Help, hope and purpose

Mind Australia Limited

Submission to the Victorian Royal Commission into Mental Health Services

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Introduction

Mind Australia Limited (Mind) is one of the country's leading community-managed specialist mental health service providers. We have been supporting people dealing with the day-to-day impacts of mental illness, as well as their families, friends and carers for over 40 years. We provide recovery-focused, person-centred support including residential rehabilitation, personalised support, youth services, and family and carer services, and support facilitation and coordination. We deliver services in our own centres, and outreach programs and residential services in partnerships with clinical agencies around Australia. In the last financial year, Mind provided over 400,000 hours of support service to over 9,000 people.

We also work with people to address poverty, housing, education and employment. It is an approach to mental health and wellbeing that looks at the whole person in the context of their daily life. We value lived experience, and many of our staff have been through their own recovery journey and faced similar challenges.

Mind significantly invests in research about mental health recovery and psychosocial disability and shares this knowledge, developing evidence informed new service models, evaluating outcomes, and providing training for peer workers and other mental health professionals. We also advocate for, and campaign on basic human rights for everyone; constantly challenging the stigma and discrimination experienced by people with mental health issues. Our current research and advocacy priorities are unpaid carers, housing, and legal empowerment.

Mind presents the following submission to the Royal Commission into Victoria's Mental Health Services. Years of underinvestment in the context of rapid population growth has seen Victoria go from being a leader in mental health service provision in the 1980s to now being one of the worst performers nationally. Victoria currently has the lowest per person expenditure on specialised mental health services in Australia. One result of this is that the promise underlining the large-scale deinstitutionalisation in Victoria in the late 1980s and early 1990s has not been met for a significant number of individuals who experience severe and/or complex mental illness, and their families and/or carers.

The Royal Commission represents a once in a generation opportunity push reset on Victoria's mental health system, not only in terms of funding but significant systems reform. We are particularly keen to focus attention on what we call 'the missing middle' of service provision in Victoria; the space between what the National Disability Insurance Scheme (NDIS) provides those with psychosocial disability and what is provided by clinical and acute services. This space, occupied by community mental health providers such as Mind, is a vital component of a comprehensive mental health response[1]. Under threat due to range of policy and funding pressures, it is now in danger of disappearing, with major implications for mental health service provision.

The following submission will address those areas of the Royal Commission's terms of reference where Mind feels it can contribute policy commentary and practical solutions, several of which are capable of being rapidly scaled up. In particular, our submission focuses on the reforms that are needed to improve the delivery and outcomes of mental health services for people with high and complex needs related to mental ill-health. For maximum

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[1] In this submission, we refer to community-managed mental health providers collectively as the NGO sector.

clarity, where possible we have structured our responses to those terms of reference as ‘problem’, ‘impact’ and ‘solution’.

Importantly, this submission is informed by interviews with Mind staff, and the outcomes from a public consultation process held in cooperation with Wellways (another major community-managed mental health provider). This involved face-to-face consultations with consumers and their carers and families in metropolitan and regional areas. Feedback was also sought via an online survey. Mind thanks the people who took part for having the courage and determination to share what were often painful memories from their interaction with the mental health system in the hope that their experience might inform the Royal Commission’s recommendations. The de-identified participant feedback from these processes will feature throughout this submission, including quotes, which appear indented in italics

Mind’s top ten recommendations for the Royal Commission’s workplan are:

1. Provide clarity on the question of what role the Victorian government should play in the space between what the NDIS provides to those with a psychosocial disability and what is provided by clinical and acute services. In terms of the Commission’s deliberations on this matter, we also suggest that attention should be paid to what gaps exist or are emerging for people with complex and/or enduring needs, regardless of whether they are eligible or ineligible for NDIS.

2. Introduce a single entry point into the mental health service system, via a high quality standardised and comprehensive approach to assessment that can be undertaken at multiple points in diverse systems. This should be available to anyone whose needs cannot be met through treatments provided under the Medicare Benefits Scheme alone. The Victorian government should also advocate that this approach be adopted nationally.

3. Strengthen recovery outcomes by extending the range of services delivered through clinical-NGO partnerships, and introduce new models delivered through partnership across the continuum of need from acute care through to longer term rehabilitation and support.

4. Develop and implement a comprehensive workforce strategy to meet current and future demand, which recognises the essential contribution of a specialised NGO workforce that provides important psychosocial and social supports.

