



Royal Commission into Victoria's Mental Health System

Submission



Contents

Commissioner for Senior Victorians	3
Introduction	4
1. Positives to build on	6
2. Reflections on the current system	7
2.1 System architecture, funding and co-ordination	8
2.2 Age delineation at 65 years and planning	9
2.3 Access to information and care	10
2.4 Access to social supports	10
2.5 Carer needs are often invisible in the system.....	11
2.6 Issues related to diagnosis	11
2.7 Access to other systems as needs increase.....	12
2.8 Role of GPs and the wider private system.....	13
3. Key Focus areas re those with lived experience	13
3.1 Decision making processes.....	13
3.2 Overarching approach to mental health	14
3.3 Model of care.....	14
3.4 Interface with other systems.....	15
3.5 Inclusion and equity.....	15
3.6 Strengthen social support programs.....	15
3.7 Mental health and elder abuse	16
3.8 Needs of those without carer support.....	16
4. Key focus areas for older people as carers/supporters	16
4.1 Greater supports for carers and supporters.....	16
4.2 Risk of burnout – the carer could be the next client.....	17

List of Attachments

Attachment 1 Commissioner for Senior Victorians Terms of Reference

Attachment 2 Ageing is Everyone’s Business – a report on isolation and loneliness among Senior Victorians

Attachment 3 Government response to Ageing is Everyone’s Business

Attachment 4 Evaluation Report Strengthening Seniors Inclusion

Attachment 5 Projects Announcement – Strengthening support for Seniors

Attachment 6 Victorian Elder Abuse Staff On-line Training Modules

Commissioner for Senior Victorians

Gerard Mansour was appointed Victoria's first ever Commissioner for Senior Victorians in August 2013. The Victorian Government created this role as part of its response to the Victorian Parliamentary *Inquiry into Opportunities for Participation for Victorian Seniors*.

At the end of 2016, as part of the Victorian Government response to the Family Violence Royal Commission, the Commissioner was asked to play an additional role as Ambassador for Elder Abuse Prevention.

In May 2019 the Victorian Government announced the reappointment of Mr Mansour as the Commissioner for Senior Victorians for another four years. **(refer Attachment 1 – Terms of Reference)**

The Commissioner for Senior Victorians provides advice to the Victorian Government on issues relevant to senior Victorians and positive ageing and participation, as well as being an independent public voice to educate the community on seniors' issues, actively promote the positive contribution of seniors and encourage seniors to fully participate in our community.

A key component of the role is to actively advocate for a "seniors' perspective" in government deliberations on issues relevant to senior Victorians including positive ageing, participation, and the needs of vulnerable, at risk and disadvantaged seniors.

The Commissioner meets regularly with seniors and seniors' organisations from across Victoria to discuss a wide range of matters relevant to people as they age, provides an independent public voice to educate the community on seniors' issues including prevention of elder abuse, actively promotes the positive contribution of seniors, encourages seniors to fully participate in our community and seeks to building greater respect for the rights of older people.

The Commissioner also promotes community awareness and understanding of other matters such as advance care planning, powers of attorney and loneliness and isolation.

In 2016, the Commissioner published the report *Ageing is Everyone's Business* – a report on isolation and loneliness among senior Victorians **(Attachment 2)** which has informed the government's response to the issue of isolation and loneliness. The Victorian Government response to the Commissioner's report is contained at **Attachment 3**, as well as an Evaluation Report regarding key projects funded by the Government **(Attachment 4)** and the recently announced further funded projects **(Attachment 5.)**

As the Ambassador for Elder Abuse Prevention, he has provided significant policy advice on the prevention of elder abuse, and the importance of supporting multicultural and emerging communities.

Introduction

As the Commissioner for Senior Victorians, I hear first-hand from older people about their experiences regarding the 'journey of ageing'. That is, the experience from turning 60 years of age as people aim to continue to live their life to the full.

My policy role commences from the time that adults become entitled to the Seniors Card, which is at the age of 60 in Victoria.

Ever since my appointment in August 2013, I have ensured that a significant part of my time is spent out in the community listening and talking with older people, in small groups, larger groups of 80 to 100 and one on one. I travel extensively across Victoria in metropolitan areas, regional centres and in rural communities. Because of my extensive interaction and communication with older people, I have been able to build a broad knowledge about the range of issues that impact on people as they age.

Sometimes older people raise matters with me regarding their own life experience, sometimes it is in their capacity as a carer or supporter of others such as family members and at other times it is from 'younger' senior Victorians who are concerned about the capacity of their mother or father to remain safely at home.

