# Mental Health & Human Rights

A submission to the Royal Commission into the Victorian Mental Health System

### Why I made a submission

I often worry about my mental health. I don't sleep particularly well, get really down for long periods of time, my thoughts are very intrusive, I find myself talking out loud and I have some strange behaviours. But like many people with mental health issues, I learn to employ a mixed method of accepting, managing and masking them. I have been given multiple diagnoses, but don't find any match or improve my experience.

Sadly, I know I'm not alone in feeling alone. Many people in Victoria are living and dying in mental and emotional distress. I know as someone who lives with these experiences, uses the mental health system, but also as someone who has worked in it.

So, when I heard that there would be a Royal Commission into the Mental Health System (RCVMHS), I was ecstatic. The inevitable comedown arrived when I learnt that nobody with disclosed lived experience of mental health issues was appointed as Commissioner of the Royal Commission, or to lead the expert advisory panel. As someone with mental health issues, working in the mental health system, I understand the importance of being heard and taken seriously. I can think of few other areas where a Commissioners and Terms of Reference could be decided without meaningful involvement of the peak representative body.

My views emerge from my personal experiences of mental health and the system.¹ While many people I have spoken to highlight the gaps in the system and the difficulties getting support, just as many are not heard when they speak up about their experiences of the system, which involve cruelty, neglect and a lack of accountability. A system that is meant to heal seems far too capable to hurt.

Some of these issues will be traced to funding, but much of it is shaped by how we understand mental health, the role granted to people with lived experience in community and the system, as well as the laws and regulatory systems that safeguard rights.

My submission focuses on these themes, because I acknowledge my experiences and expertise are best placed here. It does not detract from those with greater peer work, systems, clinical and carer experience, from whom I'm deeply interested to hear from.

 $<sup>^{\</sup>rm 1}$  These are my personal views and do not reflect the views of any current or previous employer.

## **Summary Recommendations**

Victoria's mental health system needs significant reform. All stakeholders seem to agree at this level. For my submission, I have focused on the need to reform the legal and regulatory systems by taking into account models of mental health and the role of lived experience, data and human rights. With that in mind I have made the following recommendations for the Royal Commission and government:

- 1. Review language guidelines to promote lived experience perspectives
- 2. Quarantine funding in mental health budgets for social services that focus on addressing the social determinants of mental health
- 3. Commit to addressing a trauma prevention and treatment strategy, including increased funding to specialist trauma services in and outside mental health services, as well as trauma-informed practices embedded in all state-services
- 4. Commit to coproduce all state welfare and health services, including the necessary funding for research into and implementation of, this strategy. For example, the creation of a coproduction hub to lead public policy and service development in Victoria
- 5. Commit to an appropriately funded mental health and homelessness strategy
- 6. The Royal Commission should formally acknowledge the human rights abuses Victorians have experienced in mental health settings historically and presently.
- 7. The Royal Commission should recommend the creation of a state redress scheme, similar to the Royal Commission into the Institutional Responses to Child Sexual Abuse.
- 8. Broad legislative reform, including development of OPCAT monitoring frameworks, operationalizing the principles of the *Mental Health Act 2014* (Vic), reinforcing safeguarding oversight mechanisms, and Freedom of Information and other health information legislation
- 9. Create a self-advocacy strategy, funding peer groups and networks, systemic consumer advocacy positions, and self-advocacy resources
- 10. Increased funding for consumer and carer organisations such as the Victorian Mental Illness Awareness Council, Independent Mental Health Advocacy, and Tandem
- 11. Mandatory public sharing of data from DHHS bodies and mental health services
- 12. State-wide reform to the consumer consultant and peer support roles in clinical and community services
- 13. Promote independent research into the institutional and structural factors leading to compulsory treatment orders, such as the practitioner, service, length of practice, and interdisciplinarity of teams
- 14. Legislative reform to require the Mental Health Tribunal to transcribe hearings and further promote the principles of the Act in their practice.
- 15. Creation of benchmarks by the Office of the Chief and Mental Health Complaints Commissioner, alongside OPCAT monitoring mechanisms
- 16. Require public communication of powers used under the Act from safeguarding bodies, for example, including recommendations or directions given, and follow up from services

- 17. A review into the Second Psychiatric Opinion service, coproduced by consumers
- 18. Creation of coproduced Office of the Chief Psychiatrist practice guidelines into Second Psychiatric Opinions
- 19. A review into safeguarding bodies and processes and whether they are effectively protecting consumer and carer rights.
- 20. Creation of a safeguarding oversight panel comprising of important stakeholders such as IMHA, MHCC, OCP, SPOS, AHPRA, MHT.

Mental health, mental illness, psychiatric disorder, brain disorder...?