5. Fund innovative approaches, backed up by concrete workforce planning measures, to encourage the greater development of a lived experience or peer workforce. Many of the negative impacts of Emergency Department presentations on both patients and the staff would be considerably ameliorated by the insertion of mixed teams of peer/community mental health workers into the Emergency Department.

6. Determine the best configuration of mental health and housing support for people with complex and/or severe mental illness who are not eligible for the NDIS, and introduce targeted initiatives to meet their long-term accommodation needs.

7. Introduce a program that that provides up to three months’ supported accommodation to NDIS participants while they wait for the Scheme to approve and provide their housing.

8. Reform the governance, funding and commissioning of mental health services, including a reduction in regulatory burden, longer contracts, and funding that covers the full cost of service provision, including the time and emotional labour involved in servicing relationships and liaison between workers, different organisations and service systems.

9. Construct a greater role for the Victorian government in supporting NGOs to improve data collection, assessment, benchmarking and outcomes, including examination of the feasibility of government developing an improved data collection and reporting system that can be licensed to the NGOs and utilised across the sector.

10. Demonstrate greater recognition of the important role that families and carers play in supporting people with mental illness by increasing the level and variety of supports and funding to help them do their job, based on the principles of control and choice that underpin many contemporary service delivery systems.

Principles and assumptions framing Mind's response

A number of key principles and assumptions frame Mind's response to the Royal Commission. It is useful to briefly spell these out as they inform and cut across a number of areas discussed in this submission.

a) The importance of emphasising the social and economic determinants of mental health and illness

> *The only treatment model that is ever discussed in relation to mental illness is the medical/clinical model. This is why it can be hard to have a discussion with a doctor. We need to crack this discussion wide open.*

This submission to the Royal Commission is informed by a clear focus on the social and economic determinants of mental health. Mind would like to see policy and program solutions that remedy inequalities in social and economic determinants in equal measure to those that deal with the clinical treatment of and management of the symptoms of mental illness.

A number of factors contribute to mental health and can exacerbate the problem for those who experience it. These include issues such as lack of housing and accommodation solution for the mental unwell, lack of access or marginalisation in relation to education, training and employment, social isolation, financial crisis and debt, and comorbidities such as physical disability and problematic drug and alcohol use. Susceptibility to mental ill-health and the severity with which it may be experienced can also be mediated by gender, sexual identity and cultural factors. Stigma also continues to be significant issue for those experiencing mental illness, not only in the general community but the very clinical and service settings in which it is supposed to be treated.

Our focus on tackling the economic and social determinants of mental illness, as well as its clinical dimensions, is in line with the orientation pursued by the World Health Organisation, which has noted that mental health is shaped to a great extent by the social, economic and physical environments in which people live.[2] In particular it stresses that social inequalities are associated with increased risk of many common mental health conditions. This approach also framed the recent New Zealand inquiry into mental health and addiction.[3]

In the Victorian context, a clear focus on the social and economic determinants of mental health and illness has implications in terms of the number and type of people who need support, the provision and funding of services, and what organisations are best placed to deliver them. It also has implications for how we conceptualise the architectural and delivery framework within which services are delivered. The current configuration of funding and delivery for mental health and related service interventions views clinical, psychosocial and social supports as distinctly separate aspects of an individual's recovery, whereas this is not the experience of those with a lived experience of severe and persistent mental illness. A focus on social and economic determinants shifts the locus of service delivery towards the integration of the treatment and management of symptoms of mental illness with interventions that deal with the impacts of these symptoms on people's lives.

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[2] World Health Organisation, *Social Determinants of Mental Health*, 2014.

[3] *He Ara Oranga: Report on the Government Inquiry in Mental Health and Addiction*, November 2018.

b) The importance of not losing focus on the cohort of people with complex and enduring mental illness

Mind's submission emphasises the needs of people with persistent, complex, and unpredictable or episodic cycles of mental illness. Taking the focus off the most socially isolated and marginalised of those experiencing mental illness not only risks a further deterioration of their health but will result in significantly greater service system costs in the long term, as their needs defray to more costly tertiary systems. This is a point that is reinforced by 2014 KPMG modelling of mental health outcomes commissioned by the National Mental Health Commission (NMHC).[4]

Overlooking this cohort also fuels misconceptions about the nature and risk factors behind mental illness and disguises the political, social and economic dimensions that often under pin and exacerbates it such as poverty, housing insecurity, and social exclusion. This includes the ongoing impact of stigma, which operates to focus a great deal of discussion on less acute conditions such as depression and anxiety, as opposed to the more complex end of the mental illness spectrum.