My submission to the Royal Commission

I have two key reasons for my submission to the Royal Commission.

The first of these is to point out to the Royal Commission just how important it is for you to focus, as part of your inquiry, on the lived experience of older people more broadly and the operation of the aged persons mental health system in particular. The reality is that we have an ageing population, and as we move forward more people than ever before will live into their seniors' years. As a result, it is important in my view that the Royal Commission take a whole of life approach and give appropriate priority to the lived experience of those adult with mental health needs who age and thus move into the aged persons mental health system. In addition, there are the significant number of older people who, after turning 60 years of age, experience the debilitating consequences of mental illness either for the first time, or the first time for many years.

The second key reason for my submission is that older people are not just 'recipients' or 'consumers' of an aged persons mental health system. They have a much wider and vitally important role in caring for, or supporting, those with lived experience across all age groups. That is, by providing support or care for a partner, for adult children, for grandchildren or even great grand-children.

Due to my role, I have the privilege of hearing from so many older people first hand as well as many of those who were providing support or care.

Yet my observation is that many people, including older people, still find it very challenging to talk openly about mental health issues. Consequently, I decided to supplement my existing knowledge of the 'journey of ageing' by more specific knowledge about the various roles that older people play regarding the mental health system, that is, as someone with lived experience, or as a carer of someone or as a supporter.

I make a distinction between the roles of carer and supporter. There are many occasions where an older person has a key support role for someone in their family who is experiencing mental health issues, but they may not technically be regarded as a carer, or this support may be in addition to that of the carer. In some cases, the role by an older person as a carer or supporter occurs as a point of last resort when almost no other resources can be made available or that the person with mental health issues, such as an adult child, refuses to accept treatment.

This is indeed a very complex area.

To embed my contribution in the real-life experiences of older people, I brought together a specific group of people to provide input into my thinking. I convened a Mental health and older people - Consumer and Carer Workshop to guide my contribution to the Royal Commission.

This workshop was held in June 2019 and was managed by a professional facilitator to maximise the contribution of participants. With the active support of various organisations, I brought together a diverse group of older people and carers who comprised the majority of participants. In addition, several key professionals with extensive knowledge of the mental health and wider support systems were in attendance.

I would like to thank the individuals who participated in the workshop and shared their stories of lived experience and interactions with Victoria's mental health system and services, as consumers and as carers/supporters/advocates for people living with mental health issues. I hope this submission captures the essence of your contributions.

My contribution in this paper builds on the knowledge I have obtained in my role since 2013, is consolidated by the priorities identified at the workshop, and is supplemented by some of quotes of those in attendance.

Importantly, this contribution does not just focus on the aged persons mental health system.

Given the reality that many older people are carers or supporters for those receiving support in other parts of the system, older people are key stakeholders in the development of a robust and effective mental health system that is universal across all age groups.

Feedback about the wider mental health services system

This submission needs to be read in the context that participants of the workshop reflected on both:

- aged persons mental health services, and
- the wider mental health system, particularly adult mental health services.

It is very clear that older people, in the roles of carers and supporters of others, provide assistance to:

- people 65 years and over who receive aged persons mental health support
- people of all ages, including adult children, who are cared for across the spectrum of mental health services.

It is particularly significant to bear this in mind when reading quotes and comments in this submission.

While many of these relate to aged persons mental health services, some of the observations and reflections of those present at the workshop refer to experiences of caring for someone who is a client of adult mental health services.

Limitations of this submission

This submission is not intended as a comprehensive review and analysis of the aged persons mental health system nor other interfacing elements.

Rather, it is intended as a contribution that can potentially aide the Royal Commission identify priority areas for investigation as it focusses on the aged persons' mental health system, and the role of older people of carers and supporters of others within the system.

1. Positives to build on

“A knowledgeable mental health worker can make all the difference, particularly with referral to good services.”

“The new Victorian Government Carer Strategy has the opportunity to provide some much-needed additional support.”

“The interpreter services and cultural training as well as training for the police have all been important.”

“Having specialist aged mental health mobile supports teams to assist older people in the community are vital, but more are needed.”

[Above quotes from participants at the Consumer and Carer Workshop]

The participants at the workshop were asked to identify the nature of strengths within the current mental health system, both in relation to the overall system as well as the aged persons components, that could be strengthened and built on over time.

