

Submission to Mental Health Productivity Commission:

Who we are-

The North-West Loddon Mallee region of Victoria that Loddon Mallee Mental Health Carers Network (LMMHCN) covers is 25% of Victoria's area. It is contended that this region of Victoria is the most poorly serviced for mental health. The vast distances, low population densities (5% of Victoria's population) and extensive pockets of low socio-economic disadvantaged communities all combine to form considerable challenges in accessing mental health supports and services. This is demonstrated by the fact our region has a higher number of registered mental health clients (16.5 per 1000) compared to the rest of Victoria (11.3 per 1000) (Ref: DHHS 2016)

The LMMHCN has sought to connect with those with mental illness and their carers/families to help identify their critical needs and are happy to submit the following submissions made by carers within the LMMHCN region.

CARER ISSUES:

MARYBOROUGH & DISTRICT MENTAL HEALTH CARERS SUPPORT GROUP:

- A patient is discharged with no follow-up to services. No questions asked as to whom to contact or if suicidal, given a taxi fare and off you go!
- Impossible to get assistance after hours or at weekends.
- Since the NDIS was introduced in community mental health services and programs ceased for those not in NDIS and for those in NDIS they can't find services close to home and the waiting list is 3wks to 3 months causing a lot of anxiety for both consumer and carer.
- Long waiting lists for psychiatrist appointment (2-3 months)
- GP's won't take emergency bookings – person was told he had to wait weeks forcing him to the emergency department in Ballarat because Maryborough didn't have a doctor on call qualified to deal with a psychotic patient, this caused such anxiety for the carer because she was alone and felt she was in danger for the whole 1 hour trip.
- Carer has lost her long time support worker and their daughter has lost her case-manager to NDIS – both have gone downhill in their health due to this loss.
- Don't have internet so all of the self- help and information is no good to me.
- Used to enjoy a week long respite each year paid for by carer support services but now there is nothing, carers are left to deal with everything on their own. Bring back respite for carers!
- Carers and their loved ones are tired of having to repeat their story to new workers/services/GP's etc. – it's traumatic to have to re-live what is a very sad time in their life.

- Even though we are in the NDIS we have to travel to Bendigo or Ballarat to receive the services we should have in our own town, why do people have to suffer because they live in a rural town.
- In 2012 the 10 year road map was released, 48 pages singling out what needs to happen; **2019 and they** (the government) **are still asking the same questions!**
- 2012 carers were told the support would be available to assist in mainstream health and well-being; **2018 it was all taken away!**
- Carers are still suffering isolation and poor health.
- Higher emergency department attendance is due to fewer people being able to access timely community-based support services, all at the cost of sometimes human life and/or quality of life compounding cycles of disadvantage for people experiencing mental illness.
- Small town syndrome (stigma) for carers who live in rural towns is very real; they suffer in silence and eventually become a shadow in their own community.
- Carers need to be given the opportunity to be included, listened to and recognised as a valuable resource not to be taken for granted.
- Losing valuable experienced trained people who supported a variety of participants and programs and practical activities has led to the loss of valuable social interaction for many; carers/consumers are frustrated, angry and have a feeling of helplessness.
- It is important that we fight to retain carer support services and the many programs which were proving to be so successful and so vital to the overall well-being of all concerned.
- Carers and consumers want face to face interaction not a phone chat or told to go on-line for help.
- Families are reluctant to call the CAT team because they are accompanied by police where many of them are not trained in mental health and could be 'trigger happy'; a mental health nurse on call could be a better option.
- Carers need to know what prescriptions their loved ones have been prescribed, patient privacy should not take precedence over patient safety.
- If you retain the lack of services we see today then government should be prepared for long term implications when ageing carers require care themselves.
- Will mental health sufferers be allocated special accommodation with specialist staff or will we be returning to the large mental health hospitals of 1980?

KERANG MENTAL HEALTH CARERS SUPPORT GROUP:

To whom it may concern.

I am the convener of the Kerang Mental Health Carers Group, I have held this role for 10 years, during my time I have seen very little progress for some areas of carer care.

- Caring is a 24/7 job, so why shouldn't we have the right to know what is going on with our son, daughter, husband, mother?
- As carers we need to be made aware of their medication treatment and discharge plan.
- Travel is an issue in rural areas when there are no services
- Housing is a big issue for carers if their loved one doesn't live with them.
- Funding for support groups, these will die if the groups are not supported financially.

In a nut shell, please help our carers function so the consumers can enjoy a better life

Pam Lingenberg

Kerang Mental Health Carer Support Group

DROP-IN CENTRE – WYCHEPROOF:

- For rural patients the necessity to have to travel to regional towns or the main city Melbourne for treatment is added anguish to the patient and carer plus the added expenses of travel.
- On discharge from hospital there is only phone support or again travelling to a regional town.
- Face to face support is limited to a few service providers and places are very limited.
- Carer support is also limited and respite is for only the lucky few.
- Travelling is a major expense - fuel as well as meals and drinks, one hour to two hours travelling is the norm to attend an appointment. There is no public transport to use that would be suitable to meet appointments.
- Carers are depended upon to supply the daily needs of a patient even if he/she is an adult and would prefer to be independent.
- Housing is not readily available putting pressure on the patient to move to a regional town and lose family support, to be able to access professional support. Why do they have to move away from familiar surroundings and family and friends?
- Stigma is a large problem in rural communities affecting both patient and carers, causing the carer/patient to be isolated and retreat from the community activities.
- Training for medical staff at local hospitals would be an option and more patient friendly when a crisis arises and also on the return of the patient to home to support them in the recovery. This also would be a support for carers and could alleviate some of those trips to regional centers.
- Return some of the services to rural areas, travelling are an expense but if they have more than one client it could be a huge benefit to the clients plus a shared expense minimizing the cost.
- On line services are used in some cases and can be beneficial, but not everyone has reliable access to the internet or mobile phone service. So it is not helpful to be told that phone help is available. We need face to face consultations.
- Carers are part of the care and recovery so are important people, but are often excluded, privacy is important but when a patient is in a Mental Health crisis they are unable to remember instructions. Even written discharge plans would be a help provided they are also given to the carer.