> *Borderline personality disorders is one that has a very negative stigma attached to it. 'You are seen as too hard. You must be a manipulator. You suck up a lot of services, especially in the public system.*

Not paying sufficient attention to the needs of people with episodic, persistent, and/or complex mental health problems also fails to take account of precursors in childhood, such as violence, abuse and neglect, especially when these are intergenerational. As Carol Harvey and her colleagues note, childhood trauma and adversity are common amongst this cohort, and if unaddressed, may lead to poorer functional outcomes.[5] This has important implications if choice in public policy is to be expanded for people from marginalised and excluded groups.

c) The importance of providing adequate psychosocial services

Central to the effectiveness of any recommendations emerging from the Royal Commission must be an understanding of the importance of psychosocial and social supports and the aptitudes and skills of the workforce needed to deliver these. The benefits of psychosocial supports can be hard to quantify and measure, and this is one of the reasons they are generally not understood and valued in the mental health service context to the degree that clinical interventions are. Briefly defining and clarifying them at the beginning of the submission is thus useful.

The term 'psychosocial disability' has only been widely used in Australia in the last decade and particularly with the introduction of the NDIS has overtaken the earlier term 'psychiatric disability'. Psychosocial disability emphasises the social consequences of disability rather than the impairment associated with psychiatric disability.[6] The National Mental Health Consumer

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[4] KPMG, *Paving the way for mental health: The economics of optimal pathways to care*, National Mental Health Commission, November 2014.

[5] Carol Harvey, Lisa Brophy, Samuel Parsons, Kristen Moeller-Saxone, Margaret Grigg, Dan Siskind, 'People living with psychosocial disability: Rehabilitation and recovery informed service provision within the second Australian national survey of psychosis,' *Australian and New Zealand Journal of Psychiatry*, Vol. 50, No. 2 (2016), 534-547.

[6] Harvey et al.

Care Forum provides a good description of ‘psychosocial disability’ in their 2011 report, *Unravelling Psychosocial Disability*:

> Psychosocial disability is the term that mental health consumers and carers use to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and participation restrictions include loss or reduced abilities of to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives. The best outcome for people experiencing such disability will be achieved through supports that mitigate the effects of impairment or participation restriction and enhance the social and environmental opportunities to expand their capabilities.[7]

Harvey et al outlines the ‘common set of difficulties which lead to complex needs’ as follows:

> Typically, they have more severe illness characterized by frequent relapses and active treatment-resistant symptoms, severe negative symptoms, cognitive impairments and co-morbid mental health problems, such as substance misuse. Consequently, they more often require supported accommodation. Most have physical health problems due to a combination of poor diet, inadequate exercise, smoking, unwanted effects of medication and economic disadvantage.[8]

The change in practice and language can be conceptually problematic as the concept of psychosocial rehabilitation establishes goals for everyday function, such as housing and employment, that are different from recovery-oriented goals that focus on getting better. As William Anthony from Boston University, defines it:

> Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.[9]

While current policy settings dictate that all mental health services are ‘recovery-oriented’ whether delivered in the clinical or in the NGO setting, Harvey et al note that the latter sector is more explicitly funded to deliver psychosocial rehabilitation and recovery support. They also note that historically these services have been separate from mental health treatment services, the cause of much of the fragmentation that the current Royal Commission hopes to address.

Psychosocial and social supports that aim to assist people with the practical and emotional support they need to gain/regain a productive and meaningful life include home and community based services, promoting a continuum of care, access to social, legal, and other long-term social and supporting services and rights protections for the vulnerable. A comprehensive literature review commissioned by Mind and undertaken by the Melbourne University Centre for Mental Health in 2016, confirmed a strong evidence base for the success

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[7] National Mental Health Consumer and Care Forum, *Unravelling Psychosocial Disability*, 2011, 16.

[8] Harvey, et al, 535.