Feedback about the positive aspects of mental health services related to both the adult and aged persons mental health services. Some participants attending the workshop were receiving support as a client of aged persons mental health services; other were carers/supporters of someone within the aged persons system, for example their partner/spouse; some others were carers/supporters of people of varied ages, for example an adult child.

It also became clear during conversations at the workshop that many of the strengths of the current system were also the same areas that the participants identified as being under resourced and needing additional investment.

Some key areas identified as strengths are listed below. References to Victorian Government services apply to aged person and adult mental health services, as well as other relevant services which may be utilised by carers of a person with a mental illness.

Victorian Government

- Aged Persons Mental Health specialist aged care mental health inpatient, residential care and community treatment teams.
- Crisis Assessment and Treatment Teams (CATT) are viewed as important for older carers supporting adult children but can be hard to access due to demand and service configuration.
- Carer consultants within adult mental health system are valued and need to be extended to cover Aged Persons Mental Health services.
- Training for police in responding to mental health issues, paramedic training regarding suicide and Police, Ambulance and Clinical Early Response (PACER) teams, which are very responsive and respectful, although there can be disparity in performance.
- Models of consumer participation and peer workforce/lived experience workforce in adult mental health services.
- Interpreting services and cultural training of the mental health workforce is important and needs, like other areas, to be expanded.

- The Victorian Community Visitors Program, with volunteer Community Visitors who visit Victorian accommodation facilities for people with disability or mental illness to monitor and report on the adequacy of the services provided.
- The Victorian Carer Strategy 2018-22 with continued commitment to rolling out the strategy.
- Elder abuse prevention and response services.

Commonwealth Government

- General practice mental health plan sessions are positive where utilised (noting these need additional professional and funding resources).
- Commonwealth Home Support Program (CHSP) Access and Support Program providing short-term one-on-one support for individuals to access information, assessment and services, and home care packages and services for carers including respite care.
- The Commonwealth funded Community Visitor Scheme, with volunteer visitors supporting isolated older people in residential aged care or in receipt of home care, and the National Disability Insurance Scheme (NDIS) are very positive for those who do obtain support.

Community initiatives and services

- Lifeline, mental health carer helpline (Mind Australia), the carer support fund to help carers with financial support (Tandem - funded by the Victorian Government) and community education and training programs for people with mental health issues and their carers i.e. mental health first aid.

2. Reflections on the current system

“There is a lack of forward planning in the light of our ageing population. There will be much more demand for aged persons mental health services.”

“Ageist prioritisation and triage results in lack of consistency and poor discharge planning.”

“You have to hit rock bottom before services are offered.”

“Families are not actively engaged by the system and it depends on the approach by individual practitioners.”

[Quotes from participants at the Consumer and Carer Workshop]

The participants at the workshop were asked to reflect on the current mental health system and respond to the question:

‘How well is the current mental health system supporting older people with lived experience as well as carers or supporters of those with mental health issues?’

It is important to note responses in Section 2 of this submission arise from the differing and interwoven roles that older people typically have regarding mental health, that is:

- Those older people who have lived with mental health issues over an extended period of their life. This could mean the older person has been reliant on, or engaged in some way with, the mental health system for many years.
- Those older people who after turning 65 years of age, have identified mental health issues for the first time, or for the first time for many years. Data tends to indicate that the most common forms

of mental health concerns for these older people are depression and anxiety disorders. According to the Australian Bureau of Statistics older people are especially at risk of anxiety and depression particularly where there are co-occurring physical health issues, dementia and disability or for those experiencing bereavement, loss of independence or social isolation.¹

- Those older people identify as informal carers of others who are living with mental health issues. In this context, the person they are caring for may be from any age cohort across the spectrum of mental health, that is, child and adolescent services (0 – 18 years), adult services (16 – 64 years) and aged persons services (65 years plus).
However, most of those in attendance as carers were currently providing support to a person engaged with either the adult services or aged persons services.
- Those older people who identify as a supporter of someone with mental health issues. As with carers above, the person they are caring for may be from any age cohort across the spectrum of mental health, that is, child and adolescent services (0 – 18 years), adult services (16 – 64 years) and aged persons services (65 years plus). While not identifying as a carer, they provide a range of supports from housing, to financial, and as the ‘backstop of last resort’. Sometimes the distinction between the role of ‘carer’ and ‘supporter’ related to the willingness of the person they are assisting to themselves identify that they have a mental illness, for example the challenges that can arise if they refuse to take medication.
- Finally, it is important to note that some participants had multiple roles. That is, they have been a carer or supporter for someone with a mental illness for many years, and now themselves are also dealing with their own mental health issues.

