Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF ERANDATHIE JAYAKODY

I, Erandathie Jayakody, say as follows:

1 I make this statement on the basis of my own knowledge, save where otherwise stated. Where I make statements based on information provided by others, I believe such information to be true.

2 This statement is about my experience as a member of the lived experience workforce over the past eight years and my views on how the mental health system needs to change so that it better meets the needs of mental health service users, their families and carers.

Background

3 I am currently employed as an Assistant Director of Strategic Advice in the Psychosocial Disability, Advice, Research and Evaluation Division at the National Disability Insurance Agency (**NDIA**). I have held this position since November 2019. In this position, I provide advice to the NDIA on psychosocial support policy issues, underpinned by analysis, contextual awareness and stakeholder consultation.

4 I am also:

(a) a Tribunal Member of the Mental Health Tribunal Victoria. I have been a Member since April 2018; and

(b) a member of the Royal Commission into Victoria's Mental Health System's (**Royal Commission**) Expert Advisory Committee, established by the Commission's Terms of Reference and which is consulted during the course of the Commission's inquiry about matters such as the Commission's findings and recommendations.

5 Between 2012 and 2019, I worked at Mind Australia, firstly as Project Worker and later as Team Leader of the Consumer and Carer Participation team.

6 I was admitted to the legal profession as an Australian Lawyer in Victoria in 2006.

7 I have a Bachelor of Commerce and a Bachelor of Laws from Deakin University. In 2018, I completed a Community Managed Mental Health Leadership and Management Program through Leadership Victoria and Mental Health Victoria.

8 I am giving this evidence in my personal capacity and not on behalf of my employers or organisations that I am a member of.

9 I have worked in the lived experience workspace for the past eight years. I also have personal experience with mental ill health and recovery, and I draw on both these experiences in this statement.

10 Attached to this statement and marked ‘Attachment EJ-1’ is a copy of my CV.

Stigma and Discrimination

The impact of stigma (including self-stigma) and discrimination on people living with mental ill-health

My personal experience

11 I first became unwell when I was a teenager. At that time, the discussion on mental health was not as evolved as it is now – there was hardly any discussion around mental health.

12 I felt like the narrative was “*stop being so sensitive*” and “*you’re weak*” and “*you’ve just got to try hard*”. The feeling I had from that narrative was that I was not strong enough.

13 At the time, I only knew two people who had mental health conditions. One of whom took their own life, and the other was in an asylum (psychiatric institution). There were no role models of people living successfully with mental health conditions. I thought these were the two options (suicide, or living in a mental health ward), so I did not want to acknowledge my challenges with mental health. Accepting that I had a mental health condition meant that my life was limited.

14 The narrative also reflected the prejudice of society towards mental health. These prejudices remain prevalent today. It is so overt sometimes yet it is not recognised because we as a society are blind to it.

Mental health conditions compared to other forms of health conditions

15 In my experience, the way the health system treats someone with a chronic physical health condition compared with a chronic mental health condition is vastly different. In my family we have one person, my father, with a chronic physical health condition (diabetes) and one person, myself, with a chronic mental health condition. The way the system and society treats a person with diabetes is completely different to the way that I am treated and perceived.

16 From the outset I acknowledge that the two conditions are very different. Mental health affects someone's thoughts, perception, mood and emotions. It can affect your cognition. However, it is a good comparison as both are health conditions to be managed and are health conditions that are ongoing.

17 Firstly, people know how to talk about diabetes but they do not know how to talk about mental health. Society knows how to support someone with diabetes. No one batts an eye lid or is confused if a person requests a sugar free dessert, however, if I were to request a quiet space to manage sensory overload or overstimulation, people would be confused and may not know how to accommodate that request.

18 Diabetes is a condition that can be managed similar to mental health. Diabetes can be managed through one or more of appropriate food, exercise and medication. Similarly, mental health can be managed through one, or a combination of, self-care strategies, various types of therapies and medication. There is understanding and no judgment when a person has to take insulin. Yet if a person takes medication for a mental health condition the commonly held perception is the person is not able to cope, they're really sick or they're dangerous. Some of the more common responses I get when I disclose that I take medication are "*oh but you are so normal*" or "*why do you need medication?*" No one would dare make similar remarks to someone taking insulin.

19 Conversation does not stop when the subject turns to diabetes and insulin. Yet the conversation becomes awkward when the subject turns to mental health and associated medications, in particular anti-psychotics and mood stabilisers.

20 All these prejudices compound what is already a very distressing health condition.

Stigma in the Mental Health Sector and the Lived Experience Workforce

21 I have worked in the lived experience work-space for the past eight years, and you would be surprised by the things I hear. For example, "*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*".

22 Such views are not acceptable. They come from the fundamental belief that people with lived experience are weak, incompetent and somehow 'lesser' than other workers because of their mental health challenges. Yet, people actually do not think twice before making such comments. These statements often go unchallenged in meetings. That is how blind we as a society are to overt stigma and discrimination. Those kinds of comments reinforce the sentiment that "*people with mental health challenges are*

incompetent and are incapable and are weak." By not challenging these statements we continue to perpetuate that narrative. This narrative is incorrect.

23 I am a woman and a first generation migrant. No one has ever said "*oh you can't do this job because you are a woman*" or "*this job is not suited to you because you are a migrant*". People might think it but it would be completely unacceptable to say such things as it would be discriminatory. If such things were said in a meeting participants would be horrified. In my experience, even when I have clearly disclosed I am a consumer worker, people say and get away with statements like "*peer workers can't work full-time*". There is lack of recognition that such statements are discriminatory. It is often left up to the consumer worker like myself to challenge these statements.

24 I notice that in the workplace those sorts of views are often framed around the person with the lived experience, rather than an examination of the environment. For example, I have repeatedly heard people say "*the peer worker can't cope so they're leaving*", without having any regard to issues with the environment in which they are working. I am shocked by how prevalent these kinds of comments are . I believe these deeply held beliefs, that people with lived experience are incompetent and incapable because of their mental health challenges, holds the lived experience workforce back. It is difficult for peer workers in these circumstances. Why a peer worker decides to leave is never about working conditions, team dynamics, role clarity or personal choice. There is no examination about whether a person can actually flourish in the environment. This is not limited to lived experience workers in the mental health sector, it applies in any work environment where a person experiencing mental health challenges works; whatever the role it is always about the person with lived experience, and not the environment.

25 This standard is not extended to other disciplines and so is a double standard. The best example of this double standard is when last year Professor Gordon Parker AO, Scientia Professor of Psychiatry at University of New South Wales and former Executive Director of the Black Dog Institute spoke about how bad the New South Wales psychiatric system is and 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.*"[1] The conversation on this topic looked beyond the personal and looked at the system and the environment: for example, the Sydney Morning Herald reported that "*The 'psychiatric breakdown of the public system' is driving away overburdened psychiatrists*".[2] The

---

[1] The Sydney Morning Herald 'Overburdened psychiatrists abandon 'broken' public system' <https://www.smh.com.au/healthcare/overburdened-psychiatrists-abandon-broken-public-system-20190528-p51s3j.html>.

[2] The Sydney Morning Herald 'Overburdened psychiatrists abandon 'broken' public system' <https://www.smh.com.au/healthcare/overburdened-psychiatrists-abandon-broken-public-system-20190528-p51s3j.html>.

language used here reveals the double standards. Words like *'disillusioned'* and *'overburdened*' are used to describe psychiatrists leaving the system and words like *'can't cope*' and *'job is too complex*' are used to describe peer workers who leave the system.

26 There is no acknowledgment that, not only are peer workers working in a broken system, they are also working in a system that is saturated with stigma and discrimination. In relation to the junior psychiatrists leaving the sector, there was no comparison to other fields of medicine, the discussion was framed around working conditions. In contrast to this, when the conversation is about lived experience or peer workers it is always about their mental health challenges and not about the working conditions. What we as a society need to realise is the conversation is different because of the underlying misconceptions regarding the inherent value of people with mental health conditions and the contribution they can make to the workforce.

27 I have worked hard to reject the prejudice. But I am exposed to it all the time. Society tends to see people with mental conditions in a one-dimensional way, that is, it only sees the mental health condition (or probably more accurately, society's perception of the mental health conditions). In a recent discussion about workforces a colleague said "*personally I think people with a lived experience should be given part time jobs not full time jobs*". I thought "*oh wow, how could you hold that view?*" and then immediately after I thought to myself "*oh yes, I did take a bit of sick leave last year*". I am amazed how quickly I revert back to that 16 year old self where I think "*I'm weak*". It is so quick. That is the effect of the prejudice, discrimination and stigma – that people with lived experience accept the prejudice as truth. I then have to pull myself up again, and reject the prejudice, which is exhausting. So much energy is spent doing a good job and managing a health condition and then on top of that you have to constantly challenge these prejudices with little support and not let it get to you.