# Let's get some agreement on what "mental health" is first

Despite significant promotion on mental health awareness and stigma reduction, I'm not sure anyone is totally clear what we are talking about. Is it "mental illness", "mental health", "mental disorders", "brain disorders", "psychiatric disorders", "emotional distress", or "psychosocial"

# What's important about "semantics"?

There is an important nexus language-power. Who determines language? gets to use it? What interests does that language protect and promote? It leads to me provisional use of terms like

dysfunction"? These matters have been heavily debated and still remain unresolved. What is clear is that the terms used have some relationship with the type of conversation we are having, the industry or profession we work for, and the type of solution we are advocating.

Terms such as "mental illness", "brain disorders", or any disorders for that matter, are ones that I think are more damaging than helpful. Referring to something as an *illness* overstates our knowledge of mental health, and places it firmly within the conceptual control of clinicians — stakeholders who I believe hold an important part, but not whole, of the conversation about distress. Equally, characterizing something as a *brain* disorder narrows the focus too much — particularly to an organ that we've shown an outstanding inability to understand. And finally, disorders, as a label in and of themselves, represent stigmatizing language that we need to move away from, as they presume a broad

 $<sup>^2</sup>$  For a brief account of how diagnoses and labels like this can be unhelpful: Kinderman P, Read J, Moncrieff J, et al Drop the language of disorder. Evidence-Based Mental Health 2013;16:2-3.

range of experiences and behaviours to be wrong – some kind of disordered departure from the mean, or "normal".<sup>3</sup>

It's also about what this language risks leaving out. Amongst those with mental health issues or emotional distress, are those whose "symptoms" are understandable responses to interpersonal issues such as family violence<sup>4</sup> or grief after someone's passing. That violence can be family violence or child sexual abuse, but it can also be more structural forms of violence, like state-endorsed racism or colonialism, punitive welfare systems or homelessness due to underfunding.

Perhaps the most important concerning feature of these labels, is that those given them were never part of their political construction. A power relationship is inscribed through language, where a person is defined, often involuntarily, by someone they may not have known (such as in the public system), with tools that are foreign to them. While discussing and reflecting on stigma, the Royal Commission should reflect on the political construction of diagnoses, and how that reflects ongoing discrimination against people with mental health issues.

There is no history of consumer participation in the construction of mental health diagnoses such as schizophrenia, bi-polar affective disorder or schizoaffective disorder.<sup>5</sup>

Solutions to this may be difficult, but can include a change in how we educate the community, by placing mental health issues and emotional distress in its social context, by imbuing these definitions with explanations of those with lived experience — not just of an *illness*, but of the intra— and inter—personal as well as structural causes of their experiences.

<sup>&</sup>lt;sup>3</sup> Kinderman, P. (2014). A prescription for psychiatry: Why we need a whole new approach to mental health and wellbeing. Springer. Gambrill, E. (2014). The Diagnostic and Statistical Manual of Mental Disorders as a major form of dehumanization in the modern world. Research on Social Work Practice, 24(1), 13-36.

<sup>4</sup> Burstow, B. (2005). A critique of posttraumatic stress disorder and the DSM. Journal of Humanistic Psychology, 45(4), 429-445; Humphreys, C., & Joseph, S. (2004, November). Domestic violence and the politics of trauma. In Women's Studies International Forum (Vol. 27, No. 5-6, pp. 559-570). Pergamon.

<sup>5</sup> That I am aware of.

## Recommendations

- 1. Ensure language guidelines developed or endorsed by government promote the broad lived experience of Victorians and its social causes.
- 2. Remove terms such as "mental illness" and "mental disorder" from future State written and state-funded publications
- 3. Promote lived experience as well as social and emotional wellbeing, including First Nations and Culturally and Linguistically Diverse understandings of mental health through research and education.

## Getting "Early Intervention" right

# Let's ensure we grapple with the empirical and ethical issues at the heart of early intervention strategies

It is understandable why we want early intervention. If, like proponents say, it prevents someone from experiencing distress or developing a more severe mental health issue, reduces the impact on family and other social networks, and saves money for the individual and State down the track, then we should take the conversation seriously.

This is has led many to advocate for early intervention in mental health policy, and it appears to be a focus of this Royal Commission. Early intervention can mean different things to different people, with some of the more prominent examples being EPPIC here in Australia. This is often characterized by assertive outreach teams intensively case-managing young people, providing them low doses of antipsychotic medications.

However, there is cause for pause and concern. Early intervention research has been criticized for being overblown and full of "spin", with some studies implying results more positive than their data. There is some evidence it can work, but some of our best reviews suggests that it is inconclusive, that the clinical models that relying on "risk" and "transition" concepts often hide heterogeneous populations which is problematic, and that the purported evidence for economic benefits remains in question. Moreover, we are yet to adequately grapple with the psychological, social and physical

<sup>&</sup>lt;sup>6</sup> Mihalopoulos, C., Harris, M., Henry, L., Harrigan, S., & McGorry, P. (2009). Is early intervention in psychosis cost-effective over the long term?. *Schizophrenia bulletin*, 35(5), 909-918.