As a result, the feedback in this submission covers both the Aged Persons Mental Health system plus feedback of older people who are caring for someone in other parts of the mental health system, particularly Adult Mental Health services.

2.1 System architecture, funding and co-ordination

“We don’t look systematically – we look at things programmatically.”

“Lack of overall investment in mental health service system.”

“Service model is not appropriate and sufficiently responsive from community based to crisis response.”

“Need for a system that intervenes earlier in cases. Compared to the youth system, there is less of a prevention and early intervention focus in aged persons mental health.”

“The Mental Health Act 2014 needs to be reviewed. Should these be removed – seclusion, ECT, restraint of older people. Is the Mental Health Tribunal remit right?”

“We need a Commission that oversees the system architecture, from prevention to early intervention to acute and crisis care.”

[Quotes from participants at the Consumer and Carer Workshop]

¹ Department of Health and Human Services (2015) *Mental health and wellbeing of older people – 10 -year mental health plan technical paper.*

Participants considered there is a lack of co-ordinated support from all elements of the system. There is inadequate information, connection and referral across the different parts of the service system. The sense is that each element, and professionals within each element, tend to operate too much in isolation.

There is a disconnect between the private and public systems. Feedback from participants indicated there are times when practitioners in the private system seem not to sufficiently refer patients to supports available under the public mental health system. It was perceived that a consequence of being in the private system is a lack of access to other parts of the service system.

There was a lack of clarity about the extent to which each of the Departmental regions reflect an overarching system design. There was a lack of confidence that regions are implementing similar approaches, services and care models. There seems to be variations in the experiences of participants from different geographic areas about the nature of the service mix, and gaps, within their locations. For example, there was inconsistent feedback about experiences related to community-based crisis responses; the nature of sub-acute responses; access to short-term professionally supported residential accommodation for older people who are experiencing a mental health problem but don't need to be admitted to acute care.

In addition, compared to other areas of the mental health system, there was an insufficient focus on prevention and early intervention for older people. Questions were raised about the appropriate approach to oversight of the whole system, and whether an independent entity should be created to fulfil this role.

Consequently, the Royal Commission is asked to consider what would be an appropriate approach to oversee the mental health system overall. This includes a greater focus on prevention, the pathways for those moving from the adult system to the aged persons system, as well as the experience of those moving into the aged persons mental health system for the first time. In the light of our ageing population, this was considered to be a priority.

2.2 Age delineation at 65 years and planning

"We need to re-vision the model across the spectrum of illness the episodic nature of mental illness and the division between age cohorts. Services are less accessible for people aged over 65 and there is a lessening of the range of supports available, including a decline in psychosocial rehab services."

"My needs don't suddenly change when I turn 65."

"De-stigmatisation for older people by discussing mental health with older people regularly as part of planning and assessment for health, retirement and aged care services."

[Quotes from participants at the Consumer and Carer Workshop]

At an overall level, there are various concerns about moving from the adult system of mental health to the aged persons system. There are concerns such as:

- As a person receiving support under the adult system turns 65 years of age, there are fears access to some services under the adult system will be withdrawn
- How appropriate is it that someone can be in the adult system, turn 65 years of age, but remain receiving the same adult system services rather than transferring to the aged persons system?
- Lack of forward planning for the transition of people from the adult to the aged persons system
- There are navigation issues given the complexity of the interplay between NDIS, state funded mental health services and the aged care system funded by the Commonwealth.

It was acknowledged that it is important to build on, and not to lose the existing strengths of, the aged persons services.

In addition, there is the opportunity to focus on prevention and early intervention as a part of the transition into the seniors years, including at retirement planning and key transition points like becoming a carer or accessing care services.

Hence a key issue for the Royal Commission is to identify the range of and mix of services needed within the aged persons system for the future, how to better prepare older people to address mental health issues as part of their transition into the seniors years, at what age point these should commence.

2.3 Access to information and care

“Human rights need to be embedded in care both for consumers and carers.”

“For 55-75 year-olds, you almost must be fully broken down before help is provided, and sometimes this is a complete family or financial loss.”

“Need for a system that intervenes earlier in cases. Compared to the youth system, there is less of a prevention and early intervention focus in aged persons mental health.”

“Systems don’t support episodic changes in people’s circumstances.”

“The funding for community health services that has been re-directed to NDIS has led to a decline in community-based services, particularly for older people.”

