Loddon Mallee Mental Health Carers Network submission to Victoria's Royal Commission into Mental Health

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mental health
carers network

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BACKGROUND

The Loddon Mallee Mental Health Carers Network (LMMHCN) was formed in 2010, later becoming an incorporated community based organisation in 2016 with a strategic focus *"to provide a strong, independent and collective mental health carer voice for the Loddon Mallee region".*

The north west Loddon Mallee region of Victoria that the LMMHCN covers is large (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 1,000) compared to the rest of Victoria (11.3 per 1,000).

The LMMHCN has sought to connect with those with mental illness and their carers, help identify their critical needs and then work toward policy, system and process improvements. LMMHCN seeks to achieve this by working with existing government agencies and organisations within the mental health sector.

LMMHCN Committee of Management consists of persons from across the region collectively with the diverse range of skills, experiences and qualities needed overall to be an effective representative body. LMMHCN believes it helps fill a gap that has existed in understanding community mental health needs in this region.

In 2016 the LMMHCN commissioned two research projects to capture the voices of mental health carers across the ten Local Government Area's within the region (Mildura, Swan Hill, Campaspe, Buloke, Gannawarra, Loddon, Central Goldfields, City of Greater Bendigo, Mt Alexander and Macedon Ranges). One area of research was undertaken to report on Carer's experiences (the first ever region-wide consultation with mental health carers), while the other project focused on 'The Perspectives of Carers on Housing Needs and Mental Illness'.

LMMHCN were provided the opportunity to meet with Minster Foley during the Terms of Reference consultation in Bendigo in January 2019. We noted – with disappointment – that none of the proposed 10 themes of the Royal Commission mentioned carers or families, even though they have long been recognized as playing a crucial role in supporting loved ones living with a mental illness.

The report "The economic value of informal mental health caring in Australia" by Mind Australia: Summary report, 2017 validated the huge effort mental health carers contribute. The value of this caring role effort outstrips the actual expenditure on mental health by government each year by a considerable margin. It is obvious that carers play a huge role and support for them is critical to any mental health services program. Hence the LMMHCN unashamedly makes this submission based around the key priority areas from the Victorian Carers Strategy 2018-2022.

INTRODUCTION

Our submission has primarily been shaped by making reference to the following documents:

- Victorian Government's 'Recognising and supporting Victoria's carers – Victorian Carer Strategy 2018-22'
- LMMHCN 'The Perspectives of Carers on Housing Needs and Mental Illness (2016)'
- LMMHCN 'Carer Consultation (2016)'

The Victorian Carers Strategy outlined 5 key priority areas:

1. Carers have better health and wellbeing
2. Carers are supported in school, study and work environments
3. Carers can access support and services that meet their needs
4. Carers have less financial stress
5. Carers are recognised, acknowledged and respected

In Part 1 our submission will, therefore, focus on these 5 areas and our perspective of how well these are being addressed. Discussion will also include direct quotes from mental health carers from across our region. We will also respond to the 11 questions posed by the Commission in Part 2.

PART ONE - DISCUSSION

1. CARERS HAVE BETTER HEALTH AND WELLBEING

Without continuity of care and seamless transitions between the various parts of our current mental health system, care recipients continue to cycle in, out and around the system. The bulk of care is still being provided by families and carers who despair at this repeated cycling, particularly as it does not offer much hope of genuine recovery. An individual who is chronically unwell (e.g. constant self-harming or suicidality) may receive support by being admitted to hospital but will quickly be discharged without any real resolution of the reason they were feeling that way to begin with; discharged back to people who are trying to support them without the skills and training to do so. Some people who have presented to hospital have had extremely negative experiences and, therefore, both they and their carers are reluctant to then seek support again. In these instances, carers are paying the price for the lack of government funding, at a very high cost to their own health and wellbeing.

There is a distinct lack of therapeutic services within the system, requiring individuals and/or carers to go through the process of going to a GP, getting a mental health plan, sourcing a (hopefully) suitable therapist, paying exorbitant gap fees, then being expected to have often complex issues resolved in ten sessions. This is all on the assumption that the person experiencing the mental illness is even willing to be involved in this process, and that GPs are accessible. Carers can access six free counselling sessions through Carers Victoria but this also is totally inadequate. Carer needs must be viewed separately from the person they care for; their needs are different, their loved one may not choose to seek support from services, and carer needs may be quite intensive depending on their particular circumstance.