<sup>&</sup>lt;sup>7</sup> McGorry, P. D. (2007). The specialist youth mental health model: strengthening the weakest link in the public mental health system. *Medical Journal of Australia*, 187(S7), S53-S56;

<sup>&</sup>lt;sup>8</sup> Amos, A. J. (2014). A review of spin and bias use in the early intervention in psychosis literature. *The primary care companion for CNS disorders*, 16(1).

<sup>9</sup> Marshall, M; Rathbone, J (2011). "Early intervention for psychosis". Cochrane Database of Systematic Reviews. 6 (6): 1111 - 1114..

 $<sup>^{10}</sup>$  van Os, J., & Guloksuz, S. (2017). A critique of the "ultra-high risk" and "transition" paradigm. World Psychiatry, 16(2), 200-206.

<sup>11</sup> Mihalopoulos C, McGorry PD, Carter RC (July 1999). "Is phase-specific, community-oriented treatment of early psychosis an economically viable method of improving outcome?". Acta Psychiatr Scand. 100 (1): 47-55; Amos A (2012). "Assessing the cost of early intervention in psychosis: a systematic review". Australian and New Zealand Journal of Psychiatry. 46 (8): 719-734; Jorm AF. Do early intervention for psychosis services really save money? Aust N Z J Psychiatry 2013; 47: 396-7; Mihalopoulos, C., Harris, M., Henry, L., Harrigan, S., & McGorry, P. (2009). Is early intervention in psychosis cost-effective over the long term?. Schizophrenia bulletin, 35(5), 909-918; Raven, M. (2013). EPPIC mirage: Cost-effectiveness of early psychosis intervention. Australian & New Zealand Journal of Psychiatry, 47(7), 599-601.

implications of early labelling and antipsychotic medication use on young people.  $^{12}$ 

I raise this at a time where we are rushing to inject funding into mental health services, as if we have all the answers. Addressing the "treatment gap" is something often highlighted by proponents of the global mental health movement and advocates in Australia. To promote increased funding for services, many have cited the World Health Organisation report which states:

'the world is suffering from an increasing burden of mental disorders, and a widening "treatment gap". Today, some 450 million people suffer from a mental or behavioural disorder, yet only a small minority of them receive even the most basic treatment.'  $^{13}$ 

On this account, governments have a moral duty to redress this gap. In arguing for increased funding, many have utilized the language of crisis, and that we have the answers. But it is worthwhile to pause to separate the "treatment gap" from the ideas, treatments and services that we use to fill it.

Will they be clinically-led or peer-led mental health services? Will they focus on mental health issues of individuals, or on the social determinants that give rise to them? Will it focus on awareness? If so, what are we making people aware of?

If we don't pause, we will increase funding to services despite the fact that it hasn't to date shown improvements in our collective mental health and wellbeing.  $^{14}$ 

## Is our conception of "early intervention" and focus on the "treatment gap" too narrow?

It very likely is. Speaking on the challenge of addressing mental health issues, the United Nations Special Rapporteur on Mental Health stated in June 2019 that

'There is still a tendency to use individualized, causal models to identify determinants of mental health, such as youth violence and self-harm. That tendency results in interventions that focus on immediate, individual behavioural factors,

<sup>&</sup>lt;sup>12</sup> Jorm AF (2012). "Ethics of giving antipsychotic medication to at-risk young people". Australian and New Zealand Journal of Psychiatry. **46** (9): 908-909.

<sup>13</sup> World Health Organization. (2001). The World Health Report 2001: Mental health: New understanding, new hope. Geneva: World Health Organization.

https://www.who.int/whr/2001/en/, 1.

14 Jorm, A. F., Patten, S. B., Brugha, T. S., & Mojtabai, R. (2017). Has increased provision of treatment reduced the prevalence of common mental disorders? Review of the evidence from four countries. World Psychiatry, 16(1), 90-99. Jorm, A. F., & Reavley, N. J. (2012). Changes in psychological distress in Australian adults between 1995 and 2011. Australian & New Zealand Journal of Psychiatry, 46(4), 352-

rather than adequately addressing the structural conditions, which are the root causes. $^{15}$ 

A broader approach recognizes that our mental health is situated and emerges from the social environment that we grow up and live in. $^{16}$  And as such, achieving communities that promote the right of lives of health and dignity requires a focus on relationships and social connection by addressing structural factors in and outside the healthcare system. $^{17}$ 

We can broaden the lens to include these factors. We know the role socioeconomic status, housing, education and gender-roles and structures can have on mental health. These conditions are compounded when 'the denial of humanity, the denial of existence, and the denial of identity' of our First Nations People is allowed. 19

I have seen how discharge into homelessness results in re-admission to mental health services, how family violence can give rise to mental health issues, how services often apply gender-blind approaches which reinforce abusive dynamics, how acute and developmental trauma affects people's life-course, and how from lower socioeconomic backgrounds who don't have private health insurance do much worse in public services.