[Quotes from participants at the Consumer and Carer Workshop]

At an overall level, the participants consider the service system is not sufficiently person-centred, and services tend to be siloed and divided. To become more person-centred, it would also be necessary to have a greater focus on multi-disciplinary approaches.

While there is clear evidence of good practice in different agencies and locations, service quality and experiences were felt to be too ad-hoc.

There are major life transition points, for example loss of a partner or becoming a carer, where the system could intervene proactively much earlier. Feedback from participants indicated there times where support only occurs after a life breakdown or a significant loss. Too often people are discharged from hospital with limited or no support.

One of the most common concerns expressed at the workshop is the view that the system is too “crisis driven”. Often appropriate supports only become available once a situation reaches crisis point. At times the family violence system comes into play as a last resort mechanism in the absence of early interventions that would have addressed a problem before it became a crisis.

The system assumes people will be able to navigate its complexity. Older people provided feedback that it can be challenging to find out what supports are available from within the mental health system.

2.4 Access to social supports

“We needed support to re-enter social and work environments, but no support was available.”

“There is social isolation due to stigma and lack of money.”

“We need more social program support to connect to the community and a more social model.”

[Quotes from participants at the Consumer and Carer Workshop]

Isolation and loneliness are major public health issues facing older people. The potential impacts on older people are significant, with just some of the associated risks including increased rates of cognitive decline, mental health and wellbeing issues and increased risk of heart disease and stroke. The impacts of isolation and loneliness are serious for older people with a mental illness who live in the community but have very limited forms of social connections or interactions. This can be complicated by declining mobility and other health challenges.

Participants at the workshop considered changes over the last few years have significantly reduced access to psychosocial programs. Feedback identified two areas of concern:

- Adult program changes due to NDIS implementation
- Aged persons with mental health issues who need social support programs.

The Royal Commission is requested to investigate the impact of these changes and the degree to which the psychosocial needs of those within the mental health system will be met in the future.

The importance of maintaining social connections over the life course was one key finding of my 2016 report *Ageing is everyone's business – a report on isolation and loneliness among Senior Victorians*. Tackling isolation and loneliness amongst older people requires a coordinated response across local, state and commonwealth government, communities and service sectors. **(refer Attachments 2,3,4,5)**

It is vitally important that people with mental health issues retain sufficient levels of social and community connections in order to avoid the serious health risks that result from significant levels of isolation and loneliness.

Not only does this have a significant detrimental impact on older people with mental health issues, it also has a detrimental impact on their role as carers and supporters for others who are missing out on these programs. The pressure can fall onto carers and supporters to fill this gap.

2.5 Carer needs are often invisible in the system

“Carers deliver so much but are invisible at the point of assessment and treatment planning.”

“Need for a better balance between people who have free will and consent and the effect of their behaviour directly on others. Needs to be a risk framework applied as it's only at the point of a crisis that intervention occur, and often this is an intervention order.”

“Carers themselves are ageing and themselves have issues that need to be addressed.”

“Increase respect for older people.”

[Quotes from participants at the Consumer and Carer Workshop]

Participants at the workshop expressed concerns that carers find it difficult to navigate the system, and their own needs are often invisible to the system. Carers are expected to provide support –but the pressure takes a toll.

Participants expressed the view that it was not easy to find information about what services are available, including the challenge in having their own health and wellbeing needs as carers recognised. We cannot assume carers know about the role and support available from various peak bodies and support organisations such as Tandem, Victorian Mental Illness Awareness Council, Carers Victoria, COTA Victoria, Dementia Australia Victoria.

The carer is expected to “be there” to provide care and support, but feedback was provided that they can feel excluded at key times and in decision-making. There can be a “confidentiality barrier” for carers and supporters where there is not enough notice taken of their input and role when dealing with the patient, but then expected to fill the gaps. This can result in a fracturing of other relationships and isolation.

2.6 Issues related to diagnosis

“When people are discharged, there is no holistic communication across services and referrals for example, rehabilitation, drug and alcohol, community care etc.”

“A holistic approach is needed to make sure we get the right diagnosis.”

“Remove ageist related diagnosis and labelling of older people, and remove systemic issues that can label an older person with dementia.”

[Quotes from participants at the Consumer and Carer Workshop]

The Australian Institute of Family Studies has identified the challenges in identifying and diagnosing mental illness in older people when changes are seen as just part of ageing. This means that targeted supports are less likely to be sought or offered.²

It is important that diagnoses of mental illness are accurate and reviewed over time. Diagnoses that are years old can continue and not be challenged or reviewed in the system.