28 There is no understanding about how damaging these seemingly 'insignificant' comments can be. It undermines a person's capabilities to work and limits their ability to reach their full potential. People begin to doubt themselves and it erodes their self-confidence. Not only is it a loss of opportunity and loss of potential at an individual level, but it is a loss for the organisation, the mental health sector and the community.

29 It is these attitudes that influence the way decisions are made and why opportunities are withheld. There are more part time jobs available for lived experience workers than full-time jobs. There is little training for staff on how to support a person with mental health challenges seek employment. When such values underline our mental health services, how can a service user reach their full potential and lead a meaningful life?

Reducing the stigma and discrimination associated with mental health

30 I believe the conversation needs to move away from a one-dimensional view of only focusing on the mental health and instead look at the whole environment and an examination of the structural and cultural context. We need to take collective responsibility. We need to ask questions such as *"What is happening here?", "What are the underlying assumptions that are driving us?" and "What are the structural barriers?"*

31 We also need to examine the way we talk about mental ill health. It is a condition to be managed. For a vast majority of people it is not something that goes away. Regardless of how mental ill-health manifests itself, for example, depression, anxiety, voices, moods or other behaviours, it is something that a person can learn to manage and live with. We need to move away from the idea that with medication mental illness goes away. It is not that simple. Recovery can be a journey and is often a life long journey.

32 We also need to move away from focusing too much on diagnosis outside of a clinical setting. Mental ill-health manifests in many ways but ultimately what it is about is the experience and the distress of the person. A diagnosis does not necessarily correlate with the level of distress a person is experiencing at any given time.

33 As a comparison, if in this country, we are not having a mature debate about race, (which I do not think we are) the conversation around mental health can seem prehistoric. When it comes to race we are able to recognise and call out the prejudice and discrimination but we are not able to do the same for mental health. We need to recognise the prejudice and discrimination around mental health. Without this it is very difficult to have a conversation about lived experience.

Community-based services: effectiveness and experiences

Need for diverse platforms of community-based mental health care

34 Contemporary community-based mental health care needs to include diverse platforms for delivering mental health services. Service models need to look beyond traditional mental health service provider and service recipient relationships. More prevalent service delivery platforms like education, legal services and financial counselling can be adopted to deliver mental health services. These services are more 'accepted' or inclusive as these are services sought by everyone not just people experiencing mental health challenges. Therefore, they do not carry the same stigma and prejudice. What is important is that these services are adapted to the mental health context to make them available, accessible and responsive to the needs of people with mental health challenges.

35 Recovery colleges provide an education platform for delivering mental health services. It steps away from the traditional relationship and creates a student teacher relationship where it is about skill acquisition not ‘receiving help’. This shifts the conversation away from mental health to a more holistic conversation about aspirations.

36 Health justice partnerships are another platform. It is common for people with mental health challenges to have a need for legal services for matters such as fines and consumer transactions for example utility bills, telephone bills and credit card debts. When unattended these matters spiral out of control and can exacerbate mental health challenges. Legal services, even Community Legal Centres are not easily available nor accessible for people experiencing mental health challenges.

37 The traditional way of conducting a legal service such as making appointments and receiving instructions from a client is not likely to be effective in a mental health context. A legal practitioner needs to build rapport and trust before a person with mental health challenges will confide in them. Therefore co-locating legal services and mental health services where a legal practitioner spends time with people experiencing mental health challenges is a way of encouraging people with mental health challenges to seek legal services. Resolving matters may take longer as health challenges will be prioritised over legal problems. Legal services also need to be responsive to the episodic and fluctuating nature of mental ill health, therefore standard strict protocols such as time limits for opening and closing files will generally be unsuitable in a mental health justice partnership.

A ‘recovery-oriented approach’

38 In my view, a recovery-oriented approach is a way of supporting a person: using interventions to support a person to manage their mental health so that they can lead a meaningful life as determined by the individual. I believe that mental ill-health is a condition to be managed like any other health condition. It does not have to be a lifelong sentence that limits your life. With the right supports and learnings the condition can be managed and a person can lead a full and meaningful life.

39 At the heart of a recovery-oriented approach is a recognition of the most basic human desire to have control of one’s own life and future, and the belief that people with mental health challenges have the ability and autonomy to achieve that.

Settings beyond traditional mental health services that should be considered for the delivery of mental health support

40 Mutual self-help networks or peer support groups are an effective way of providing mental health support. A peer support group is where a group of peers come together to

discuss shared experiences and support each other. This is different to peer support groups offered by a health service or an organisation. A peer support group offered by a health service where there is a paid worker is not a mutual self-help group. Not all participants are equal in such a scenario as the paid worker will be perceived as the 'expert'. At a mutual self-help group everyone is equal and everyone is an expert. Mutual self-help networks are not a paid services and are run by volunteers. They are similar to an Alcoholics Anonymous meeting. Peer Support groups run by an organisation with a paid worker is effective and valuable. In this section I discuss peer support groups run as mutual self-help groups.

41 Peer support networks are very powerful as the process is owned by the participants. Again, everyone is equal and everyone is an expert. This creates a very safe space for people to open up. There is no judgment and everyone understands each other at a fundamental level. Through shared experiences people learn from and support each other. It also creates a sense of belonging which is a very important part of mutual self-help networks, as isolation is a big challenge experienced by those experiencing mental ill health.

42 In my experience, peer support groups also provide a much needed space for laughter; opportunity for laughter can be rare for someone experiencing mental health challenges. You can be completely honest and people are able to relate to you and you can laugh at things that people outside of the room would be horrified at.

43 I was privileged to be part of two peer support groups. I first came across a group called "Open Minds" in the Victorian Public Service in 2009. It was established by Maria Katsonis, a Victorian Public Servant, after she had her own experience of mental ill health and recovery. Attending those meetings was a life changing experience for me. It was the first time I was in a room with people who were 'like me'. It was a relief to finally be able to open up and speak with so much honesty to someone who understood exactly what I was talking about. The energy at those meetings was palpable. I felt empowered.

44 I then ran a peer support group for lawyers called 'Pleading Sanity' under the auspice of the Tristan Jepson Memorial Foundation (now called Mind Counts) for a couple of years. It was a great experience and we had people attend who had never before attended peer support groups. Once again we shared stories and supported each other. What I found interesting was that people were really concerned about their privacy because many had not disclosed their struggles with mental health to their colleagues. Once again the secrecy and shame was very evident. I think that this in itself is such a tragedy as these were highly accomplished and capable people who would make great role models for the profession as the legal profession has very high rates of mental ill-health. The legal profession should be embracing their colleagues who are resilient

instead people are worried they will be shunned if they disclose their mental health challenges.

45 I stopped running the group after a couple of years as I had competing demands. I still meet with two other peer support groups regularly but do not run a group. This is often what happens with peer support groups. They are run by a few dedicated individuals and that is not a sustainable model and cannot be replicated. Peer support groups need to be auspiced by the system yet separate and completely independent. There cannot be any reporting requirements or budgets. The resources required to run a peer support group would be similar to running a new mother's group. A consumer that comes into contact with a mental health service can be automatically connected up with a peer support group. There should be information sharing protocols whereby information is referred to the peer support group so that the group can reach out to the consumer. The responsibility of reaching out to the peer support group should not be left with the consumer who is overwhelmed by their distress.

Lived experience

The lived experience workforce

46 In my view, the lived experience workforce flourishes when the environment is right. I am referring to the environment at both a macro and a micro level. That is at an organisational level and service level. There needs to be good managers and teams who understand what lived experience is and value peer support, and who are supportive of the role. Whilst funding and resourcing are important to creating this environment it also requires culture change. Creating a flourishing environment also means that we need to take a good honest look at our values and beliefs in relation to marginalisation and power dynamics. For example, there needs to be consideration of why the lived experience workforce and consumer participation does not get prioritised and why there are so few lived experience positions at senior levels. These can be uncomfortable conversations, but change needs to begin with these reflections. Otherwise we will be building a lived experience workforce on faulty foundations.

47 Creating the right environment needs to begin at the top with a commitment from the organisation. The responsibility to create the right environment is a collective responsibility and not just the responsibility of lived experience workers. An organisational commitment needs to be more than a value statement or part of a strategic goal. It needs to be both a cultural commitment as well as an operational commitment. There needs to be a clear operational plan that articulates in detail how the organisation will grow and sustain a peer workforce. The commitment needs to be manifested through investment. For example, a budget and an allocation of other resources (such as human resources), learning and development expertise, and

information technology. Building organisational capacity to support and grow an emerging lived experience workforce is not a short term commitment. It is also not a time-limited commitment as it can takes years firstly to create an environment that can start a peer workforce and then secondly to grow and sustain a thriving peer workforce.