Local research with mental health carers in 2016 confirmed that consumers can also have active caring roles. The LMMHCN Mental Health Carer Survey in the Loddon Mallee Region found 33% of carers experienced mental health issues as a result of their caring role. This reflects issues raised recently by Carers Victoria regarding the need for recognition of carer needs and complimentary data collection by mental health service providers.

Frequently the person living with the mental illness will have a co-occurring condition, with each condition presenting differently for each person. All too often services refer people on because they are 'too complex' or 'too risky', yet carers are expected to cope regardless.

Many carers are exhausted, confused and frustrated at the amount of change in the sector over the last few years. Recommissioning in 2014, NDIS in 2017, and now the incoming Integrated Carer Support Service have resulted in less services, loss of networks, and disconnection from those they trusted. This is particularly evident in rural and regional areas where relationships were formed over time and, with organizations withdrawing and NDIS providers not replacing them, consumers and carers alike are feeling isolated and abandoned more than ever.

By far the biggest issue facing carers is the lack of appropriate accommodation for their loved ones. This is a persistent and pervasive issue which needs critical and immediate action. Without it many carers are forced to house their loved one, regardless of the toll it takes on their wellbeing, finances, employment, social and community participation, and other relationships. The issue of housing is discussed further in point 4.

Some quotes from mental health carers:

> *"Carers have lost their 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."*
>
> *"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 was a very sad time in their life."*
>
> *"In 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."

"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."

"Losing valuable experienced trained people who supported a variety of participants and programs and practical activities have 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."

"Retain the lack of services we see today and government should be prepared for long term implications when ageing carers require care themselves."

"Don't have internet so all of the self- help and information is no good to me."

"Carer support is also limited and respite is for only the lucky few."

"Stigma is a large problem in rural communities affecting both Patient and Carers, causing the carers/patients to be isolated and retreat from the community activities."

2) CARERS ARE SUPPORTED IN SCHOOL, STUDY AND WORK ENVIRONMENTS

We would question how this can be achieved without a mental health system that is accessible, cohesive, responsive, reliable and holistic. Carers needs are still considered as secondary; as a 'by product' of the person they care for. A decent mental health system would be comprehensive enough to support people at all stages of their recovery, thereby allowing carers to pursue education, work etc… However, this is not currently the case and carers can't always make a commitment to workplaces or schools. These types of environments are not likely to be flexible enough to meet the needs of carers. A carer who is currently studying at TAFE has had to take numerous days off to attend appointments for her son, has had to regularly request assignment extensions, which in turn place greater stress on her as she has even less time to attend to her studies. Lack of qualifications or opportunities to gain additional skills impacts greatly on carer's financial capacity; the illness may not only affect the income of the individual but also the income of those around them.

Carers also sometimes need support in the home to increase opportunities to connect with other family members, attend to other needs, have a break away from caring responsibilities, and generally reconnect with themselves.

Some quotes from mental health carers:

> *"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."*
>
> *"Carers are usually family members, and they are constantly torn between their role as mother, father, sibling, son, daughter, grandparent, uncle, or aunt, and their carer roles."*

3) CARERS CAN ACCESS SUPPORT AND SERVICES THAT MEET THEIR NEEDS

Available evidence confirms that the role of carers is vital to support the management and recovery of people with mental illness and their ongoing wellbeing. Carers may be involved in monitoring symptoms, ensuring medication compliance, consumer advocacy and access to professional support for a person with a mental illness. The price of caring can be very high, with mental health carers at a greater risk of negative physical and mental health effects, with working carers who provide high levels of care notably vulnerable. The LMMHCN 2016 research with Mental Health Carers across the Loddon Mallee Region (LMR) highlighted that the caring role can often result in caregivers experiencing a range of significant issues and barriers to accessing mental health services:

- *34% could not access mental services, in-patient hospital beds, a psychiatrist, a GP or a psychologist in the previous 12 months when their loved one became unwell.*
- *70% indicated that the person they care for had another condition or disorder in addition to their mental health issue.*
- *51% travel more than 100km (round trip) for specialist mental health services with 18% travelling more than 200km.*
- *90% of carers who filled in a survey were personally facing issues/challenges as a result of their caring role.*
- *89% of carers shared that they had felt anxiety/stress as a result of their caring role; and*
- *33% of carers experienced mental health issues as a result of their caring role.*

