

# 2019 Submission - Royal Commission into Victoria's Mental Health System

## Organisation Name

N/A

## Name

Miss Paige Lerman

## What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

N/A

## What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

N/A

## What is already working well and what can be done better to prevent suicide?

N/A

## What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

"Speaking with service providers at one of the Commission community forums crystallised a central concern that I've spoken about with many consumers and carers: fragmentation of services. This concern encapsulates a few distinct but interrelated issues. The first is fragmentation between services. Many consumers receive clinical care in different catchments and engage a complex of social supports and community-based and clinical mental health services. Communication and, by extension, information is fragmented between these services. A consumer's experiences in one service may not be chronicled alongside their experiences in another. For service providers, this means spending unnecessary resources obtaining and providing information about their clients in order to have a complete case file; alternatively, it may mean working with incomplete information, which can lead to adverse outcomes for clients and families. For consumers, this fragmentation means they bear the burden of communicating the same information time and time again; alternatively, or eventually, it may also mean not communicating that information, leading again to an incomplete case file. This issue is not just one of practice and practicality, but one of in/justice; it not only leads to suboptimal care, but also has a negative emotional and psychological impact on consumers who are expected to be able and willing to recount past, oftentimes negative experiences. Simply put, the onus of quality care should not be put on consumers. The second issue of fragmentation is one within services. Clinical services are often structured such that clinicians rotate through consumers' care. With psychiatrists' biannual rotations, this means that consumers are charged with re-presenting their case multiple times. Those who become frustrated or shun this responsibility risk being seen as uncooperative. Again, this fragmentation has practical and ethical consequences, both encumbering the quality of care that can be delivered and received and negatively impacting consumers' experiences within and beyond services. Fragmentation within services and between services can impede both access to and delivery of mental healthcare of the highest quality. How can we remedy this fragmentation? I propose that Advance Statements represent a vital way

forward. Advanced Statements were introduced in the 2014 Mental Health Act as one of many mechanisms to promote supported decision-making, or the notion that consumers are capable of making autonomous decisions related to their care but may require varying levels of support in doing so. According to legislation, an Advance Statement is a document that a consumer can complete when they're well which will come into effect when they're unwell i.e. a patient under the Act. However, through my fieldwork I've found that Advance Statements are much more multifarious in their everyday usage. Consumers who are already on a Community Treatment Order (CTO) i.e. who are already patients will complete an Advance Statement in order to establish a legal basis for their treating team(s) to consider their treatment preferences. Advance Statements can also influence the outcome of Tribunal hearings, enabling consumers to request, for example, a CTO instead of inpatient care or assert their preference for a particular hospital. In other words, the boundaries of Advance Statement usage when and how consumers engage them, when and how they affect care is not fixed. This is a good thing. In spontaneous grassroots and not-for-profit initiatives, Advance Statements have demonstrated immense off-label utility in remedying service fragmentation while improving experiences and delivery of care. Imagine what could be done with sufficient funding, robust implementation efforts, and standardized procedures of completion, storage, and usage. Advance Statements should be incorporated as core business. In addition to fragmentation of information sharing between and within services, there is also an issue of fragmentation of values, with recovery-oriented and human rights-based practices, such as Advance Statements, being shunted to community-based care. Instead, clinicians should be held accountable for a) ensuring that consumers are given information about Advance Statements at discharge and b) engaging with consumers' Advance Statements and providing a reason for overriding them. I will discuss these issues and provide possible solutions in the space below.

a. Ensuring that consumers are given information about Advance Statements at discharge The question of when to engage consumers in Advance Statement completion is one that requires further research. However, speaking with consumers during my research, it seems that inpatient care especially when compulsory may not be opportune. This is because of the power asymmetries inherent in the patient-clinician relationship. I've spoken with many consumers for whom it was unclear whether or not completing an Advance Statement was a condition of their release. In other instances, consumers have expressed unease at the prospect of having a clinician assist them with the process, questioning the extent to which clinicians are adequately equipped with an understanding of recovery and supported decision-making for their support to be helpful. That said, more still have noted that they were never informed about Advance Statements during their stay or at their point of discharge. This could be rectified if Advance Statements (and Nominated Persons) were incorporated as core business, on par even with medication compliance and intermittent check-ups. Discharge protocol should include Advance Statements and there should be an accountability mechanism for ensuring that they are discussed with consumers as they're leaving clinical care. Such a measure could also be a vital remedy for service fragmentation, as it would connect consumers' inpatient experiences with post-discharge follow-up. Initiatives like Expanding Post-Discharge Support, which are already being rolled out, provide an opportune infrastructure through which Advance Statements can be prioritised and improve the continuity of care between services.

b. Engaging with consumers' Advance Statements and providing a reason for overriding them Current legal provisions grant psychiatrists broad discretion in the extent of their engagement and their decision to override an Advance Statement: according to the 2014 Act, they must have regard for a consumer's preferences and, if they choose to overrule them, are only required to provide an explanation upon a consumer's written request. This is problematic because many consumers are not informed about this responsibility and again, simply put, the onus of quality care should not be put on consumers. After leaving the