## What are some things we can do about it?

of Technology.

Examples such as the consultations for the *Gender Equality Bill* and the Treaty process with Aboriginal Victorians should be commended.

Building on this, the RCVMHS can recommend Government to:

• Commit to funding services that address the social determinants of mental health, such as housing, family violence, early parental supports, reforms to the child-protection system, and awareness campaigns that address discrimination against marginalized groups

<sup>&</sup>lt;sup>15</sup> UN Human Rights Council, Special Rapporteuri Report on the right of everyone to the enjoyment of physical and mental health, A/HRC/41/34, p2. Available at: <a href="https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/HRC/41/34;">https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/HRC/41/34;</a> Rosenfield, S. (2012). Triple jeopardy? Mental health at the intersection of gender, race, and class. Social science & medicine, 74(11), 1791-1801.

<sup>16</sup> WHO (2014). Social determinants of mental health. Geneva, World Health

<sup>&</sup>lt;sup>16</sup> WHO (2014). Social determinants of mental health. Geneva, World Health Organization

<sup>17</sup> UN Human Rights Council, Special Rapporteuri Report on the right of everyone to the enjoyment of physical and mental health, A/HRC/41/34, p2. Available at: https://www.un.org/en/ga/search/view\_doc.asp?symbol=A/HRC/41/34

18 WHO (2019) Gender and mental health. World Health Organization. Geneva. Available from: https://www.who.int/mental health/prevention/genderwomen/en; WHO (2008). Closing the gap in a generation. Geneva. World Health Organization. Available at: https://www.who.int/social\_determinants/final\_report/csdh\_finalreport\_2008.pdf

19 Zubrick, S. R., Silburn, S. R., Lawrence, D. M., Mitrou, F. G., Dalby, R. B., Blair, E. M., Griffin, J., Milroy, H., De Majo, J. A., Cox, A., J., L. (2005). The social and emotional wellbeing of Aboriginal children and young people: summary booklet. Perth: Telethon Institute for Child Health Research and Curtin University

- Commit to coproduce all state-funded services so that services meet the needs of community
- Commit to a state-wide trauma prevention and treatment strategy, focusing on scaled and planned funding of specialist trauma services as well as integrating trauma-informed practice into social welfare services
- Create more gender-informed support and peer services to create safe spaces in the community

### Recommendation

- 4. Quarantining funding in mental health budgets for social services that focus on addressing the social determinants of mental health
- 5. Commit to addressing a trauma prevention and treatment strategy, including increased funding to specialist trauma services in and outside mental health services, as well as trauma-informed practices embedded in all state-services
- 6. Commit to coproduce all state service, including the necessary funding for research into and implementation of, this strategy. For example, the creation of a coproduction hub to lead public policy and service development in Victoria
- 7. Commit to a mental health and homelessness strategy, including:
  - a. Researching the housing needs of Victorians, including the particular needs of those who identify as having mental health issues
  - b. Expand tenancy saving programs such as  ${\it Private \ Rental \ Access}$
  - c. Dramatically expand public housing

## We must look back before we look forward

The mental health system needs to front up to its failures and human rights abuses

It is not anti-psychiatry or unhelpful to raise human rights abuses and past practices of psychiatry in this process. It is essential to creating a rights-based mental health system.  $^{20}$ 

As a community, we have granted a great deal of power and authority to a profession that has many questions to answer for.

### What is psychiatry's human rights record?

The short answer is we don't know, and we may never fully know. Private and public mental health treatment occurs in private and in closed environments. This is an obvious necessity in some respects, given paying consumers want to have private and safe conversations. And yet, in public settings there are two countervailing forces: people are in closed environments hidden from proper public scrutiny, but at the same time, have to communicate many of their personal circumstances in a room full of professionals that they don't know and often aren't there with their consent. Moreover, many settlements in relation to care or abuse may not become public.

That said, we know that mental health services have unscrupulously used treatments on consumers and subjected them to inhumane conditions.  $^{21}$  More recently, we know that:

- That mental health services, the Mental Health Tribunal and the Victorian Civil and Administrative Tribunal misinterpreted the law in granting authority for electroconvulsive treatment. It is important to note that this decision was possible because electroconvulsive treatment enjoys greater oversight than more common involuntary treatments, such as antipsychotics.
- That consumers have been detailing the experiences for a long period, about the harmful effects of <u>involuntary treatment</u>, including the loss of dignity and life-long trauma

<sup>20</sup> Cosgrove, L., & Jureidini, J. (2019). Why a rights-based approach is not antipsychiatry. Australian & New Zealand Journal Of Psychiatry, 53(6), 503-504. doi:
10.1177/0004867419833450; McLaren, N (2019) Criticising psychiatry is not
'antipsychiatry'. Australian & New Zealand Journal Of Psychiatry:
https://doi.org/10.1177/0004867419835944

<sup>&</sup>lt;sup>21</sup> For documented accounts, see: Bentall, R. P. (2009). Doctoring the mind: Why psychiatric treatments fail. Penguin UK; Scull, A (2015) Madness in Civilization: A cultural history of insanity, from the Bible to Freud, from the Madhouse to Modern Medicine. Princeton University Press: Princeton.

