

Submission to

The Royal Commission into Victoria's Mental Health System

by [REDACTED]

1. Our qualifications to comment on Victoria's Mental Health System

Our son was diagnosed with schizo-affective disorder in 1997, at the age of 18. We have 22 years of experience of his and our interactions with the system.

2. Where the system has failed our son and ourselves.

The system runs on a medical model: a person becomes ill, is treated in hospital and discharged. By and large, though with some exceptions, here the system's responsibility for the person's health is seen to begin and end.

For illnesses such as acute appendicitis this seems an adequate model. The illness presents, is treated and cured, and the person resumes life as normal.

For the most part, mental illness is chronic with episodes of acuteness. The system appears to see these episodes of acuteness as the illness, and in particular as what needs to be treated. This view is shallow and inadequate. It ignores important aspects of the problem, among which are:

- The treatment does not effect a cure. For a person with a psychotic illness treatment with neuroleptic drugs merely dulls the person's connection with their psychotic thoughts. It also dulls the person's whole range of abilities to deal with the problems that present in their life. Taking these medications is in general a necessary step.
- A self-perception of being a victim of circumstance. In order to improve their situation people suffering from these illnesses need to be able to see themselves as active contributors to the continued improvement of their mental health and wellbeing. This is no small problem.
- In general (excepting cases of serious family dysfunction) families are crucial to a person's improved mental health. They are usually committed long term to helping their family member in the community in various ways. They are especially needed as these illnesses often lead to sufferers having little or no support network amongst friends. Unlike the acute appendicitis patient, their discharge from hospital following treatment does not mean they can return to dealing with life as normal. In some cases, such as our son's, they come to see the system as part of the problem. With reluctance, we find ourselves forced to agree with this view.

Improvements in the condition of people with chronic mental illness need to be seen as occurring gradually, contingent on continued and effective support from the person's social network. The person needs help to progress beyond the immediate family which usually provides the first line of that person's social support network. Family often remains crucial because the person suffering from these illnesses has 'burnt off' many friends by antisocial behaviour towards as a consequence

of their illness. The system pays lip-service to the importance of family and carers, all the while operating on the medical model.

This is in no small measure because the system is grossly underfunded, and can't afford appropriate outreach and community support programs and staff. Instead we have experienced a culture of defensiveness against families on the part of services. When we approached the service our son is associated with asking for the organisation to cooperate with us in the interests of our son's health instead of working against us, their response was dismissive.

We wrote to the [REDACTED] expressing our frustration with this attitude of the service, and we include this letter (see Appendix) in this submission because it details briefly some of the sorry history of our attempts to engage with the service in our son's interest. Only with the intervention of [REDACTED], as a result of this letter, were we able to win a small, token concession from the service – they gave us the name of a person we could ring if we were worried about our son's mental state. That is, we no longer had to contact triage in the first instance. This small but welcome result was the fruit of two and a half years of advocacy. In a decent system this would have been achieved by a single phone call. Instead the service had to be dragged kicking and screaming.

Support services should provide opportunities for people with mental illnesses to make connections in the community and to access part-time work because it is vital to help them to overcome social isolation, feelings of failure and shame and loss of confidence in finding work. The decision in Victoria to bring such services under the NDIS umbrella means that people who, like our son, do not apply for NDIS consideration have simply lost these services. They are now even more isolated; less able to find any kind of work. This decision should be reviewed with a view to counteracting the contraction of availability of opportunity it has meant for people in need.

3. How we would like the system to change

Ideally the system would be seen, by itself, by the person and by the person's family and friends, as a part of the person's support network.

1 Caseworkers

A basic feature of a better system than the one we have would be the **provision of a caseworker**, as a matter of course, for each person with a severe mental illness who is treated by the service in his or her area. Such provision would recognise the likely continuation of serious health and social difficulties for those suffering from mental illness. Our current experience is that when our son becomes psychotic the mental health service tells us that he is presenting as 'a new case', which makes no sense at all.

An assigned caseworker would be charged with keeping in contact with the person, communicating with the service about the person, and, as appropriate, with the person's family and carers in the community. They would be adept at encouraging the person to be engaged in the project of improving their own health, and at helping them to provide opportunities for constructive social engagement for themselves. Such caseworkers would be appropriately remunerated for their highly developed interpersonal skills. At different times (regrettably relatively short times) our son has been fortunate in having such a person. One such person, for example would visit him occasionally, perhaps playing a game of golf with him, and talk to him about how he was managing with his problems in life. The short but lucky period in which this happened showed us a way in which the system could be much more productive than it now is.

This is a simple change which would lead to other more sophisticated changes in approach once it was put into effect.

We ask the Royal Commission to recommend that caseworkers be assigned to every person with chronic and severe mental illness.

2 Review of the decision to require NDIS participation in order to access social services.

As we remark above this decision has closed off opportunities to many who don't wish to use NDIS, thus increasing the burden of mental illness on families and on the state. We need a more open and sensible system.

3 Amendment of the terms of the Mental Health Act 2014

When our son has been admitted to hospital in an acute psychotic state he has typically regarded his friends, his extended family and the system itself as enemies arraigned against him. He usually instructs the system not to contact his parents, and the system unquestioningly complies. This has extended to refusing to advise us whether or not our son has been discharged or of the date or the conditions of his discharge.

In a meeting we had with the director of the service, his deputy and a representative of [REDACTED] arranged after prolonged resistance from the service, the director advised us that he would comply with these requests from our son even though doing so may be deleterious to his health.

In our view this is an unethical position for a medical service to adopt.

It was justified with reference to section 346 of the Mental Health Act 2014 (Disclosure of health information) which directs services not to disclose information to family or carers if the person in question expressly forbids it. The Act should make it clear that for this directive to apply the person in question must be of sound mind at the time he or she vetos communication with family or carers, and that in any case the ability and need of family or carers to help the person when he or she is discharged should be an overriding consideration.

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