Participants expressed concerns with the diagnosis and treatment of dementia, but the nature of these concerns varied. There were examples where the complexity of changes arising from the onset of dementia was not accurately diagnosed early enough which resulted in older people being unnecessarily pushed into the mental health system. On the other hand, examples where a dual diagnosis was appropriate, that is both dementia and mental illness, yet access to the mental health service system was unnecessarily delayed.

Participants questioned whether there is an issue of ageism at play to explain their perceived lack of investment in aged persons mental health services. That is, does the limited investment in aged persons mental health result from inadvertent ageism in system design?

Participants commented that people with cultural, gender identity or diversity needs are not able to access sufficient levels of specialist support. In some services, there is a lack of awareness for the importance of cultural appropriateness aspects of care for Aboriginal and Torres Strait Islanders, people from lesbian gay, bisexual, transgender and intersex (LGBTI) communities, culturally diverse individuals, people with disabilities and so on.

“There are many family tragedies for older people where they have tried to support one of their children with mental health issues. Unless you can convince the adult child to seek assistance, you cannot intervene. Older parents end up providing a lot of support and care but then their other children can distance themselves from the parent’s situation. But the older person feels compelled to help their child with mental health issues. The sad consequence is that the older person then loses support of their well-functioning children. This ends up isolating the older person, from their other children, grandchildren, other family members and from society.”

[Quote from participant at the Consumer and Carer Workshop]

2.7 Access to other systems as needs increase

“Need for greater data sharing as at times various elements of the service system are all dealing with the same people, that is family violence, mental health, drug and alcohol services”

“The Commonwealth vs State divide of services and support creates navigation issues. In addition, the aged care system doesn’t have sufficient competency and support for those with mental health issues.”

“Lack of focus on the ‘whole body’ experience of someone living with mental illness and this includes the long-term impact of medication.”

“There are key issues for ageing carers, who are looking after a person with a disability and/or with mental health issues. There is a real fear of what will happen to their children as they age, as there is a lack of confidence there are the residential care systems that are needed when the older person can no longer provide this care.”

“Knowledge empowers.”

[Quotes from participants at the Consumer and Carer Workshop]

² Australian Institute of Family Studies (2019) *Normalising mental illness in older adults is a barrier to care.*

There were a range of issues raised by participants at the workshop about the importance of access to other service systems as the needs of those with mental illness changed over time.

Many participants spoke about their challenges in navigating or accessing other supports, for example, from NDIS, family violence, aged care, drug and alcohol services. People with mental health issues are ageing with increased frailty and need support both from the mental health system and other systems such as Commonwealth funded aged care. The feedback from participants is that increasing delays arise when the older carer themselves becomes frailer and need additional supports. Consequently, gaps in pathways and navigation support into other key systems were identified.

Feedback from participants was the mental health system has an important role to play in proactively aiding referrals and navigation into other service systems. For example, the aged care system was considered to be particularly challenging to navigate, with extended waiting lists, and so it is important for referrals and navigation assistance to occur as early as possible.

There are pressures on older parents who are caring or supporting an adult child. For example, an ageing carer with increasingly serious health issues who questions what will happen to their adult children after they are gone.

2.8 Role of GPs and the wider private system

“GPs focus too much on medication rather than general health and wellbeing. They are time poor to help patients with mental illness.”

“GPs should make referrals for carers to access their own support.”

“A vulnerability is that private psychiatrists may only be dealing with their patient including medications and not referring for the support needs of the carer.”

[Quotes from participants at the Consumer and Carer Workshop]

There was varied feedback about the private system, while some felt there were less silos others considered it is too dependent on the skills of individual professional and/or team providing support.

An area for the Royal Commission to investigate is how extensively, and effectively, people with mental health issues access supports available through the private system but also the role of GPs in providing support. There may be opportunities to explore the interface between Victorian-funded and Commonwealth-funded mental health services such as the degree to which older people utilise the Better Access (to Psychiatrists, Psychologists and General Practitioners) initiative by gaining greater clarity about older people’s use of mental health plans.

3. Key Focus areas re those with lived experience

This section of my submission summarises key areas the participants at the workshop wanted to bring to the attention of the Royal Commission. While a number of key areas have been identified above, this section of my submission outlines responses of participants to the question ‘What priorities would you like to bring to the attention of the Royal Commission?’

The identified priority areas are listed below.

3.1 Decision making processes

It is important to consider whether the *Mental Health Act 2014* appropriately embeds the rights of both consumers and carers within its Guiding Principles.