PERSONAL STORY FROM A CARER/MOTHER:

Involuntary Order - Trauma in Mental Health Services ruined my son!

Entering a mental health secure unit was the most traumatic experience not only for our son but for my husband and me because we were responsible for him being admitted involuntarily.

It started with us calling the CAT team when our son became psychotic but instead of the CAT team attending they sent the police who arrived guns drawn, they threw our son into the back of a divvy van with him screaming threats to harm, they didn't even search him until he arrived in Bendigo some 5 hours later where a knife was found in his pocket! Initially the police took him to our local hospital where he had to wait 4 hours cuffed to a chair (still in a psychotic state) while awaiting a doctor who could certify him; they then took him in the divvy van to the Alexander Baines Centre (ABC) in Bendigo where he was placed in isolation in a padded room for 24 hours.

We weren't informed as to what was happening to him, each time we would ring up we would speak to a stranger who would say *"we cannot share that information with you; you will have to speak to his treating team"*. A week went by before we were given permission to visit, the reason they (the experts) gave us was that he was still aggressive toward seeing us. Another 3 weeks went by before a treating doctor diagnosed him with schizophrenia, I remember at the first meeting with the treating psychiatrist when he said our son could recoup at home; we were overly concerned that he still had anger issues toward us which threatened our safety, we asked the psychiatrist if he could suggest where he go for treatment and he said *"he has a home and a family where else would you suggest he go"*? We had no idea what to do and there was no advice forthcoming we were left to scramble through the maize totally alone.

It wasn't until his tribunal hearing that we were given a voice albeit a whispering voice we told them of our safety concerns so his discharge was put on hold. Our son was forced to spend 6 weeks at the ABC where all they did was administer medications without any explanation; he was then discharged from ABC and transferred to Vahland House where he was to receive further treatment for a further 6 months; he was constantly told that being involuntary meant he had no choice but to obey the treatment prescribed by a somewhat heartless psychiatrist, in his eyes he was imprisoned for being unwell!

After he was discharged he was once again ordered to attend the Mental Health Community Services in Maryborough; he was very sceptical about being forced to see a psychiatrist and chose his words very carefully for fear they may send him back to the ABC, to say the next twelve months was difficult for him is an understatement and his paranoia grew out of control, it consumed his daily living and before long he was just the shell of the person he once was, our lives were being consumed by our son's mental illness and any thoughts of a happy retirement went out the window and our plans and dreams went too!

The psychiatrist visits the Maryborough Mental Health Community Services ½ day each fortnight so the time he spent with our son was minimal just enough time to make sure his prescription was up to date!

Our son still lives with the trauma daily not only does he suffer schizophrenia but social anxiety, mistrust of anyone with authority (including his GP), extreme paranoia, he has lost his self-esteem and drive for life that he once had, the only benefit he received from this experience is a regular prescription of Zyprexa (Olanzapine) and a monthly injection of Risperdal that help to keep him from relapsing (we think) not once has anyone suggested that he be re-assessed.

He rarely goes out, he won't go to places where there are crowds, and his life has been 'on hold' because of the way he was treated initially when he was treated like a criminal by the so called professionals who were employed to take care of him!

Do you get a 12 months involuntary order placed on you if you have cancer?

He would qualify for the NDIS but because of the trauma caused there is no way he will want to re-live those traumatic years by answering the multitude of questions NDIS ask; so NDIS is out of the question which leaves my husband and me who are in our 70's to 'keep on keeping on' and hope for the best.

Name withheld
Central Goldfields

PERSONAL STORY FROM A CONSUMER OF MENTAL HEALTH SERVICES:

The last time I went into hospital was just as scary and lonely as the very first time. I remember the coldness of the bars on the windows and the big double-bolted doors. The sterility of the hospital and the weirdness of the other patients all frightened me no end.

I fought the staff over medication and was unceremoniously held down and given an injection I didn't want. I hated the medication and all the side effects and didn't think that I was abnormal. It wasn't till I got better did I understand just how sick my thoughts actually were.

The fear I felt in the hospital was very real and scary. I was totally alone and isolated from the world and going back into society was daunting after the security of the hospital, and the routine you soon get in to is easy and being back with normal people who didn't understand me was terrifying.

It's not an easy time, but I am glad for the staff who looked after me and got to know me, and to the patients, as well as my husband who has been my rock. I am forever grateful to them all.

Name withheld
Central Goldfields

This submission focuses on a multitude of problems where mental health services and carer support services in the Loddon Mallee Region needs immediate attention.

We thank you for the opportunity to put forth our submission.

Yours faithfully

LMMHCN Committee of Management