48 Often what happens is that peer workers will be employed in a haphazard manner because there is commitment at a team or service level and not at an organisational level. This means there is no consistent approach and the individual services are left to fend for themselves trying to find the budget for training and supervision, and trying to navigate human resources requirements on their own. Therefore, it is difficult to grow the peer workforce from the bottom up.

49 The other scenario is that there is an organisational commitment as a result of one or more champions. However, as soon as those champions leave the organisation and priorities change, the lived experience workforce will be put on the back burner with budgetary and operational constraints cited as the reason. The commitment and investment to grow a thriving peer workforce needs to endure management and governance changes.

50 At the heart of this problem is that lived experience is seen as icing on the cake and is expendable. It is not considered as an essential key ingredient in the way mental health services are delivered. For example in Victoria in both the public and community sector, there have been lived experience positions at senior levels, which have been short lived. These positions get lost in restructures or when the person occupying the position leaves the role changes so that it is no longer designated as a lived experience role.

51 At a governance level the board skill matrix will include legal skills, auditing skills, risk skills and IT skills. In a mental health organisation the lived experience skill (discipline) must become an essential skill in that skills matrix. This will ensure that the lived experience skill set is present from a governance level, and this will have a flow on effect to senior leadership, project governance, the service level and team level.

52 Lived experience gets marginalised too often because of budgetary, time and operational constraints. People will talk about how important lived experience is and how committed they are to it and then in the same breath say "*unfortunately we don't have time to do consumer consultation or we don't have the budget*". That is incongruous. To me it says is that there is no real commitment. It is very rare that you get someone who will be honest with you. I once had someone say to me "*I know it is important and that is the right way to do it but unfortunately my priority is financial sustainability*." In my experience such honesty is rare. Instead what I get is people trying to placate me. I would rather people be honest with me because then there is a genuine starting point.

53 The under-resourcing of the mental health sector is cited as a reason for why staff cannot attend training or why lived experience workers cannot attend supervision. However, I am pleasantly surprised by how managers who are committed to having lived experience workers in their teams prioritise these things making sure training calendars and rosters align so that all team members can attend training and that lived experience workers can attend supervision. My observation is that those who are committed will allocate the budget, organise training and put the necessary structures in place. It begins with the commitment. If there is a will there is a way.

54 It is also important to bear in mind that this is an emerging workforce. As at October 2017 there were only what amounts to 187 full-time lived experience workers in Victoria.[3] If Victoria is to grow this workforce in a sustainable manner it needs to look at the long game. This is an investment over the next ten to twenty years. The investment and the nurturing of the workforce needs to continue until it reaches a critical mass. Only then will we be able to embed the lived experience perspective across teams, services, organisations, policy and the sector. We have to continually keep investing and work at growing and supporting the lived experience workforce until the lived experience discipline reaches parity with other disciplines, Only then will the lived experience workforce operate on an even playing field. To do this we have to keep having the difficult conversations and reflect on our assumptions and beliefs that drive our actions such as why there are more part time lived experience positions than full time lived experience positions, why there are a lack of lived experience leadership and why there is a marginalisation of lived experience in funding.

Isolation and Supervision

55 Isolation is one of the biggest challenges for people experiencing mental health challenges.[4] Having lived experience workers working on their own replicates those challenges. It is best practice to have two or more lived experience workers in a team; there is strength in numbers for lived experience workers. It is important for lived experience workers to have other lived experience workers around them to consult with and receive the support of a fellow lived experience worker. You need great resilience to keep going in a lived experience role; lived experience workers are always asking questions, challenging and holding services accountable.

---

[3] Edan, V., and Cadogan, E., Chapter "'Honouring, developing and growing Victoria's lived experience workforce' from Meagher, J., Stratford, A., Jackson, F., Jayakody, E., & Fong, T. (Eds). (2018). *Peer work in Australia: A new future for mental health.* Sydney: RichmondPRA and Mind Australia, 158,

[4] Bell, T., Panther, G., & Pollock, S., *Establishing an effective peer workforce. A literature review. Prepared for the Frankston Mornington Peninsula Mental Health Alliance by Mind Australia Research, Development & Advocacy Unit* May 2014, 22.

56 There is often a significant power imbalance between the lived experience worker and the colleagues they work with. This is especially true for consumer consultants, policy and project workers. For example, as a project manager and a team leader I often found myself at meetings with senior people, such as senior executives, directors and general managers. I would be the only lived experience worker at those meetings, and I was not privy to the same information as other senior members. I'm not referring to the meeting papers or the papers pertaining to the specific project but the broader organisational information only available to management such as strategic and financial decisions. This means there is such disparity in the way that I, the only lived experience worker, approach the meeting or a project. It's akin to finding your way in the darkness when everyone else has a torch. This is why it is really important that there is lived experience at a senior management level. Lived experience needs to be represented at a horizontal and vertical level of the organisation.

57 As with any other discipline such as psychology, social work, nurses or occupational therapy lived experience workers need practice supervision. Challenges such as isolation and power dynamics, and marginalisation as discussed above means that it is essential lived experience workers have lived experience supervision. Lived experience is hard work, you need a lot of resilience to keep going. You are constantly getting knocked back and the work keeps getting marginalised.

58 You have to remember that there are often times you are challenging the status quo and that this can come at a personal and professional cost. The personal cost is that you might be perceived as being difficult to work with, making you feel really isolated and the professional cost is that you might miss out on professional opportunities because you are calling out the status quo. Therefore, it is really important that there is lived experience practice supervision to allow space for reflection and to help hold the course and stay true to the values and philosophies of the lived experience discipline.

59 Lived experience workers also need broader training not just training relevant to the lived experience discipline. If we are to create career progression and introduce lived experience positions in senior management the workers need to have the appropriate training such as financial literacy, governance, management and leadership training. Such opportunities are rare for lived experience workers. A recent paper, which considered the global need for lived experience leadership stated that "*Persons with lived experience of recovery need to occupy senior leadership roles impacting social policy, system management, planning, education, program development and evaluation. While varying degrees of progress are being made….., it is, in our opinion the third level*

[this being senior leadership roles] that is presently the most critical and yet least advanced.”[5]

Importance of lived experience supervision and support

60 I have been extremely fortunate in my work. Until recently I worked in teams with lived experience workers. That meant we all approached our work the same way, we operated on similar assumptions, philosophies and values. Within the team there was not that constant need to articulate the basis from which I was approaching my work. We spoke the same language. It also meant that when I encountered difficulties there was always someone to problem solve with. It also meant that if you come out of a difficult meeting where you get completely shut down there was someone who understood.

61 I have also had close lived experience mentors. They have been instrumental to my growth as a lived experience worker. I knew very little when I started my first role as a lived experience worker and I had only a very basic understanding. What was vital to my growth was the daily discussions that I was exposed to with my team of lived experience colleagues and the fact that I worked with two senior peers that mentored me.

62 I also attended group supervision. I first attended as a participant and then facilitated these groups. Group supervision was really important as it provided a structure to reflect and improve our practice. It was also helpful to hear about the experience in different settings and to understand how lived experience translated to different roles. Importantly it created a network of peers that I could reach out to. That sense of community is really important.

63 I currently do not work in a lived experience team, but I have a very supportive manager and team who understands what I bring and what I do. What is also really important to me is that I have built up a strong network of peers including senior peer workers that I can reach out to. Even though my team is very supportive my peer network gives me a lens that my team cannot give. I know my experience is extremely rare and I have been very fortunate. Most peer workers are given little training and are left on their own to navigate the difficult terrain with no one to reach out to and no opportunity to build a network.

Why co-production is important

---

[5] Byrne, L., Stratford, A., & Davidson L, ‘Speaking Out, The Global Need for Lived Experience Leadership’ (2018) 41(1) *Psychiatric Rehabilitation Journal* 76-79.

64 Co-production has become a buzz word in the mental health sector without any real understanding of what it means and why it is important. Ultimately what co-production aims to do is to redress the power differences so that service users receive high quality mental health services that meet their needs.

65 We reach out to mental health services when we are at our most vulnerable. People have little choice and rarely have the opportunity to speak to others or seek a second opinion. We rely and trust the mental health service to provide high quality care that will support us to manage our mental health. Therefore, mental health services need robust and sophisticated systems to ensure the delivery of high quality care and also to protect and uphold the inherent rights and dignity of service users.