Some human rights advocates have expressed serious concerns about the current system, while other consumer advocates have labelled the protections in place as a "joke". These examples, and the ones not available for public comment, are left against epistemic struggles where consumers are either not believed, or do not have the economic or institutional means to document and communicate their stories. 22

### Why are we still in the dark about these practices?

Before we look to solutions, we need to understand why we don't know what we don't know. Some structural reasons are:

- Funding consumer and carer bodies are not as well funded or
  organized as professional bodies, such as the Royal College of
  Psychiatrists, or unions representing professional interests.
  Consumers accessing the public mental health system may also be more likely to come
  from lower socioeconomic backgrounds and therefore have fewer structural privileges
  or opportunities to influence
- Responsibility & support for consumers consumers are given all of the responsibility but little means and support to raise their own human rights violations. In order to promote real change, consumers must monitor and advocate to regulatory and safeguarding bodies in order to promote the necessary service and system changes
- Asymmetric information (production and access) There are two kinds of asymmetries in information and knowledge.
  - o Access consumers are given less information than psychiatrists when making clinical decisions. This constrains their opportunity to make informed decisions about what they want. They also have limited information about the mental health service or clinician treating team whereas the clinician has all of the information about them. For instance, without VMIAC's Seclusion Report, they wouldn't know how safe a mental health service was likely to be for them. More data transparency, as well as funding to examine and communicate that data is necessary for consumers to make informed choices.
  - o **Production** consumers have limited ability to produce information about themselves and about their treatment. Limited access to comment on their clinical notes, provide written updates on their treatment, and keep track of feedback they have been given the service, such as local complaints, means they have little overall documentary evidence of any concerns. This is against the

 $<sup>^{22}</sup>$  Newbigging, K., & Ridley, J. (2018). Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. Social Science & Medicine, 219, 36-44; Crichton, P., Carel, H., & Kidd, I. J. (2017). Epistemic injustice in psychiatry. BJPsych bulletin, 41(2), 65-70. For a critique of a previous examination into mental health and how this failed to look adequately at human rights issues: Gosden, R. (1999). Coercive psychiatry, human rights and public participation. Technology and public participation, 143-167.

epistemic struggles they face to be believed in the first place, and that this type of documented evidence is critical when they attempt to recollect potentially traumatic experiences.

• **Decision-making** — key decisions about reform are made without consumers in the room. For example, the RCVMHS limited terms of reference (not placing significant focus on human rights) and appointment of no Commissioners with lived experience.

As a result of these factors, we have an impoverished community debate and understanding of the real human rights issues that circulate in our mental health system. We need truth-telling, structural reform and lived experience leadership to find solutions. Two critical ingredients of all solutions are healing and reestablishment of trust in the system and profession.

#### Recommendations

- 8. The Royal Commission should formally acknowledge the human rights abuses Victorians have experienced in mental health settings historically and presently.
- 9. The Royal Commission should recommend the creation of a state redress scheme, that, like the Royal Commission into the Institutional Responses to Child Sexual Abuse:
  - a. Acknowledges that many people have been abused and/or had their human rights violated in mental health institutions
  - b. Recognise the harm caused by these violations and abuse
  - c. Holds institutions, including mental health services, courts, tribunals and regulators, accountable for the direct causes of this abuse, as well as the foundations that enabled this harm
  - d. Helps people who have experienced human rights violations and abuse gain access to counselling and psychological services, a direct personal response, and a monetary repayment.

## Nothing about us, without us

Providing real power and authority of citizens — consumers and carers — to make decisions about their mental health treatment

I was sitting in the GP's office, a day after telling my mum that I was going to kill myself. He didn't look me in the eye, but kept drinking out of his "world's best dad" cup.

"Do you hear from people that aren't in the room?" he asked.

"No" I answered, knowing in my gut not to tell him my previous 24 hours. He had, after all, ruined a perfectly routine sexual health test months earlier by continuously asking "what are you looking for?", and never believing my answer "nothing, hopefully."

"Now", as he took a breath, apparently laboring under the weight of having to make eye contact with me "which psychologist am I referring you to?"

"23 I was nervous and wanted the exchange to be over - "if you just google her name...". "No, tell me her details." His toleration of me was waning as our consultation moved into its fourth minute. I slowly grabbed her card from my wallet, and put it on the desk in front of him. \*Bang\* as he slammed - and he really did slam it - his pen-pad. "Write it down."

I didn't know why he was talking me like this. It made me feel so small at a time when I really couldn't handle it. And yet, I'm fortunate that it's nothing like I've seen everyday working in the clinical system.