Feedback from participants indicated there are practical challenges in balancing the privacy rights of the client with the support role of carers, including their involvement in decisions about assessment, treatment and recovery.

3.2 Overarching approach to mental health

A priority identified at the workshop relates to the need for a greater focus on the overarching system design to ensure greater consistency in services. This was considered to require a greater investment in funding, workforce development and programs across the mental health system, including aged persons mental health. At the same time participants believed there are many strengths within the current system that can be built on over time.

The expressed view was that professionals and practitioners at all levels need more time to listen and engage. That is, with the patient, carer, their family and key support people in the lives of the person with mental health issues.

It was unclear to what degree the longer-term determinants of mental health wellbeing, including social determinants, are being addressed. This is relevant in strengthening the approach to prevention.

Participants at the workshop are clear that the current systems, that is, both the mental health system and other service systems, suffer from elements of ageism that need to be identified and addressed. For example, that mental health issues can at times be glossed over and put down to 'that's just the ageing process'.

One of the other key issues identified was the difficulties that can arise in obtaining an accurate diagnosis, and the complexities that can arise in those instances of dual diagnosis such as dementia. This would benefit from further investigation.

3.3 Model of care

"A multi-disciplinary and holistic approach is required to get the correct diagnosis, right medication, identify side effects, look at physical wellbeing and need for other services like alcohol and drug."

"Track the lived experience of people using the system, not just numeric data, to understand what is working and what is not."

"The model needs to be person and relationship centred, holistic, recovery oriented, human rights based, trauma informed. There needs to be rural, regional equity too."

"Make the service system more accountable to deliver a family inclusive response to mental health clients, and carers need to be included."

[Quotes from participants at the Consumer and Carer Workshop]

Participants at the workshop considered improving 'models of care' to be a priority focus area. This includes how to better integrate the approach to the whole of life experience of those with mental health issues, strengthen knowledge about evidence informed practice, and better connect with those who provide both informal care and support. It should take into a wide range of factors including physical health, social connections, family context, employment needs and financial capacity

This practice needs to be person centred, trauma informed, and a greater focus on shared learnings to embed systemic practice change.

The models of care need to build on family centred practice, and this includes the point of triage to better engage with the person, their carer or supporters, family context, their diversity needs and acceptance of who that person identifies as their carer.

The models of care need a greater focus on early intervention and prevention, including for those aged 65 years and over. There is often an oversight when thinking about prevention that it only involves those of a young age. Someone who is just turning 60 years of age will on average still have about 25 years of life left to live. The concept of prevention remains relevant for aged persons mental health.

In addition, it is important to strengthen the focus within the model of care regarding pathways to recovery. This would have the added benefit of playing a role in seeking to prevent or limit subsequent crisis situations as well as improving quality of life outcomes for older people.

There is also the need for greater mental health system integration, to think about concepts such as a 'one stop shop' or 'no wrong door' so that people can better access the right supports in a timely manner.

3.4 Interface with other systems

"The new aged care mental health mobile support teams are a good addition to support older people in residential aged care."

[Quote from participant at the Consumer and Carer Workshop]

Some of the most complex issues for older people, either as the person with mental health issues, or as the carer and supporter, arise at the time of life when they need additional supports from other service systems to maintain their overall health or improve their quality of life. For example, the ability to access treatment for physical health conditions or the ability to navigate entry to the aged care system.

This means the interface and connections with other support systems are essential, including for example NDIS, disability, drug and alcohol, aged care, police and so on.

The Royal Commission is asked to consider how to improve service coordination between mental health services and the range of other support systems, so that timely and appropriate supports are available when needed.

3.5 Inclusion and equity

The Royal Commission is asked to consider diversity, culture and identity issues when reviewing the aged persons mental health system. Diverse communities may have different experiences and there is a need to address structural barriers regarding disadvantage.

The Victorian Government recently released its long-term vision, *Everybody Matters*, for the creation of a family violence system that is more inclusive, responsive and accessible for all Victorians. This aim of 'inclusion' and 'equity' is also relevant for the mental health system. *Everybody Matters* recognises:

"Individual characteristics that inform our social identity do not exist independently of each other."

"People have many layers .. multiple characteristics that are interconnected or intertwined ..."

"We need to build a system based on inclusion and equity."

"An inclusive system is demonstrated by attitudes, behaviours, policies and practices that enable full and equal participation for everyone."

"Increase access to interpreter services and improve cultural competence of all workers."

Everybody Matters: Inclusion and Equity Statement

3.6 Strengthen social support programs

A key gap identified by workshop participants relates to the availability of appropriate psychosocial support programs.