66 In my experience I was desperate, I was just thinking "*give me something*" and "*make it go away*". I did not care about the mental health plan or anything else that was put in front of me I just signed it so I could get help. At other times I felt I could not trust my judgment, my cognitive facilities were off. I had to be able to trust that those around me would be able to give me the right supports so I could trust myself again. These changes in mental state happen fast, there is no time for second opinions and even if you were to seek a second opinion the wait is ridiculously long. Furthermore, because of the secrecy, shame and stigma it is not possible to speak to others to seek their views or share the burden. So you are left at the mercy of the mental health service. Unlike any other health service mental health services wield enormous power over you as they have the power to detain you and give you treatment against your wishes.

67 Mental health services have not always been good at delivering services that meet the needs of service users. As Premier Daniel Andrews has said we have a 'broken' mental health system. As there is very little power and choice when receiving mental health services it is important that there is service user involvement in how services are planned, designed, delivered and evaluated. Co-production provides a methodology for this.

68 Unfortunately, people talk about doing co-production but what often happens is consultation and feedback. In a recent publication regarding co-production it was stated that *"Co-production raises the bar for working with consumers, shifting from seeking involvement or participation after an agenda has already been set, to seeking consumer leadership from the outset so that consumers are engaged in the initial thinking and priority setting"*.[6]

---

[6] Roper, C., Grey, F., & Cadogan. E., 'Co-production Putting principles into practice in mental health contexts' (2018).

69 We need to start asking the question *"where is the consumer voice when the agenda is being discussed"*. Instead what often happens is that agenda, budget and timelines are set up without consumer involvement and half way through the project consumers will be consulted but only in a very limited way (often citing budgetary and time constraints). The consultation will often occur in a very superficial way such as with respect to the colours of a building or the name of a service.

70 Currently there is a lot of investment on independent living facilities in Victoria and across the country with very little consumer and carer input. Service providers, architects and construction companies with the very best of intentions, that is, in a very paternalistic way, are designing and building residential facilities for consumers. These facilities will be around for at least 30 years regardless of whether they meet consumer needs. Consumers have very little choice but to use these facilities. A cynic could say that there is little incentive for service providers to involve consumers to understand their needs but I think what is happening is that service providers do not know how to do co-production. We are so used to using words like co-production, co-design and lived experience that we do not stop to really think what these words mean.

71 The diagram below shows how a co-production scenario would work. The diagram sets out that there should be:

(a) Consumer input at governance level that sets the agenda and strategic direction (For example, consumer board members);

(b) Consumer input at setting timeliness and budgets, governance arrangements, selecting partners and stakeholders that understand and are keen to learn more about lived experience (For example, lived experience in senior leadership and lived experience in interview panels that select project manager and partners);

(c) Consumers in the project team developing and testing solutions (for example a project manager and/or project workers) as well as consultation with past, existing and potential service users with consumer consultants;

(d) Lived experience in delivery (for example, peer support workers); and

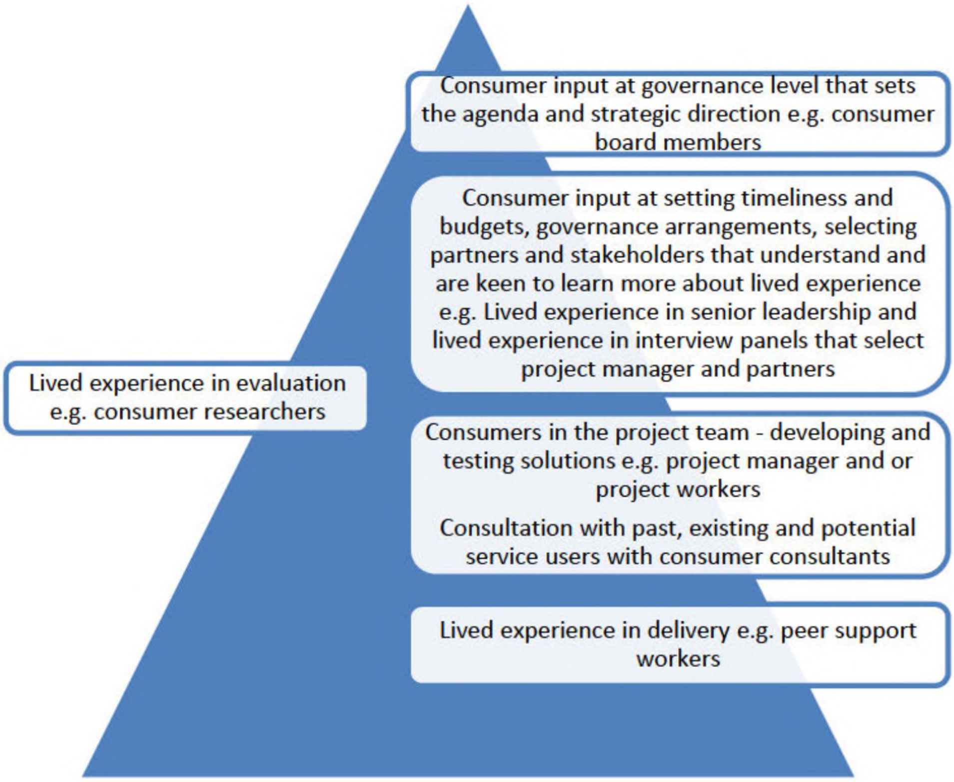
(e) Lived experience in evaluation (for example, consumer researches).

72 There are three important things to note here:

(a) There needs to be diverse range of consumer roles that can contribute to each level in a meaningful and effective manner.

(b) Consumers need to be part of the decision making at each level and not just provide input. For example, in the evaluation phase consumers need to be part of the decision making process for how to evaluate and how to design the research. Genuine co-production cannot happen if the consumer researcher is recruited after the research project has been approved.

(c) It is important to acknowledge power differences in having a consumer in any of these settings. There are often times where there will be one person bringing a consumer perspective to the table with all other participants being non-consumer experts. Therefore, it is really important that consumers receive the relevant training, supervision and mentoring to make a genuine and effective contribution.



Mechanisms and structures to ensure that people with lived experience are represented in governance and decision-making

Legislative measures

73 Experiences have shown that legislative and funding requirements are an effective way to ensure people with lived experience are represented at a governance and decision-making level. Without such external forces the lived experience expertise will continue to be overlooked, it will not be prioritised and it will be marginalised as a result of financial, operational and time constraints.

74 A good example of a legislative requirement is the Independent Advisory Council (**IAC**) at the National Disability Insurance Agency (**NDIA**). The NDIS legislation states that

there must be people with a lived experience in the IAC.[7] As it is a legislative requirement, there has been lived experience expertise in the IAC from its inception and this will endure as long as the legislation remains in place. The NDIA has to prioritise legislative requirement. This cannot be overlooked due to financial constraints or timeline constraints in the way that lived experience expertise can usually be marginalised.

75 A similar example to the IAC is the Expert Advisory Committee (**EAC**) to the Royal Commission. The letters patent require that people with a lived experience must be part of the EAC. This ensured that lived experience expertise was part of the EAC from its inception and that this will continue until the conclusion of the Royal Commission.

76 Without legislative requirements, including lived experience expertise at a governance level continues to be overlooked. For example, there was an absence of the appointment of someone with a lived experience in setting up the Interim Office and there was no lived experience counterpart to the Chief Advisor in the announcement of the Interim Office. As a result of that, there is an absence of lived experience in how that office will be set up and operationalised. Whilst there will be consultation with people with a lived experience, and employment of people with a lived experience, there is no lived experience as part of the decision making process for setting up the governance, agenda, budget and strategic direction.

Funding requirements

77 Another way to ensure that lived experience expertise is involved at a governance level is through funding arrangements. The reason that Australia's lived experience workforce has expanded is because the Commonwealth government introduced the Personal Helpers and Mentors (**PHaMs**). PHaMs required that at least one team member had a lived experience of mental ill health and recovery. One could argue that this was setting up the workforce to fail as there was no organisational readiness and supports for the lived experience workforce. There is some truth in this statement. There were many challenges in the implementation of PHaMs. Many mistakes were made and a lot of services did not get it right at the beginning. However, a lot of lessons were learnt through the introduction of PHaMs. There were examples where organisations effectively just ticked the box, and the rationale behind having someone with lived experience was not fully realised.[8] However, the introduction of PHaMs was the impetus to starting the peer workforce in this country. As a result of that, organisations had to learn about peer work, develop training, human resources capabilities and supervision arrangements.

---

[7] Section 147(5)(c)(i) *National Disability Insurance Scheme Act (2013)* (Cth).

[8] Sierakowski, E, 'Peer Support in Mental Health: An exploratory study of PHaMs in Victoria'.