LMMHCN carer consultation research in 2016 showed that 45% of mental health carers were 'slightly satisfied', 'dissatisfied' or 'very dissatisfied' with the quality of service/support the person they cared for received in the past year. Furthermore, only 43% of carers understood the service system that supports the person they care for 'a little' or 'not well at all'. There is wide acknowledgement that the current system is fractured and lacks consistency of communication between the 'silos': one example of this is private psychiatrists not sharing information back to GPs, even when they have been the referring doctor. How is a GP expected to maintain a professional standard of care with such a lack of critical information?

Carers living outside major cities are more likely to report strong social networks and to know someone they can ask for information and advice. This is important because carers in regional and rural Victoria are less likely to have health and support services nearby and may need to rely more on those local networks.

However, carers in outer regional areas experience higher rates of disability or long-term health problems. They have lower employment rates than carers in metropolitan areas. They are more likely to live in a jobless household and experience greater financial hardship. Services need to be responsive to these additional needs of carers in rural and regional Victoria.

There has been much uncertainty around future supports for mental health carers within the new NDIS environment. LMMHCN note the transition of psychosocial rehabilitation services in Victoria to the NDIS, and the call by Victorian community mental health sector for $50 million each year to fulfil the needs of those with mental illness who are unable or unwilling to access the NDIS. Carers of people with poor mental health are likely to be significantly impacted as funding for the Mental Health Respite: Carers Support (MHR:CS) program, which was the second highest funded carer support service in 2015-16, has been committed to roll into the NDIS. Psychosocial rehabilitation services can significantly support the independence of consumers and have been a key component of the service teams carers liaised with. Carers are concerned the absence of psychosocial rehabilitation services in rural Victoria will result in an increased reliance on informal support to meet the independence goals of consumers they care for in circumstances where this is not often possible.

Valued services and supports such as Mental Health Carer Support Services and Carer Support Groups in rural areas are also operating in a context of regional GP shortages. GP supports were rated as the most valuable (49%) by carers surveyed across the LMR, followed by Carer Support Groups (46%) and the Carer Support Service (35%). These three services play a significant role in the provision of information which is helpful to Loddon Mallee carers in their role.

Services are becoming even less accessible since the roll out of the NDIS, and the forthcoming transition to the new Integrated Carer Support System (ICSS) in September. The Carer Support system that has been in place has, over the last few years, gradually had funding reduced. Both of these changes have had a fundamentally negative impact for service participants and their carers. For example, a successful (and much needed) Carer Hub in Mildura will likely have to close due to no ongoing committed funding support. Furthermore, our own network can only be sustainable through continued financial support of regional health organizations. Without their valued support we would not be in a position to give voice to the needs of mental health carers in this vast region of Victoria that we represent.

Some quotes from mental health carers:

> *"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 3 weeks 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."*
>
> *"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."*
>
> *"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."*
>
> *"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."*
>
> *"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 centres."*
>
> *"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."*
>
> *"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!"*

4) CARERS HAVE LESS FINANCIAL STRESS

Unless we create an expansive and fully funded system that can operate in an integrated way with other systems (i.e. housing, employment, health, AOD), then carers and families will continue to be financially and economically disadvantaged in their efforts to keep their loved ones as safe and well as possible. For example, if an NDIS participant is admitted to hospital their support is suspended; this never used to happen under the former community mental health system, participants' could remain connected to their worker which would hopefully result in a smoother transition from hospital back to the community. However, even under the previous system this was not consistent due to a frequent lack of communication between the various parts of the system. Of particular concern is the lack of inclusion of families and carers in the discharge process, and transport to and from services. There is an expectation that carers are available 24/7 and have no other obligations or responsibilities, and have funds readily available to travel hundreds of kilometres on a regular basis. Our experience has also shown that the Carer Support Fund has increasingly been used to cover everyday expenses and basic needs, rather than things such as respite or something that can really assist carers sustain their caring role.