 $<sup>^{23}</sup>$  Not her real name.

 $<sup>^{24}</sup>$  Don't mistakenly think he was on a busy schedule. The waiting room was like a wasteland.

It's no wonder that many consumers and carers don't trust the system. They were never brought to the table when it was being designed and redesigned. The mental health industry and psychiatry have long been engaged in a monologue about madness. 25

#### What are the structural issues?

The same is true of mental health and people who have used mental health services. There are historical and structural constraints on our psychological, social and political agency. Unlike other health or commercial (consumer - service) relationships, consumers face the following barriers to achieving, health, human rights, and dignity:

- System design services have been designed without consumers at the table. Therefore, service user and service provider don't speak the same language
- Rights people who access mental health services are not informed about the nature of those services and what they can reasonably and legally expect. Therefore they have no opportunity to create accountability and service improvements
- Data there is limited public data about services. Therefore, consumers cannot make informed decisions about where they go or  $live^{26}$
- Mechanisms where someone fails to follow the law, leading to harm, it is not clear what legal recourses are available to consumers. This leads to unequal access to justice
- Stigma & discrimination stigmatic language is common, such as "non-compliant", "raging borderlines", "revolving doors". 27 For example, one manager of a service equated advocacy for consumers to "defending a murderer when you know that they are guilty". This language maintains cultural divides between service user provider
- Communication consumers have their communication restricted. 28 This can mean that their ability to seek help or document their experiences is limited
- Collective action collective action can be difficult, as consumers don't fall as easily under professional banners. This means that consumers who attempt to assert rights, access law, or regulatory systems, do so on their own against large institutions. This enables regulatory, legal and political responses to maintain the status quo as real change becomes too difficult

 $<sup>^{\</sup>rm 25}$  Foucault, M. (2003). Madness and civilization. Routledge.

 $<sup>^{26}</sup>$  Where you live is relevant if it is going to be connected to a community treatment order. I have met many people who were willing to move to other parts of Victoria just so that they could be treated by another mental health service.

These are terms I commonly hear.

For example, by having their phones taken away, by having to ask for complaints

processes from the person they are complaining about, or the person who has used [legally authorized] violence such as seclusion and restraint, by having restricted access into the notes that are written about them which are instructive of how they are treated, by having decisions made about them without them in the room.

- Compulsory treatment unlike other health and commercial service relationships, the creation of a relationship via compulsory treatment immediately places consumers in a vulnerable situation, where their rights, psychological agency and credibility are threatened
- Closed spaces the treatment and ill-treatment of consumers occurs in closed spaces. This creates significant barriers to consumers raising concerns about their treatment and being believed. The Office of the Public advocate has spoken openly about this.
- Public narratives where consumer concerns are heard, they often become ensconced or coopted to reinforce an existing industry-led narrative. For example, consumer accounts of ill-treatment may be accounted for by inadequate funding, whereas the answer may also include professional cultures, non-compliance or a lack of awareness of human rights law, and regulatory failures.

### What can be done to resolve these structural issues?

While individual responsibility and funding will also be key to changes, structural problems require structural solutions. Some include:

- Legislative reform reforming current legislation to operationalize the rights, create mechanisms for accountability and drive clinical standards. Example reforms are detailed in the recommendations below
- Consumer/peer strategies creating a funded framework for consumer workforce. For example, a self-advocacy strategy that provides consumers of mental health services with the means they need to resolve their own concerns while also driving systemic change. This means understanding and promoting self-advocacy as a public good and a form of human rights advocacy.
- Mandatory data sharing ensuring outcome and consumer/carer feedback data about specific services is shared by key stakeholders. This can open up closed spaces and drive sector change. This shouldn't be left to peak bodies such as VMIAC and the Seclusion Report.
- Funded advocacy increased funding advocacy for organisations such as the Victorian Mental Illness Awareness Council and Independent Mental Health Advocacy (IMHA). For example, the funded creation of an opt-out system of mental health advocacy as recommended by a recent of IMHA.<sup>29</sup>
- Research into compulsory treatment research into the institutional and structural factors
  that lead to compulsory and coercive treatment, with a goal to reduce and eliminate compulsory
  treatment.

<sup>&</sup>lt;sup>29</sup> Maylea, Chris; Alvarez-Vasquez, Susan; Dale, Matthew; Hill, Nicholas; Johnson, Brendan; Martin, Jennifer; Thomas, Stuart & Weller, Penelope (2019) Evaluation of the Independent Mental Health Advocacy Service (IMHA), Melbourne: Social and Global Studies Centre, RMIT University.