78 Similarly, in Victoria, the Expanding Post Discharge Support Initiative (the Initiative) required mental health services to recruit peer support workers. Learning from past experiences like PHaMs, this program came with more supports such as training for the new recruits. The Initiative has been described as follows: *"The Expanding Post-Discharge Support Initiative created a sense of urgency that we needed to invest more towards developing peer support capabilities among our lived experience workforce. A program of workforce development activity was developed in partnership with experienced lived experience workers…."*[9]

79 In my view, this funding model (making peer workforce recruitment a condition of funding) had a lot to do with the way the lived experience workforce grew in this country. Similarly, the Victorian government mandated consumer consultants and provided specific funding for those roles. It was through these external forces that the peer workforce built up.

80 Some may argue that making peer workforce recruitment a mandatory requirement means that there is no incentive to introduce more roles other than the ones that are mandated. This is not necessarily true. The introduction of PHaMs and consumer consultants through government funding has led many organisations to grow their lived experience workforce and develop their own training. For example, at Mind Australia peer support workers were recruited as part of the PHaMs program, which became the catalyst for the organisation to explore the value of the peer work. Since then, peer support workers were introduced in all services, a five day peer training was developed and a dedicated lived experience team was set up. It took a long time and it is still a work in progress.

81 Statistics show that the growth of the lived experience workforce cannot be left to the goodwill of mental health services. Victoria first employed four consumer workers in 1996. Twenty one years later as at October 2017 there were only 341 Lived Experience positions that amounted to 187 full-time positions.[10] At this rate it will take us another 40 years to have 1000 lived experience positions in Victoria. Therefore, we will need external forces such as legislative requirements and funding requirements to drive the growth of the lived experience workforce.

---

[9] Edan, V., and Cadogan, E., Chapter 'Honouring, developing and growing Victoria's lived experience workforce' from Meagher, J., Stratford, A., Jackson, F., Jayakody, E., & Fong, T. (Eds). (2018). Peer work in Australia: A new future for mental health. Sydney: RichmondPRA and Mind Australia, 163.

[10] Edan, V., and Cadogan, E., Chapter 'Honouring, developing and growing Victoria's lived experience workforce' from Meagher, J., Stratford, A., Jackson, F., Jayakody, E., & Fong, T. (Eds). (2018). Peer work in Australia: A new future for mental health. Sydney: RichmondPRA and Mind Australia.

Governance and accreditation standards

82 Accreditation standards and clinical governance arrangements can play a role in ensuring that the lived experience workforce is represented in governance and decision-making. Again, it is about everybody taking responsibility; auditors and accreditors need to have an understanding of the substantive content of the standards, particularly when it comes to lived experience and co-production. This would mean that during accreditation and auditing, auditors and accreditors look beyond the surface and are able to understand and assess what the standards mean, and whether these standards have been met in a meaningful way.

Same rights and protections as other disciplines/workforces

83 If we are to create an environment where lived experience providers emerge, the lived experience workforce needs the same rights as non-lived experience workers.

84 When it comes to income protection mental health conditions are often excluded. Yet the lived experience worker's income is dependent on managing their mental health condition.

85 For example, I have never applied for income protection insurance as it is not generally afforded to lived experience workers. The things the insurers take into account against meeting the criteria for insurance, such as medications and doctor attendances are precisely the same things that keep me well. This makes me feel like I am being penalised for managing my mental health.

86 The reason this does not get picked up is that most of us are so grateful to be working, we do not think about these protections, which is rather ironic. You have to remember that a lot of lived experience workers face interrupted education or job losses along their recovery journey. I recently raised this with a colleague who has been a lived experience worker for a long time and their response was *"People (like myself) are not at great advocating for things because being included at all feels like a win*". That made me feel really sad. It's like after all these years we are so happy to be invited to the party we do not even realise we are not being asked to dance.

Workforce

A great experience with a professional involved in my care and support

87 I have been seeing my current doctor, a private psychiatrist, for twelve years. As I outlined above, I started from a position of believing I was weak, that I was somehow less and that my opportunities and options were limited. I had to be careful not to overdo things so I did not fall sick again, effectively internalising all the prejudice. I

started seeing my psychiatrist after a particularly bad episode, I had just found work again and I honestly did not think I would be able to hold down a job in the long term. I approached him from a position of weakness where he had enormous power over me.

88 One of the things this psychiatrist constantly kept telling me was "*you need to learn to figure out what works for you, you need to learn to manage this*". So he made me responsible. At first it was rather frustrating because I kept asking "*what do you mean 'I need to learn to manage this?' You have to tell me how to do this.*" It was an ongoing conversation.

89 At no stage did he ever say "*oh you won't be able to do this*", or *"you better be careful that might be too much for you"*. His questions have always been "*well how are you going to manage that? How are you going to do that?*" He never, at any stage, made me feel like I was incompetent, weak or that my options were limited. We have come to an arrangement now after all these years where I will be the one to say *"I think I need to change my meds"* and he will trust me, or his question will be "*do you think we need to do that*". I know that he would prefer to have me on a completely different medication, but I have decided against it and we came to a decision where we agreed to try the medication I preferred. He still brings up the alternative every now and then, but it is my decision.

90 He has always been honest about limitations. He does not hesitate to say "*We won't know for sure. We can try it*". He will explain the background, the research his experience with other patients, and how we might try something. At the beginning this used to frustrate me and I used to think *"you are the doctor!"* It is only now that I have come to appreciate his honesty. In a way it is humbling, as he is a psychiatrist with many years of experience.

91 Continuity of care has been crucial. The other aspect is the trusting relationship; it takes a long time to build a trusting relationship. Importantly, because my doctor has been able to see me over the long term, he has been able to pick on things and he will say "*you're not doing so well at the moment, are you?*" On two occasions he has said *"I think you need to take this medication"*, even when I thought I was not that bad. He suggested just to fill out the script and to keep it with me. I realised that I trusted him completely. You cannot have that trust without the continuity of care, it is a give and take relationship. Without this, I think my trajectory would have been very, very difficult because of the fundamental (prejudicial) beliefs that have been instilled in me.

92 My psychiatrist treats me with respect when I question or challenge him, and at times encourages me to find out more. On one occasion I took something to him and afterwards said "*Google must make your life very difficult, as patients must come up with all sorts of things*." His response was "*Well that's the reality these days. You have*

to deal with it". One time when I was hesitating to try a certain medication he asked me *"is there someone you know who has tried this medication you can talk to?"*. I did reach out to someone and that is what ultimately led me to work in the mental health sector.

93 My psychiatrist encouraged me to apply for my current position as Tribunal Member of the Mental Health Tribunal Victoria; he said to me "*you're a very competent person, the lived experience will be an advantage*". His vote of confidence meant a great deal to me. I would like to think that I have grown up so much that, even if he did not encourage me, I would have done it anyway – but it would have been difficult and this encouragement and support was instrumental. This is someone who has seen my all my weaknesses, all the stupid things I have done and the struggles I went through and still go through. If at any stage he told me that my possibilities were limited and that I should aim low it would really have affected my self-confidence. His belief has been we're both professionals who can also work together.

94 In my opinion this approach is what recovery-oriented practice is about, making sure, even though it might be difficult when a person is at a very difficult stage, to say: "*you're in the driver's seat. You need to learn to manage. I'll help you learn to manage it*". It is a strength based practice of seeing a person as a whole.

95 In recovery oriented practice we always talk about trustful relationships. The clinician needs to trust and respect the lived experience and the patient needs to trust and respect the clinician. It is very difficult for the patient to trust the clinician. When a patient has been told over and over again that what they are feeling, hearing or seeing is not real, they are overacting, or that they need to try harder, why would they suddenly trust a doctor. Also, you have to make yourself really vulnerable with a stranger about what is happening to you, you have to open up and be exposed in a way that you do not have to in any other health condition. You cannot do that unless you feel safe. It is up to the clinician to build that safe environment and gain the trust of the patient. The only way to do that is to respect the person's lived experience. That is, to find out the patient's experience and reserve judgment. You have to put in the time to gain the trust. A clinician needs to be honest about their limitations and empower the patient to question, negotiate and problem solve. Both parties need to accept that they are experts in their own fields. This takes great skill, time, empathy, patience and, most of all, respect from the clinician.

96 In my view, my psychiatrist's attitude and approach can be replicated. The starting point has to be shifting the prejudice. There needs to be an unshaken belief that a person can recover and lead a meaningful life. With that comes the respect, patience and the willingness to put in the time.

97 I often hear mental health professionals say that they feel uncomfortable if a client is to work with them or that a client cannot be a mental health professional. In fact some organisations have policies that prevent clients from working in the same organisation or impose arbitrary timelines such as six months or twelve months before a client can work for the same organisation. This is a reflection of the deeply held stigma within mental health services that people with mental health challenges are not able to lead meaningful lives and work as professionals. How is it possible for a person to recover when the professionals meant to support them do not believe in the person they are supporting or think that they are not equal? What hope is there if the people who are meant to support you undermine you because they think you are not capable and that you cannot do better? What is the mental health professional's role if they are not going to support the person to manage their mental health and achieve their goals?