Housing has long been highlighted as a particular issue in our region and was shown through our research to be the highest priority mental health service need. It is widely recognised that, without appropriate housing, managing a persons' mental health needs is almost impossible. Only 17% of respondents in our research owned their own home. The remainder were either dependant on living with family, or having to try and secure social, public or private rental.

Apart from the shortage of public and social housing stock generally, the stigma of mental health is a formidable barrier to securing any sort of rental housing. Further, in rural areas often any available housing is inappropriate given its remoteness from supports and mental health services. Over the last 12 months this lack of appropriate accommodation has been our main strategic focus; we have advocated and spoken with key stakeholders to move this project forward. We are actively seeking a sector organisation that has the capacity, along with community support, to drive the development, building and operating of a suitable housing model. Currently there is no pathway to achieve mental health housing. Government assistance is required to provide this pathway.

Some examples of need are:

- Separated male in his 40's schizophrenia, history of cardiac issues having to live with his elder brother in Echuca as no other accommodation options available
- Sibling brothers living in a remote town with their grandmother very few supports, constantly have social issues including substance abuse due to limited accommodation issues
- Aboriginal male in his 40s having to live in hostel type accommodation, regular relapse of his psychosis due to poor accommodation and lack of housing support
- Male in his 50s living in a caravan park, unable to continue living with his brother due to social issues caused with wife. Caravan park in a small town contributed to support issues
- Separated male in his thirties with psychosis having to live with his mother due to not being able to afford other accommodation
- Separated male with Bi polar living with his separated partner small town due to no other accommodation options that are affordable

Some quotes from mental health carers:

> *"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."*
>
> *"Travelling is a major expense, fuel as well as meals and drinks; one 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."*

> *"Return some of the services to rural areas, travelling is an expense but if they have more than one client it could be a huge benefit to the clients plus a shared expense minimising the cost."*
>
> *"Even in 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."*
>
> *"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?"*
>
> *"Will mental health sufferers be allocated special accommodation with specialist staff or will we be returning to the large mental health hospitals of 1980?'*

5) CARERS ARE RECOGNISED, ACKNOWLEDGED AND RESPECTED

Co-design and co-production are in policies at State and organisational level but not widely applied in practice. At best there may be a 'reference' group, at worst there is tokenistic or no 'consultation'. Focus is still given to the larger cities and towns within the region, with carers in outlying areas not provided the same opportunities to contribute. Similarly, the National Mental Health Standard related to Carers may be being met through Quality Audits, but our evidence strongly suggests carers continue to be neglected and not considered part of the 'care team'. Audits can only capture a very small percentage of client and carer experiences and we would like to see National Mental Health Standards monitored in far more detail than happens currently. Our research showed that only 41% of mental health carers in our region were 'often' or 'always' included by professionals, while only 26% had any assistance from professionals to support them in their caring role.

Despite the excellent work done by peak bodies such as Tandem Carers and VMIAC, they don't have a high profile in some of the regional areas. Expecting these organizations to be able to represent the entire state with small teams and limited funding and resources is an unreasonable expectation. For genuine representation of regional and rural carers you need representatives who live in, and understand, these communities. Although the LMMHCN attempt to fill this gap in some way, and we have a strong alliance with Tandem Carers, we rely on volunteers for our Committee of Management, and funding from local health providers to continue our work.

Even where carer consultants are employed on staff, they face enormous challenges in trying to embed carer inclusion into the workplace culture. Carer Consultants and Carer Peer Support workers operate separately from the mental health clinical team, yet another silo. It is unrealistic to expect clinicians, who already have excessive case loads, to be required to be family inclusive if they only have capacity to be crisis driven. Co-location and integration of Carer Support staff with the clinical teams would allow them to support and learn from each other, and ensure information is shared not only between the teams, but with patients and families. For instance, our local health service has a comprehensive 48-page 'Patient, Family and Carer Guide Service Guide' yet many patients and carers have never heard of it, let alone received a copy of it. This guide makes several statements pertinent to carers and family:

- *"Treatment will be based on decisions made collaboratively between the clinical treating team, the patient, their family/carer and anyone else involved in providing care."*
- *"The patient and their family/carer are supported to ask questions and have any concerns addressed."*
- *"Family/carers should expect to remain informed and involved in the care and treatment planning processes from entry to the service to discharge."*

Unfortunately, our experience shows that genuine consultation with, and inclusion of, mental health carers is the exception rather than the norm. One carer, whose adolescent son has had multiple admissions and almost weekly presentations to the Emergency Department, had never seen this Service Guide until a week ago when it was provided by a mental health carer support worker who had stumbled across it, even though that worker has been in the sector for 10 years.