#### Recommendations:

- 10. Legislative reform, including:
  - a. Develop the Optional Protocol on the Convention Against Torture monitoring framework that is coproduced with consumers of mental health and other services.
  - b. Review the principles of the  $\it Mental\ Health\ Act\ 2014\ (Vic)$  and generate provisions to ensure oversight
  - c. Create a statutory requirement for co-written notes so that consumers are able to access and produce information
  - d. Reform Freedom of Information law and clinical practice guidelines from the Office of the Chief Psychiatrist to allow better access to clinical notes, particularly during someone's admission
  - e. The creation of a funded opt-out system for IMHA
- 11. Create a self-advocacy strategy, funding peer groups and networks, systemic consumer advocacy positions, and self-advocacy resources
- 12. Increased funding for VMIAC and IMHA
- 13. Mandatory public sharing of data from DHHS bodies and mental health services, including the Mental Health Complaints Commissioner, the Office of the Chief Psychiatrist, the Departmental statistics, as well complaints and *Mental Health Act 2014* (Vic) compliance data for specific services
- 14. State-wide reform to the consumer consultant and peer support roles in clinical and community services, including:
  - a. State government requirements to place consumer consultants on executive governance levels in mental health services
  - b. Establish a state-wide committee of consumer consultants and the peak body (Victorian Mental Illness Awareness Council) to meet in the Department of Health and Human Services
  - c. Provide funding for this committee to undertake public consultations and research briefings for the Minister for Mental Health, similar to the National Consumer Carer Forum
- 15. Promote independent research into the institutional and structural factors leading to compulsory treatment orders, such as the practitioner, service, length of practice, and interdisciplinarity of teams.

## We must improve regulation

# We must regulate better to reduce compulsory treatment and improve human rights

It isn't well accepted yet, but the use of coercion and compulsion should be seen as a systems-failure.<sup>30</sup> By that metric, Victoria has a lot of work to do given the high rates of compulsory treatment.<sup>31</sup> There should be a commitment to reduce and eliminate compulsory treatment given that we know the harm it can do consumers.<sup>32</sup>

But even if we accept compulsory treatment as the current glue holding the system together, it doesn't explain why I so often hear "but I have no rights!" In Victoria, people are subjected to the law, but without any of the rights and protections meant to "safeguard" them and its proper use.

There is a gap, between what the law says, and what the law does. Where there is a gap, we require regulation.

## Why is regulation important?

It creates reinforces the legal frameworks, but is key in driving cultural standards in services. It's also cheaper and more accessible than government directly delivering services. Consumers and carers wanting to make changes to the system, can do so without the lengthy and costly investments of litigation, which often focuses on individual circumstances and may have limited systemic impact beyond their sets of facts or specific legal question.

It is difficult, though. Victoria's mental health system, like many others, works within a complex polycentric regulatory space, where consumers, carers, professionals, services, regulators, advocates and government have distinct and overlapping roles. This complexity can mean that there is sometimes less meaningful oversight of regulators, or that it is not clear who is tasked with resolving a particular issue.

My experience is that we are not doing this well. Standards and access to justice are failing consumers: while they receive compulsory mental health treatment as per the legislation, they do not receive the accompanying rights. Principles of the *Mental Health* 

 $<sup>^{30}</sup>$  This was acknowledged by the Lancet's Future of Psychiatry Commission: Bhugra, D., Tasman, A., Pathare, S., Priebe, S., Smith, S., Torous, J., ... & First, M. B. (2017). The WPA-lancet psychiatry commission on the future of psychiatry. The Lancet Psychiatry, 4(10), 775-818.

<sup>&</sup>lt;sup>31</sup> Light, E., Kerridge, I., Ryan, C., & Robertson, M. (2012). Community treatment orders in Australia: rates and patterns of use. *Australasian Psychiatry*, 20(6), 478-482.

<sup>482.

32</sup> Rose, D., Perry, E., Rae, S., & Good, N. (2017). Service user perspectives on coercion and restraint in mental health. BJPsych international, 14(3), 59-61.

33 Healy, J., & Walton, M. (2016). Health ombudsmen in polycentric regulatory fields: England, New Zealand, and Australia. Australian Journal of Public Administration, 75(4), 492-505; Carney, T., Walton, M., Chiarella, M., & Kelly, P. (2017). Health complaints and practitioner regulation: justice, protection or prevention?. Griffith Law Review, 26(1), 65-88.

Act 2014 (Vic) and the Charter of Rights and Responsibilities Act 2006 (Vic) require services to support consumers to make or participate in decisions about their assessment, treatment and recovery, provide the least restrictive assessment and treatment possible, and uphold a person's dignity and rights. $^{34}$ 

And yet this doesn't happen. Treatment without consultation, a failure to provide statement of rights (let alone explain them), compulsive use of coercion by mental health services, unregulated use of restrictive interventions, clinical governance structures that prevent supported decision-making<sup>35</sup> - these are **core** all features of the clinical mental health system I have seen directly.

## How can our regulatory systems be improved?

There are laws, although imperfect, that say much of this shouldn't happen. Therefore, attention turns to who is enforcing these laws and safeguarding human rights.