[9] William A Anthony, ‘Toward a Vision of Recovery for Mental Health and Psychiatric Rehabilitation Services’, Boston University, Centre for Psychiatric Rehabilitation, 2007, 7.

of targeted psychosocial interventions in promoting recovery, particularly if they are applied early.[10] The interventions that received a high endorsement in the literature were:

- Social skills training
- Supported employment
- Family psycho-education and support
- Outreach treatment and support services
- Cognitive remediation
- Cognitive behavioural therapy for psychosis
- Illness self-management
- Supported education and housing
- Physical health management
- Peer support/consumer networking

Of these interventions, the evidence base is particularly strong for personal choice and recovery outcomes, social skills training, supported employment and supported housing to reduce future support needs.[11] They also meet commonly expressed needs and goals for people with mental ill-health and support personal recovery.

Failure to address these social and psychosocial needs has considerable consequences for the individuals concerned. There are also considerable cost implications, as people's conditions worsen and they require responses from costlier tertiary services, including hospitals, homelessness, and criminal justice, not to mention the wider opportunity cost in terms of potentially lost productivity, as people fail to recover and participate in education, training and employment.

d) Recognising the crucial interplay between Commonwealth and state funding and services

> *How can you talk about mental health services in Victoria and not mention the NDIS?*

Victoria's system of mental health care, treatment, prevention, promotion and community support is funded and administered across federal/state jurisdictional and bureaucratic boundaries. While Commonwealth services are obviously not in the direct remit of the Royal Commission's terms of reference, their critical interplay with state mental health services makes detailed mention of them unavoidable. Victoria has been particularly impacted by the NDIS. While it is important to acknowledge that many of the problems and the unmet demand attributed (by some) to the NDIS existed well before the scheme came into being, NDIS implementation has been major disruptor across the Victorian service system. The Victoria bilateral agreement has transitioned funding for virtually all community mental health services into the Scheme. The impacts of this have been further exacerbated by the fact that psychosocial disability remains unclearly defined within the NDIS's architecture, both conceptually and in terms of service response.

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[10] Laura Hayes, Lisa Brophy, Carol Harvey, Helen Herrman, Eoin Killackey, Juan Jose Tellez, *Effective, evidence-based psychosocial interventions suitable for early intervention in the National Disability Insurance Scheme (NDIS): promoting psychosocial functioning and recovery*, University of Melbourne Centre for Mental Health, Melbourne School of Population and Global Health, and Mind, September 2016.

[11] Hayes et al, 2016, 20.

The introduction and operations of the NDIS needs to be viewed in the context of the missing middle of service provision referred to earlier. It has created significant challenges for consumers and their carers, introduced delays, created gaps and exacerbated unmet demand for some types of service, and in some geographic areas. It has also impacted on patterns of service use, benefiting some and marginalising others. Attempts by government to plug gaps and meet demand such as funding for PHNs, albeit well-intentioned, has resulted in new problems and made the situation far more complex, certainly for clients and families previously supported by community mental health organisations such as Mind.

e) A greater workforce role for people with lived experience of mental ill-health and recovery

Mind believes that mental health policy has not paid enough attention to the experience and management of mental ill-health from the perspective of people with lived experience. Whilst the value of a peer workforce and the principles that underpin its creation is recognised at the state level by documents such as the 2011 *Victorian Framework for Recovery Oriented Practice*, this has not been supported to have any measurable impact.

The use of peers has been a growing part of Mind's philosophy and operations since the 1990s. Whilst Mind is still developing our strategies and practices to ensure that our peer workforce operates safely and effectively, we contend in this submission that the peer workforce has immensely enriched Mind's practice and impact and has led to very real service improvements and better health and social wellbeing outcomes for clients.

Mind echoes one of the overall conclusions of a recently published book on peer work that we need to conceptualise the elements of peer work activity not just as a valued support activity for people experiencing mental ill-health but as a developing service modality.[12] Peer work can also extend to families and mental health carers. Carer peer workers can provide advocacy, ways to engage with services and problem solve within services in inclusive ways. The carer peer workforce can also provide pathways into other employment for mental health carers attempting to return to the workforce.[13]

This submission will provide evidence to support our view that peer work has proven effective as a complement to clinical services, and as a modality in its own right in delivering good recovery outcomes and quality of life for people impacted by mental ill-health.

g) Address current inequities in the system for families and mental health carers

Evidence captured in research on mental health carers and in the consultations for this submission shows that many families and mental health carers are in crisis. Mind would argue that there is a need to address the support needs of families and mental health carers in more consistent and proactive ways. Not just through the provision of supports that help families to navigate the system and their caring role, but also policies and strategies that give mental health carers and families reasonable choices about how much support they

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[12] Janet Meagher, Anthony Stratford, Fay Jackson, Erandathie Jayakody, Tim Fong, *Peer Work in Australia: a new future for mental health*, Richmond PRA and Mind Australia, 2018.