Compulsory treatment

Means of reducing the rates of compulsory treatment use

The right to health

98 The *Mental Health Act 2014* (Vic) (the **Act**) authorises providers of mental health services (**Services**) to give treatment against a patient's wishes. "Treatment" is defined under the Act as "things [are] done in the course of the exercise of professional skills – (i) to remedy the person's mental illness; or (ii) to alleviate the symptoms and reduce the ill effects of the person's mental illness". This includes oral medication, injection or Electroconvulsive Therapy (**ECT**) being administered without a person's consent.

99 Treatment can be administered in a community setting or an inpatient setting. In a community setting, a person on a compulsory treatment order can be required by law to take medication (oral or injections) in their home, sometimes under supervision. Alternatively, they can be required by law to attend a health service to take medication (oral or injections). In an inpatient setting, a person can be detained in a hospital and given treatment against their wishes, including ECT.

100 Compulsory treatment is a limitation of the right to liberty. The right to liberty is the right to freedom of movement and the freedom from arbitrary detention by others.

101 The right to liberty is not absolute. It can be restricted in accordance with the law in the interest of public safety or public health. A good example is the strange COVID-19 times we are currently living in, where our right to free movement and association is restricted.

102 However, when a person is deprived of their right on the basis of a unique health condition, combined with another element, for example a risk of causing harm to self

and others, it is discriminatory.[11] Under the Act the unique health condition is mental illness and the other element is risk to self or others. Section 5(b) of the Act states:

> *"because the person has mental illness, the person needs immediate treatment to prevent—*
> *(i) serious deterioration in the person's mental or physical health; or*
> *(ii) serious harm to the person or to another person;"*

103 Article 14(1)(b) of the Convention on the Rights of Persons with Disabilities (**CRPD**) provides that States parties shall ensure that persons with disabilities "are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty."

104 Australia is one of four states (out of the 177 States that are parties to the CRPD) that have declared their intention to limit the implementation of Article 14 of the CRPD.[12]

105 The Act authorises mental health service providers to use seclusion and restraint practices.[13] Section 105 provides that a restrictive intervention may only be used on a person receiving mental health services in a designated mental health service after all reasonable and less restrictive options have been tried or considered and have been found to be unsuitable. The Act also authorises mental health service providers, in certain circumstances, to restrict the right to communicate.

106 Whilst the Act sanctions the deprivation of liberty, and sanctions different types of restrictive practices on the basis of a medical model of disability, it is silent on the right to health of persons subject to compulsory treatment.

107 Article 25 of the CRPD states that persons with disabilities have the right to enjoyment of the highest attainable standard of physical and mental health.

108 Article 12 of the International Covenant on Economic, Social and Cultural Rights states that "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".

109 Australia is signatory to both of these Conventions.

110 A report published by the World Health Organisation (in collaboration with various academic institutions) on 16 January 2017 states in the summary of the first chapter:

---

[11] Report of the Special Rapporteur on the rights of persons with disabilities 11 January 2019.
[12] Report of the Special Rapporteur on the rights of persons with disabilities 11 January 2019.
[13] Note this is in contravention of Article 7 of International Covenant on Civil and Political Rights: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

> “The human right to health, understood as the right to the highest attainable standard of health, provides an overarching and exacting standard to guide the actions of governments as they strengthen their health systems by reforming their public health laws. The principles of *availability*, *accessibility*, *acceptability* and *quality* are essential elements of the right to health.”[14]

111 A standalone law on mental health that authorises the deprivation of liberty needs to address all aspects of the provision of mental health services, including the availability, accessibility, acceptability and quality of mental health services.

112 Availability and accessibility are elements of right to health. However, most people receiving compulsory treatment do not have access to some of the basic treatments such as access to psychologists. Generally speaking, access to, and availability of, psychologists in mental health services are the exception not the rule.

Need for more robust legislative framework and access to multi-disciplinary support services

113 People with mental health conditions have a shorter life span and a high percentage have co-morbidities. It is a well-known fact that most medications, such as antipsychotics and mood stabilisers, can have harsh side-effects. Yet under the Act, there is no imposed obligation to provide primary health care to monitor the side effects and manage co-morbidities of persons subject to compulsory treatment. Under section 6 of the Act ‘Treatment’ is defined around treatment for mental illness without an obligation to provide treatment and support to manage co-morbidities and side effects. The principles of the Act and in particular section 11(1)(f) of the Act provides that “*persons receiving mental health services should have their medical and other health needs, including any alcohol and other drug problems, recognised and responded to*” However, these principles are not implemented and operationalised effectively. Therefore, the Act needs to go beyond a principle and impose an obligation to provide primary health care.

114 A person who is subject to a compulsory treatment order (an order made by the Mental Health Tribunal that enables a person to be compulsorily treated) needs to be treated by a multi-disciplinary team where a full range of treatments are offered, for example access to allied health services such as a psychologist, occupational therapist, dietician as well as primary health care services.[15] Persons subject to compulsory treatment very rarely have access to a range of services.

---

[14] Advancing the right to health: the vital role of law. Geneva: World Health Organization; 2017 Licence: CC BY-NC-SA 3.0 IGO.

[15] The Trieste Mental Health Model offers mental health services provided by multi-disciplinary teams that provide better outcomes: Senator Lyn Allison, ‘Report of mental health services observed in Trieste, Italy – January 2006’

115 The Act can also provide other mechanisms whereby psychiatrist to patient and nurse to patient ratios are introduced. Such measures will ensure high quality mental health services are accessible and available for persons receiving mental health services. Victoria already has such mechanisms in place for other health services. For example, the *Safe Patient Care (Nurse to Patient and Midwife to Patient Ratios) Act 2015*. This can also be an impetus to increase the workforce as currently there is a shortage in the mental health workforce.

The need for greater transparency and accountability: a lack of robust data

116 There also needs to be greater transparency to promote accountability for the standard of care provided by mental health services under the Act. For example, there is a lack of comprehensive and meaningful data on restrictive practices. Five years after the Act was introduced, according to the Mental Health Report by the Secretary, "data on restraint is continuing to develop".[16] This is of great concern as Victoria has one of the highest rates of restrictive practices in Australia.[17]

117 Aggregate data on seclusion and restraint is reported annually as part of Victoria's Mental Health Services Annual Report and the Chief Psychiatrist's Annual Report. However, the data is minimal and provides no meaningful information. There is no comparison against key performance indicators, other jurisdictions and no breakdown of data by each Mental Health Service to monitor, understand and analyse the data in a meaningful way to identify trends enabling preventative strategies. In April 2019, the Victorian Mental Illness Awareness Council (**VMIAC**), peak consumer body in Victoria, published a report on seclusion that provided comprehensive information on restrictive practices to increase transparency and encourage accountability. It should not be left up to peak bodies to seek out this data; instead, it should be mandated by law.

118 Restrictive practices (literally) take place behind locked wards when people are experiencing great distress and are at their most vulnerable. It is an environment where medical professionals exert enormous power over a vulnerable group of people. Patients have very little access to advocacy services, families and friends in such situations. It is paramount there is greater transparency and scrutiny of such practices. Data on restrictive practices needs to be published quarterly in a meaningful way to enable proper analysis and better understanding of practice trends and how to address them ultimately leading to better quality of care.

<https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Former_Committees/mentalhealth/report/e03>.

[16] Victoria's Mental Health Services Annual Report 2018-2019.

[17] Gooding, P., Yvette, M, 'Why are the rates of restrictive practices in Victoria's mental health services so high?' <https://pursuit.unimelb.edu.au/articles/why-are-the-rates-of-restrictive-practices-in-victoria-s-mental-health-services-so-high>.

119 The Act needs to provide for inspections to be conducted of locked wards. These inspections can be based on the principles of the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (**OPCAT**). OPCAT is an international treaty designed to strengthen protections for people in situations where they are deprived of their liberty and potentially vulnerable to mistreatment or abuse. The key obligations arising from ratification include establishing a system of regular preventive visits by independent bodies….[18] While locked wards will fall under places of detention under OPCAT and will be subject to OPCAT inspections separate routine inspections must be conducted under the Act. Otherwise there is the real danger that inspections of locked wards will be lost between two legislation as experience has shown that mental health services have a tendency to get marginalised. These inspectors must include people with a lived experience.

