired by Justice Shame Marshall AM, and the lead author (Jayakody) is a member of the inquiry panel. The independent report is expected to be tabled at the end of 2023.

7 Forensicare (Victorian Institute of Forensic Mental Health) is the state-wide specialist provider of forensic mental health services in Victoria. Forensicare is the only agency in Victoria that provides clinical forensic mental health services which span all components of the mental health and criminal justice sectors – giving Forensicare a unique perspective on mental health and public safety issues.

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