The Mental Health Tribunal (MHT), Mental Health Complaints Commissioner (MHCC), Office of the Chief Psychiatrist (OCP), Second Psychiatric Opinion Service (SPOS) and Australian Health Practitioners Regulation Agency (AHPRA) are tasked with many of these responsibilities.

## With regards to MHT:

- We need hearings transcribed, in order to establish fair oversight over what is said about deliberations and decisions
- We need more active implementation of the principles of the Act, especially when they are granting coercive powers to services. That is, MHT members need to be explicitly monitoring service compliance with principles of the Act when they are granting orders.

## With regards to the MHCC:

• We need public benchmarks about: (1) how the MHCC resolves complaints, such as how they assess complaints, make recommendations and use powers; (2) how the principles of the Act clarify what is expected of services. This will enable consumers, carers and services to drive quality improvement because they will be able to better match their current/past treatment to what is expected of services. Services may identify barriers to achieving this, but the benchmarks remain what is expected.

<sup>34</sup> Section 11 Mental Health Act 2014 (Vic)

<sup>&</sup>lt;sup>35</sup> For example, "complex care committees" or their equivalents, where important decisions about a consumer's life is made without them present. This leaves aside that most decisions about a consumer's treatment occur in nurse's stations or medical offices, and the meeting with consumer is about communicating that decision. This isn't consistent with the principles of supported decision-making: Simmons, M. B., & Gooding, P. M. (2017). Spot the difference: shared decision-making and supported decision-making in mental health. Irish Journal of Psychological Medicine, 34(4), 275-286.

- We need more and public communication when the MHCC uses their powers. There are too many human rights violations that are occurring, and the MHCC is not upholding its function to protect consumers. If complaints are currently being closed, can we be certain that those issues or human rights concerns won't happen again? If it is not clear that complaint recommendations, undertakings or directions are preventing future harm, its not clear why they should be closed. More public use of powers will build trust that has been lost in the consumer community
- We need the MHCC to release service-specific data it has collected since 2014. This improves accountability and supports public trust in the independence of the MHCC. The MHCC should not be restricting the public's access to this data.
- We need the UNCRPD and other human rights principles to inform public recommendations. For example, it is not clear how the MHCC has made recommendations that people with mental health issues do not have the right or capacity to have sexual intercourse in inpatient units, despite the fact that the UNCRPD recognizes equal legal capacity of people with mental health issues, and that the Mental Health Act 2014 (Vic) recognizes decision-specific capacity rather than blanket claims about classes of people<sup>36</sup>
- We need the MHCC to promote further recommendations focusing on consumer rights, the principles of the *Mental Health Act 2014* (Vic) and *Charter of Human Rights and Responsibilities Act 2006* (Vic).

#### With regards to the OCP:

- We need data to be published by this office on system trends and human rights issues
- We need public use of the OCP powers, particularly in relation to its practice guidelines. There are is little consumer trust in this institution because of its failure to publicly uphold human rights.

#### With regards to SPOS:

- We need public data on how many second opinions have led a different opinion to the original psychiatrist. It is important to compare this to the Mental Health Tribunal data in order to assess whether this is an effective safeguarding measure for consumers
- We need an external evaluation of the service from consumers who have used the service to identify whether it was effective, what the assessment process was like, and whether the service has promoted the principles of the *Mental Health Act 2014* (Vic)
- We need practice guidelines and training developed about how the service and the sector should conduct second opinions under the *Mental Health Act 2014* (Vic), in line with the principles in the Act and of procedural fairness.

From all safeguarding bodies, we need to ask the same two questions: (1) are you seeing human rights violations? (2) if so, what are you doing about it?

 $<sup>^{36}</sup>$  Section 68(2)(a) Mental Health Act 2014 (Vic). For a different approach taking into account sexual health implications and human rights, see: Maylea, C. (2019). The capacity to consent to sex in mental health inpatient units. Australian & New Zealand Journal of Psychiatry. <a href="https://doi.org/10.1177/0004867419850320">https://doi.org/10.1177/0004867419850320</a>

## Recommendations

- 16. Creation of a safeguarding oversight panel comprising of important stakeholders such as IMHA, MHCC, OCP, SPOS, AHPRA, MHT.
- 17. Legislative reform to require the Mental Health Tribunal to transcribe hearings and further promote the principles of the Act in their practice.
- 18. Mandated public sharing of data by all key stakeholders and safeguarding institutions
- 19. Creation of benchmarks by the OCP and MHCC, alongside OPCAT monitoring mechanisms
- 20. Public communication of powers under the Act from key safeguarding bodies, for example, including recommendations or directions given, to whom, and the follow up from/to services
- 21. A review into the Second Psychiatric Opinion service, coproduced by consumers
- 22. Creation of coproduced Office of the Chief Psychiatrist practice guidelines into Second Psychiatric Opinions
- 23. A review into safeguarding bodies and processes and whether they are effectively protecting consumer and carer rights