120 It is also difficult to ascertain how many people are subject to compulsory treatment orders at any given time in Victoria. There is no reliable data on how many people are placed on Treatment Orders as there is no publicly available data on Temporary Treatment Orders. The Mental Health Tribunal publishes details on the Orders it makes and hearings. However, services do not publish data on Temporary Treatment Orders.

121 Currently, the data on restrictive practices are scattered across different reports by various safeguards established under the Act. All data needs to be compiled in one report to make it more accessible and create transparency.

122 It is also worth noting that data on restraint, seclusion and Treatment Orders are reported by the duration of restraint, seclusion and the number of Treatment Orders. This is not reflective of a person-centred system. This data also needs to be available and specify how many people are placed on Treatment Orders and how many people are put in seclusion and the length of that seclusion. If we are to have a person-centred system that respects the inherent dignity of people, data reporting needs to reflect this.

Quality of care and accountability

123 The Act also needs to provide a framework for ensuring a high quality of care in the provision of mental health services. The Act makes reference (in section 118) to promoting continuous improvement but this is insufficient. There needs to be a specific quality framework for mental health service providers that administer compulsory

---

[18] The Implementation of OPCAT in Australia Submission by The Australia OPCAT Network to the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Spt) and The United Nations Working Group on Arbitrary Detention (Wgad) January 2020.

treatment, for example something similar to the World Health Organisation's Quality Rights Toolkit.[19]

124 Currently, mental health service providers have their own clinical governance frameworks. In 2019, Safe Care Victoria, Victoria's healthcare safety and quality improvement agency, established a mental health clinical governance committee. These mechanisms do not provide comprehensive oversight of the quality of care provided by mental health service providers that administer compulsory treatment.

125 A law that authorises a mental health service provider to administer compulsory treatment and engage in restrictive practices needs a higher degree of accountability to protect the dignity and rights of persons subject to compulsory treatment. The same law needs to provide rigorous mechanisms to ensure that mental health services are delivering high quality services. The Act needs to hold mental health services accountable by increasing transparency through mandatory public sharing of comprehensive data, reporting against specific Mental Health Quality Frameworks and audits of mental health services, particularly those that engage in restrictive practices.

The need for greater transparency and accountability in decision-making

126 The Act also places the burden of seeking written material for decisions on the person subject to compulsory treatment, rather than the mental health service provider or the Mental Health Tribunal being obliged to provide such material. For example, when an advance statement (a statement setting out a person's treatment preferences in case they become unwell and need compulsory mental health treatment) is overridden by a mental health service provider that decides not to follow the directions of the advance statement, the provider does not need to provide written reasons. Similarly, the Mental Health Tribunal is not required by law to provide a written statement of reasons for Treatment Orders. In 2018-2019, only 243 Statement of Reasons were requested in comparison to the 6297 Treatment Orders made in that period.[20] In both of these instances, the obligation is on the person receiving compulsory treatment to request in writing the written reasons and statements. The period for requesting written reasons and statements of reasons are time limited. Shifting the obligation to provide written reasons and statements of reasons away from the mental health service provider and the Mental Health Tribunal is unjust. People in distress often struggling for their survival are highly unlikely to request written reasons within the time frame specified in the Act.

127 This creates a situation where there is very little information available in situations where the law has authorised the deprivation of liberty and rights. For example, after

---

[19] Introduced in 2012, the Quality Rights Toolkit provides a framework for assessing and improving quality and human rights in mental health and social care facilities.

[20] Mental Health Tribunal 2018-2019 Annual Report.

sometime – let’s say once a person has recovered from a period of illness – if a person who received compulsory treatment wishes to obtain more information on why they were detained, the only written information available will be clinical notes. There will be no written reasons or statement of reasons from the mental health service provider or the Mental Health Tribunal. Written reasons for decisions made about a person’s health are critical when people attempt to recollect, reflect and understand their experiences. There needs to be greater transparency and accountability in how decisions are made to honour the dignity of persons subject to compulsory treatment. The Act needs to create more robust structures to protect the person’s dignity, and rights when they are at their most vulnerable.

128 It is not possible to have an informed discussion about compulsory treatment without sufficient and meaningful publicly available information such as the number of people subject to compulsory treatment orders, comprehensive data on restrictive practices, reporting against a mental health service quality framework and key performance indicators, written reasons and statements of reasons on why a person is detained or treated against their wishes and preferences.

Attitudes toward compulsory treatment: a cultural problem

129 I perceive there to be a fundamental disrespect for the seriousness of compulsory treatment by mental health service providers. As a Tribunal Member of the Mental Health Tribunal, I note the presence of poor quality reports submitted to the Tribunal; a significant lack of attendance by consultants or treating psychiatrists at hearings, Registrars with no knowledge of the patient being sent in their place; case managers failing to attend hearings and a general lack of preparation for Tribunal hearings. This is a reflection of the lack of understanding and respect for what is at stake at these hearings: a restriction of a person’s liberties owing to their mental health challenges. It is also a reflection of the culture of mental health services and the deeply ingrained belief that people with mental health challenges are incapable, therefore it is acceptable to have their treatment decisions taken away from them.

130 This culture can be contrasted against the English system: “*In addition to requiring three reports, the MHT expects the author of each report to attend the hearing to speak to their report and be cross-examined. If someone stands in for the report author, they will be expected to have met the client and have some familiarity with them, otherwise the matter would likely be adjourned.*”[21]

131 English services also employ Mental Health Act administrators whose responsibilities include ensuring services comply with the Act, training staff, conducting audits

---

[21] Eleanore Fritze ‘Shining a light behind closed doors’ (December 2015), 42.

(including on the quality of reports) and producing audit reports, checking records are complete and chasing compliance with statutory deadlines.[22]

132 There needs to be greater emphasis on challenging beliefs and values about discriminatory assumptions, stereotypes, stigmas about mental health in the curriculums of medicine, law, social work and other disciplines providing mental health services. The curriculums need to go beyond a theoretical understanding of a rights framework and lived experience. The important aspect is how these frameworks are translated into practice.

133 In my experience of working with my psychiatrist never once did we talk about rights, recovery oriented practice, strength based practices or self-determination. We talked about practical things like how I was going to manage the various challenges I was experiencing and what would help me manage my moods and emotions. Therefore, curriculum and the training needs to go beyond the theoretical understanding of these frameworks. In order to do this there needs to be robust supervision and space for reflection.

134 Curriculums also need to have significant discussions on structural, professional and personal values and how this influences the way services are provided. Reflective practice needs to be part of curriculums, where students are taught to routinely explore how their own values and structural values and preferences impact working relationships. Structural values are the underlying presumptions and values of how the health services are planned and delivered. This can empower professionals to be agents of change and to influence not only their own values and practices, but also challenge the status quo and long held beliefs by the mental health system.

The right to legal representation and advocacy

135 The Independent Mental Health Advocacy service is a state funded, instruction based, non-legal, advocacy service for people receiving compulsory treatment under the Act. In addition to this, Victoria Legal Aid has a specialist disability law practice group that provides legal representation at Mental Health Tribunal hearings and the Mental Health Legal Centre (**MHLC**) provides legal advice and legal representation at Mental Health Tribunal hearings. The MHLC receives a mix of government and philanthropic funding.

136 Persons subject to compulsory treatment orders are not entitled to state funded legal representation at Mental Health Tribunal hearings. Instead, it is the responsibility of the person to arrange their own representation. Only 13% of people were represented at

---

[22] Eleanore Fritze ‘Shining a light behind closed doors’ (December 2015), 75.

Mental Health Tribunal hearings during 2018-2019.[23] There are several ways a person can find out about the advocacy services available to them: information passed on to them by their mental health service provider (this is dependent on the goodwill of the provider), visits by representatives of advocacy services to mental health service providers, promotional materials and word of mouth.

137 All persons subject to compulsory treatment should have access to state funded legal representation and advocacy should be an opt out system.[24] In such a system, all persons subject to compulsory treatment would be contacted by an advocacy service and it would be their decision whether to accept or reject advocacy and legal representation. It is unjust to create a system where the responsibility for seeking advocacy services is left with people under a law that sanctions compulsory treatment. The current situation is one where, when people with mental health challenges are at their most vulnerable, they are denied their right to liberty, with little recourse to the law.

Strengths of the Mental Health Tribunal

138 One of the strengths of the Mental Health Tribunal is its inquisitorial approach in hearings. This enables Tribunal members to engage in conversation with the person receiving treatment in a manner that promotes the building of a rapport, leading to a more meaningful discussion about the experience of the person receiving treatment, and their treatment preferences.

139 The inquisitorial approach also allows for family inclusive practice. The Tribunal promotes a family and carer inclusive practice, and encourages families, friends and support persons to attend hearings. The inquisitorial approach allows the Tribunal to be sensitive to the family and carer dynamics and negotiate with the patient about how the Tribunal can interact with the families and carers.