Carers report that over the past year, their concerns for the person they care for have not been well listened to. General practitioner's ranked highest with 66% always or often listening, and community workers ranking second at 48%. Other professionals were seen as poor listeners with psychiatrists at 39%, mental health nurse 37%, and psychologists 30%. Community workers also ranked highly as a source of information, below GPs and designated carer support services/groups but well above mental health nurses, psychiatrists and counsellors.

Carers of people with a mental illness often face unique challenges. Mental illness can be unpredictable, episodic and less visible to the community, and the role of a carer can go unrecognised or be misunderstood. Mental illness can be stigmatised, particularly in some culturally diverse communities, stopping people from accessing the support they need. Mental illness is different for everyone. Some people with a mental illness can be well most of the time but have times when they need a lot of support. Carers of people with a mental illness can feel shut out of meaningful discussion with psychiatrists or other mental health professionals because of client privacy. This can make caring more difficult.

As the sector transitions to the NDIS and we stand to lose around 1,000 community mental health workers in Victoria, the previous two points become even more statistically relevant. Mental health consumers and carers require time to develop trust and open communication with services; fundamental elements for organisations in being able deliver a quality service to them and support recovery. Mental health carers in the Loddon Mallee region have taken years to understand how the service system operates, and who the key contacts are in their respective local towns. Carers have fought hard to be recognised in their own right and the LMMHCN are proud of our record in participating in mental health networks across the region. However, these networks and connections are rapidly disappearing as we go through the transition to the NDIS. Community mental health workers are unable to sustain facilitation of these networks and carers are struggling to retain connections to workers and organisations they have built trusted and reliable relationships with. As communication channels between mental health carers and service providers evaporate, carer's ability to have a voice through these networks also diminishes.

Some quotes from mental health carers:

> *"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!"*
>
> *"Carers need to be given the opportunity to be included, listened to and recognised as a valuable resource not to be taken for granted."*
>
> *"Carers need to know what prescriptions their loved ones have been prescribed, patient privacy should not take precedence over patient safety."*
>
> *"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."*

PART TWO – RESPONSE TO THE COMMISSION'S QUESTIONS

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

- Educate GP's, medical centre staff, ED staff, first responders, mental health workers. One bad experience can cause many years of stigma and discrimination for the patient
- Put stigma on the same platform as bullying
- Mental health and physical health should be viewed and spoken of as the same
- Make access to support services easily and readily available in smaller communities throughout the Loddon Mallee region (Non NDIS & NDIS participants)
- Ensure transition through various parts of the system are seamless
- Continuity of care and trusting relationships are a key to recovery
- Continuity relies on a well skilled, committed and recovery focused workforce
- Ensure all parts of the system have a genuine recovery focus
- State and Federal Governments work collaboratively
- Differentiate between the needs of the person living with a mental illness, and those of carers/families, whilst still recognising and respecting the relationship between them
- Incentives for health, as well as mental health, services to locate in rural and regional areas
- Monitor implementation of new ICSS to ensure services and supports for carers are not decreased, they need to be increased
- Fund an independent body (e.g. Tandem) to monitor how well standards that are relevant to mental health carers are actually applied in the system, and how included they are
- Increase the funding pool administered by Tandem, particularly to assist carers with costs when their loved one is hospitalised at a distant location
- Prioritise the views, ideas and experiences of consumers and carers

- Education around its links to family violence, trauma, homelessness, grief, loss, bullying, racism, sexism, unemployment etc…

2. **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?**

- Nothing of late is working well!
- Bring back the programs and support services that worked well prior to NDIS
- Ensure people who have not transitioned into the NDIS have easy and fast access to treatment and support services

3. **What is already working well and what can be done better to prevent suicide?**

- Obviously nothing is working well as suicides are on the rise, which could be attributed to the Government cuts to support services and the loss of dedicated support workers has contributed to the rise in suicides especially in rural regions
- Make the ASIST program available to everyone without cost in rural regions
- Headspace program of regional city support services for youth is constructive and needs rolling out more extensively