hospital, consumers are bound to have many responsibilities to attend to responsibilities that would be overwhelming for anyone, but could represent an added weight for someone who has just left the hospital. It is unnecessary and unjust that a consumer, after putting the time and effort into completing an Advance Statement, should also be made responsible for making sure their treating team properly follows legal provisions. It reinforces the issue of value fragmentation, where matters pertaining to recovery are shunted to consumers and community-based services instead of being reaffirmed by mainstream institutions i.e. clinical services and associated administrative and government entities. This could be rectified if psychiatrists/providers were held accountable for providing a written reason for overruling an Advance Statement. In terms of psychiatrists' engagement with Advance Statements, there also exists an issue of education and accountability. Many psychiatrists and other mental health service providers have noted that they were ill-informed about major changes in the 2014 Act. There seems to exist no requirement for Continuing Professional Development around supported decision-making and Advance Statements/Nominated Persons, and there lacks a standardised protocol around Advance Statement usage in clinical practice. In fact, just a few weeks ago I assisted in creating the procedure for clinical Advance Statement usage; this is five years after the Act has been formalised. While the 2014 Act represents a positive shift towards recovery-oriented and human rights-based care, the lack of institutional follow-up and implementation of these shifts is disappointing. There need to be robust efforts from leadership, government, and influential clinical figures to translate the immense progress of the Act into everyday practice. As mentioned, Advance Statements should be incorporated as core business for these purposes as well: to instantiate supported decision-making as vital to quality clinical care, to teach clinicians about the historic import of Advance Statements as well as how to use them in practice, to facilitate better communication and information-sharing between and within services, and to bridge the gap between the sets of values that govern clinical and community-based mental health care. A model for what Advance Statement usage could look like Consumers should be informed about Advance Statements whenever they interface with clinical services. This means at their point of discharge from inpatient care as well as when they engage services in the community. Additionally, community-managed services such as IMHA, MHLC, VMIAC, VLA, and OPA should continue facilitating Advance Statements and should also be given adequate funding and training to doing so. There should exist a standardised procedure for Advance Statement storage in a centralised place accessible to services from different sectors (provided the consumer's consent) and an affiliated standardised instruction for accessing the document. In terms of completion, consumers should be empowered to choose someone to assist with Advance Statement completion. This may mean an independent advocate, a peer or carer, a family member, or nobody at all. In any case, this process should occur over time and not be rushed, as it may be in clinical settings. Additionally, we should emphasise not only Advance Statements in their finished form, but also the process of Advance Statement completion as one which can foster personal recovery and improve the therapeutic alliance between consumers and their support systems (Swanson et al. 2006; Elbogen et al. 2007b; Easter et al. 2017). Additional training and funding should be provided for this purpose. In reviewing the 2014 Act, attention should be given to how Advance Statement legislation is structured. Currently, there is a finite distinction between treatment-related and non treatment-related preferences that follows lines of medical/objective and non-medical/subjective insights, with the former being clearly privileged over the latter. For example, in most formatting, treatment preferences are given their own space with everything else being grouped into additional concerns. Eastern Health exemplifies an impressive and not to mention, effective approach, wherein they facilitate Advance Statements with just a blank sheet of paper and allow consumers to share whatever information they feel is relevant/they want their treating team to

know about their lived experience. Peers and others are trained to identify preferences that have higher clinical relevance to increase the clinical utility of the overall document. Notably, this process tends to occur over many sittings. This blank sheet approach is important because it privileges the whole of lived experience on a common plane without starting from a premise of medical aspects of lived experience being more important than other aspects. Attention to seemingly incidental things like this are crucial for fostering a deeper growth in the values that drive services away from substituted decision-making and towards supported decision-making, away from value and informational fragmentation and towards unified, continuous care. Five years after their formal introduction, Advance Statements are still severely underutilised, with less than 3% of consumers having completed one. This is to the detriment of consumers and providers alike. Many barriers to Advance Statement usage are currently chicken-and-egg: consumers don't want to put effort into completing a document that won't be respected or utilised in practice, and clinicians can largely ignore the issue due to low prevalence and a lack of real accountability. The suggestions in this submission outline viable and empirically-informed approaches to addressing low uptake from both sides. As a final and overarching point, consumers must be included in this reform process. Not just one consumer, but many; and not just in peripheral roles, but as central players. In incorporating Advance Statements and other recovery-oriented, human rights-based practices into core business across all mental health sectors, nothing about us without us should be centralised too. Works Cited Easter, Michele M., Jeffrey W. Swanson, Allison G. Robertson, Lorna L. Moser, and Marvin S. Swartz. 2017. Facilitation of Psychiatric Advance Directives by Peers and Clinicians on Assertive Community Treatment Teams. *Psychiatric Services* 68(7): 717-723. Elbogen, Eric B., Jeffrey W. Swanson, Marvin S. Swartz, et al. 2007b. Effectively Implementing psychiatric advance directives to promote self-determination of treatment among people with mental illness. *Psychol Public Policy Law*, 13(4): 273-288 Swanson, Jeffrey W., Marvin S. Swartz, Eric B. Elbogen, et al. 2006. Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons with Severe Mental Illness. *American Journal of Psychiatry* 163(11): 1943-1951."

**What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?**

N/A

**What are the needs of family members and carers and what can be done better to support them?**

N/A

**What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

N/A

**What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?**

N/A

**Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

N/A

**What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

"There should be a top-down push for more education around Advance Statements and other instruments of supported decision-making, as well as the history of recovery-oriented activism. Ideally, mental health providers should learn about recovery-oriented and human rights-based approaches early on in their training, with these approaches being taught as a valid way to make sense of one's lived experience and measure personal progress. Early and continued education would help link the values that frame clinical and community-based mental health care, and could make room in psychiatric discourse for non-medical insight into lived experience to be valued alongside medical metrics of progress. Such education should also avoid presenting these issues antagonistically e.g. in terms of psychiatry and anti-psychiatry. Powerful entities should recognise recovery-oriented care and its precedents as valid, albeit different from stringently biomedical care, without marginalising these movements or making them peripheral responsibilities of community-based services."

**Is there anything else you would like to share with the Royal Commission?**

N/A