The role of negotiation in the provision of treatment

140 Another way of looking at compulsory treatment is to ask if the system creates room for negotiation in relation to treatment rather than subjecting people to compulsory treatment. There is minimal room for negotiation in the current system. In relation to any other health condition, there is room for negotiation. For example, if a person wishes to refuse cancer treatment, palliative care is an alternative.

141 Trieste mental health services, a service provider based in Italy, works on such a negotiation model. A former director said, “[w]e have approved, people-centred plans that are based on negotiation – sometimes very exhaustive negotiation. You have to

---

[23] Mental Health Tribunal 2018-2019 Annual report.

[24] Evaluation of the Independent Mental Health Advocacy Service (IMHA) March 2019.

listen to patients and understand them. If a person wants to go then we must convince them to stay since there are no locked doors. We must eventually convince them to take medicine but within a range of other care offers. This is all based on principles to respect people if they are in a state of severe suffering, just as if they had cancer."[25]

142 Trieste has very few persons on compulsory treatment orders, "fewer than 10 per 100,000" and there is a no restrictive practice policy including the administering of ECT.[26] Treatment is provided by multi-disciplinary teams. The Trieste model is based on the practice of promoting the social inclusion and full citizenship of users of mental health services.[27]

Compulsory treatment: the need for a paradigm shift

143 Compulsory treatment is a denial of a person's capacity to make decisions about their treatment. It undermines the autonomy of a person. It is guided by the belief that treatment should be determined by medical professionals as they know best. A law that authorises compulsory treatment, and mental health services that administer compulsory treatment, are driven by stigma; the deeply rooted belief and misconception that people with mental health challenges are incapable of managing their own mental health to lead a meaningful life. Rather, these persons are treated as objects of pity and welfare.

144 If we are to reduce and ultimately have no compulsory treatment, we need to question and challenge the values that underpin the existing laws and the mental health system. We need a paradigm shift where the law and mental health services are driven on the presumption that people with mental health challenges are capable of managing their own mental health. A presumption of recovery. Persons with mental health challenges can lead active, productive, autonomous, healthy lives, just like anyone else, if they receive the supports they require.

145 The law can be a powerful tool for change. The Act can be broadened to bring about a paradigm shift in mental health services. It can provide for things like a framework for setting quality standards, introducing treating team and patient ratios, mandating audit teams with lived experience expertise, and mandating lived experience at a governance level and an operational level.

---

[25] Roberto Mezzina, 'Country that closed its mental health institutions' <https://members.tortoisemedia.com/2019/12/16/country-that-closed-its-mental-health-institutions-ian-birrell/content.html>.

[26] Robert Mezzina, 'Community Mental Health Care in Trieste and Beyond: An "Open Door-No Restraint" System of Care for Recovery and Citizenship' (2014) 202(6) *The Journal of Nervous and Mental Disease* 440-445..

[27] Portacolone, E., Segal, S., Mezzina, R., Scheper-Hughes, N., & Okin, R., 'A Tale of Two Cities: The Exploration of the Trieste Public Psychiatry Model in San Francisco' (2015) 39(4) *Cult Med Psychiatry*.

146 It is important that these mechanisms are set in legislation because we have seen, through the course of history, that mental health services get marginalised too often; for example, through lack of funding and a shortage of qualified staff. We need to legislate for some of these requirements so that Victoria can deliver high quality mental health services and people with mental ill-health receive the right supports and are not forgotten.

147 As a Tribunal Member I sometimes get really disillusioned about our society. I find it particularly challenging to see young people come before the Tribunal. These are people with dreams and hopes. They are resilient and capable of managing their mental health to lead meaningful and contributing lives. Yet the chances of this being realised are minuscular as they are unlikely to receive the appropriate and the high quality supports they need and deserve. That is a tragedy not just for the individual but for us as a society.

148 When I arrived in Australia as a 12 year old with my family my world opened up in unimaginable ways. It really felt like the world was my oyster. Being told I had a mental health condition and having to accept this felt like a life sentence. Suddenly my life and my world was limited. My dreams were out of reach. I was made to feel that I should do things which were '*easy*' so I would not get sick again. The fear of falling apart was ever present. I have been privileged and lucky over the course of my journey to have met people who told me otherwise. Peers who showed me that having a mental health condition did not mean having to take the easy route. Professionals that treated me with respect who saw me beyond my mental illness. I am very aware that my story is the exception. It does not need to be, and should not be, this way. This needs to be the story of everyone experiencing mental health challenges. We have the opportunity to build a mental health service that respects lived experience, includes co-production, robust structures and systems, including legislative framework, to improve accountability and transparency. Only then can we, as Victorians, say that we have a mental health system that respects the inherent dignity of people with mental health challenges and their ability to lead autonomous, meaningful and contributing lives.

sign here ►

print name Erandathie Jayakody

date 4 June 2020

Royal Commission into
Victoria's Mental Health System

ATTACHMENT EJ-1

This is the attachment marked 'EJ-1' referred to in the witness statement of Erandathie Jayakody dated 4 June 2020.

Erandathie Jayakody

Curriculum Vitae

I am passionate about promoting the voice of lived experience to deliver high quality mental health services that empower people to direct their own recovery. I have experience working at strategic and operational level promoting consumer and carer participation and lived experience workforce. My experience is informed by my own lived experience and as a solicitor. My experience includes strategic and operational advocacy, project management as well as providing legal and policy advice to statutory agencies and private law firms. I enjoy working with committed people who are inspired to make a contribution to society.

Qualifications

Community Managed Mental Health Leadership and Management Program, VICSERV and Leadership Victoria	2016
Admitted to the legal profession as an Australian Lawyer, Victoria	2006
Bachelor of Laws and Bachelor of Commerce (E-Commerce), Deakin University	2005

Career History

Assistant Director, National Disability Insurance Agency **2019 to date**

Identify policy issues, undertake research, analysis and consult with stakeholders to develop and implement policies, projects and strategies in relation to psychosocial supports that have strategic, political and operational significance to the National Disability Insurance Agency.

Expert Advisor, Expert Advisory Committee, Royal Commission into Victoria's Mental Health Services **2019 to date**

Provide expert advice to the Commissioners during the course of its inquiry.

Tribunal Member, Mental Health Tribunal Victoria **2018 to date**

Conduct hearings to determine whether the criteria for compulsory mental health treatment as set out in the *Mental Health Act 2014* (Vic) apply to a person.

Team Leader, Consumer and Carer Participation Team, Mind Australia **2014 – 2019**

Lead the consumer and carer participation strategy, advocate and support the growth of the lived experience workforce. Included oversight of the Centre of Excellence in peer support.

Project Manager, Mind Australia s **2012 – 2014**

Lead and manage projects that promoted recovery oriented practices and lived experience expertise.

Legal Project Officer, Legal Services Board Victoria **2010 – 2012**

Provide legal advice and establish processes for conducting management audits of incorporated legal practices pursuant to *Legal Profession Act 2004* (Vic).

Court Liaison Officer, Supreme Court of Victoria **2007 – 2010**

Build and maintain internal and external stakeholder relationships. Facilitate and coordinate activities on behalf of the Supreme Court of Victoria; Included the first web streaming of a court room in Australia.

Professional Engagements

Committee Member, Committee of Management, Victorian Mental Illness Awareness Council	2016–2018
Member, Speaking from Experience, (Consumer Reference Group), Independent Mental Health Advocacy Service	2016-2017
Convenor, Pleading Sanity, Peer Group for Lawyers	2013-2018
Victoria Member, Tristan Jepson Memorial Foundation	2013-2017
Secretary, Association of Mental Health Peer Specialists	2012-2018

Publications

Contributor, Lived Experience Workforce Strategies Stewardship Group,(2019) *Strategy for the Consumer Mental Health Workforce in Victoria. Centre for Mental Health Learning Victoria (CMHL): Melbourne*

Co-Editor: Meagher, J., Stratford, A., Jackson F., Jayakody E., & Fong, T. (Eds). (2018). *Peer work in Australia: a new future for mental health*. Sydney: RichmondPRA and Mind Australia

Conference Presentations

Jayakody, E. (2016) *Integrating Lived Experience Perspectives at Mind Australia*, Dialog Conference, Brisbane

Jayakody, E. (2016) *Expanding the peer workforce,* VICSERV Conference, Melbourne

Jayakody, E. (2016) *Supporting the introduction of Advance Statements*, VMIAC Conference, Melbourne

Jayakody, E and Brophy L, (2015) *Supporting the Introduction of Advance Statements in Victoria, Australia*, International Academy of Law and Mental Health Congress, Vienna, Austria