4. **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.**

- Mental Health patients under a Community Treatment Order or Involuntary Patient Order feel failed, traumatised and more often than not are left feeling worse off than when they started, contributing to this is the lack of empathy and understanding in in-patient care of some mental health workers who are meant to be helping them. The language and abuse used by some mental health workers in in-patient care is most challenging due to many who do not understand the emotional difficulties faced by patients being forced to have treatment they often don't want or believe they need. This treatment is so detrimental that patients who experience such trauma with services will no longer trust workers in the future, there needs to be trust between worker and patient not threats and physical restraints. More training of skills and empathy toward patients is needed to ensure that mental health workers aren't doing more harm than good.
- It is difficult to experience good mental health when one can't get to see a GP for weeks and without mental health support services you are left to fend for yourself; hence the rise in suicides!
- Stop thinking everyone has access to online services; we need to get back to face to face support services.

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

   - Lack of support services, GP's lack of understanding mental health, being jobless, financial difficulties, rent for housing out of reach for some, homelessness, stigma, drought!
   - Address it by giving rural communities the same consideration (and funding) as Melbourne, having support services locally and not having to travel hours out of town to find support!

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

   - Since the NDIS was introduced and carer support has dwindled to zero, carers are suffering burn out due to the extreme pressure of being a carer and a mental health specialist because there is no longer anywhere to turn for assistance. Since the NDIS came into play the mental health system has become broken, there is no longer the compassion or understanding for carers or for the many thousands of people with a mental illness who didn't transition into the NDIS, its cold and it's ugly!
   - Carer Supports, and the mental health system in general, have been broken for years and both continue to degenerate further since the introduction of the NDIS. Carer needs are not really considered in the NDIS, so how will the NDIS work with the new ICSS system to provide integrated supports to families?

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

   - Better training and understanding of their work and the impact it may have on their own mental health.
   - All workers need to have confidence in job security.
   - Mental health workers, regardless of whether they are Peer Workers or not need to have stress management mechanisms in place to deal with such a highly emotional job.
   - Develop career pathways for Carer Support workers and Peer workers, and ensure these positions are not 'tokenistic' but are respected and their experience is valued in decision making.

8. **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?**

   - At the moment there is very little opportunities in rural towns for people with a mental illness to move forward, people have lost HOPE.

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

- People with a mental illness should not have to wait for treatment when in crisis nor should they have to be subject to discrimination and stigma in a hospital emergency department. When a person with a mental illness needs help they do not want to be told come back in 3 weeks; those 3 weeks may be their last on earth, they need to be able to get help 24/7 not 9-5 Mon – Fri!
- There is a huge focus on working on goals with participants which is great, but how do you get someone to talk about what goals they have for employment when they don't have a safe secure roof over their head. All they can focus on is finding a place to sleep for the night. It is very hard to engage with someone when they do not have safe secure accommodation, especially clients with a mental Illness. People who have come through the justice system and have been incarcerated are given a rail ticket and a couple of nights accommodation when they have been released. This in turn puts a lot of pressure and stress on carers when there are no other options for accommodation. Housing is an issue across the board, but there needs to be more accommodation options for people who present with a chronic mental illness and other complex issues. The way housing and the mental health services are set up currently it is not working, there are too many people sleeping rough who have a mental illness and cannot navigate the mental health system the way that it keeps changing.

10. What can be done now to prepare for changes to Victoria's mental health system and support improvements to last?

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

- LMMHCN research found mental health carers clearly nominating housing as the number one need for those with chronic mental health issues. It is next to impossible for someone to manage those issues without "a roof over their head". And yet there is no pathway to obtaining that secure appropriate housing. This is an issue of high priority to be addressed.

Authorised by LMMHCN Chair: Andrea Smith [redacted] [redacted]

LMMHCN reports referred to in this submission can be found here:

- *Loddon Mallee Mental Health Carers Network 'Carer Consultation 2016' report*

  https://www.lmmhcn.org.au/news/160-lmmhcn-carer-consultation-2016-report

- *Loddon Mallee Mental Health Carers Network 'The Perspectives of Carers on Housing Needs and Mental Illness 2016'*

  https://www.lmmhcn.org.au/news/161-lmmhcn-housing-report