Isolation and loneliness are major public health issues facing older people. The potential impacts on older people are significant, with just some of the associated risks including increased rates of cognitive decline, mental health and wellbeing issues and increased risk of heart disease and stroke.

The risk of isolation and loneliness are serious issues for those with mental health issues including older people. The risks of isolation and loneliness are also serious issues for carers given the high levels of support they often provide to those with mental illness.

As detailed in my 2016 report *Ageing is Everyone's Business*, the causes of isolation and loneliness are complex. Tackling isolation and loneliness amongst older people requires a coordinated response and the mental health system has an important role to play. The risk of isolation and loneliness occurs across the life course and so access to appropriate social programs and community connections, is a priority irrespective of age.

A particular priority relates to the need for greater access to specialist psychosocial programs (see 2.4). One of the more recent developments worthy of further investigation is the use of 'social prescriptions' by GPs and other health practitioners as an alternative, or supplement, to the prescription of medication.

3.7 Mental health and elder abuse

There are situations where the impact of mental illness is a potential risk factor for elder abuse. There is an increasing body of evidence that some of the perpetrators of elder abuse also have serious mental health issues. An example of the professional training developed as part of its elder abuse response is available at **Attachment 6**.

For example, there situations where an adult child with a mental illness has a level of reliance on their parent/s to provide support. Crisis situations can occur, or tensions build up over time, as a result of the mental health issues not being effectively managed. For example, a psychotic episode, where mental illness is poorly managed, where treatment is refused, or mental illness goes undiagnosed.

The Royal Commission is asked to identify the impact of mental illness on the risk of elder abuse, and to consider prevention, early intervention and response strategies.

3.8 Needs of those without carer support

Participants at the workshop, when identifying the key role played by carers or supporters of those with mental health issues, also noted the significant issues that arise when necessary levels of informal care and support is not available.

This is considered to significantly increase the level of vulnerability of those with mental illness. This is exacerbated when combined with other risk factors such as other health conditions, limited friendship groups or social networks.

The Royal Commission is asked to identify how well the current system meets the needs of those who are more vulnerable and at risk.

4. Key focus areas for older people as carers/supporters

4.1 Greater supports for carers and supporters

"Provide early intervention family support for carers to assist with planning before a crisis. Plan ahead how to avoid adult children refusing treatment, and plan to deal with a crisis to help prevent suicide."

[Quote from participant at the Consumer and Carer Workshop]

The participants at the workshop considered the needs of those providing care and support for someone with mental health issues. Several areas of focus are suggested for the Royal Commission to consider.

Firstly, the need for additional resources to be made available to better support the role of carers. The expressed view is that there are often insufficient resources available or that the existing supports are not sufficiently well publicised.

Secondly, the need for higher levels of support in certain situations. That is, at times the financial and personal drain on the carer is such that have to almost 'give up their own life' to fill the gap between what the system can provide and the needs of the person they are seeking to support. There were specific suggestions such as increasing funding available through the Carer Support Fund; improve access to support prior to a crisis occurring; review whether the key services are available across all regions and areas; greater access to peer support and buddy systems.

Thirdly, additional investment in workforce development is important, including how to implement appropriate levels of family centred practice. It is perceived that the life experiences of carers and supporters is often not fully understood by the mental health and allied workforces. For example, LGBTI carers not being appropriately recognised, supported and acknowledged as being the carer rather than being classed as a friend.

One of the common challenges for carers relates to the availability of respite care to give carers a break, both more often and for longer periods of time.

4.2 Risk of burnout – the carer could be the next client

“Consultation with the older carer before an adult dependent is discharged back into their care. Assessment of what support and information is needed for the carer to continue in this role – if they want to.”

[Quote from participant at the Consumer and Carer Workshop]

There is a high risk of carer burnout, particularly for those who are older and been a carer or support person for many years. One of the common themes from the workshop is that if the carer or support person does not receive timely and appropriate support, the risks increase that they themselves will come under increasing pressure, and in turn suffer from their own mental health issues. This risk was often compounded by the financial burden placed on many carers and supporters in trying to 'be there' in many ways as a back stop.

The risk is the pressure on the carer to 'fill the gaps' eventually takes its toll, becomes so great, that the 'carer' becomes the future 'client' of the mental health system. Some of the suggestions to ensure access to more timely support include: availability of Step Up Step Down services; availability of acute beds for the required length of stay; access to services for the carer as a client in their own right as an early intervention approach.