[13] Developing a Strategy for the family/carer workforce in Victoria, Carer workforce Development Consultation Paper, Consumer and carer workforce development team, State Government of Victoria 2017

provide, while also sustaining their own health, well-being and future security.[14] As part of this, Mind believes there should be a stronger emphasis on relational and family focused practices in mental health treatment and recovery supports.

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[14] See 'Caring fairly campaign - Rights, Recognition, Reform' http://www.caringfairly.org.au/

Responses to the Royal Commissions Terms of Reference

1. How to most effectively prevent mental illness and suicide and support people to recover from mental illness, early in life, early in illness and early in episode, through Victoria's mental health system, and in close partnership with other services.

Mind believes some contextualisation is important to understand the factors that have contributed to the current crisis in mental health services in Victoria and what is needed to improve the situation.

The current situation goes back to the program of deinstitutionalisation that occurred during the late 1980s and 1990s. The structural move from standalone institutions to mainstream in-patient and community-based mental health services was consistent with changes throughout the developed world.[15] By 2003 all mental health in-patient beds other than forensic beds had been moved to general hospital sites and an age-based, area-based mental health system was well established.[16]

Accompanying the closure of large stand along facilities and the establishment of a range of community and mainstreamed bed-based services was a greater focus on supported decision-making for people with mental illness and a more 'rights based' based framework of mental health law and policy. This included increased procedural safeguards for involuntary psychiatric interventions and community based support services that recast the 'psychiatric patient' in legal and policy discourse as a 'consumer' or 'client'.[17] Greater external oversight of clinical and community providers through mechanism such as the Mental Health Review Board was also introduced. Other benefits from the deinstitutionalisation noted by commentators included the creation of range of flexible and creative ways of delivering care.[18] The process also coincided with the first manifestations of a peer workforce, with 'consumer consultants' employed within Area Mental Health Services for the first time in 1994.

We must be clear, however, that there were considerable flaws in the deinstitutionalisation process which continue to influence Victoria's mental health services today. There was inadequate consideration of accommodation options for newly deinstitutionalised patients, placing the onus on families and informal carers.[19] Melbourne University's Dr Piers Gooding maintains that the assumed benefits of deinstitutionalisation, including the rights based governance regime, were also undercut by the broader Victorian restructuring of the welfare state presided over by the Liberal Government in the 1990s, which saw a wave of privatisation and the shrinking of the public sector, and significant cuts to health and community services.[20] Increased demands on services has undermined their quality, comprehensiveness and, in the case of services design for longer-term treatment, such as Community Care Units (CCU), the length of stay experienced by consumers.

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[15] Ruth Vine and Fiona Judd, 'Contextual issues in the implementation of mental health legislation,' *International Journal of Law and Psychiatry, 62* (2019), 16.

[16] Ibid, 16.

[17] Piers Gooding, '"The government is the cause of the disease and we are stuck with the symptoms": deinstitutionalisation, mental health advocacy and police shootings in 1990s Victoria,' Journal of Media and Cultural Studies, Vol. 31, No. 3 (2017), 436.

[18] Valerie Gerrand, Sidney Bloch, Jenny Smith, Margaret Goding, David Castle, 'Reforming Mental Heath Care in Victoria: a decade later,' *Australian Psychiatry*, Vol. 15, No. 3, June 2007.

[19] Gerrand et al.

[20] Gooding, 437.

The failure of successive Victorian governments to invest in mental health services in line with the state's population growth since then has compounded the problems arising from deinstitutionalisation. Victoria has gone from having the highest per capita expenditure on mental health in Australian 1994/5 to the lowest by 2015/16, including bed-based clinical and community-based mental health services.[21] There has been a long-term reduction in the number of mental health beds in acute general health services, especially long stay beds.[22] Funding for a range of crisis, continuing care, and community mental health outreach services that were associated with the early days of deinstitutionalisation, has also been reduced substantially. Victoria also has the lowest number of full time equivalent mental health staff with 121.5 per 100,000 head of population, compared with the national average of 132.9.[23]

Some Victorians who experience complex and/or severe mental illness have been able to extract considerable benefits from deinstitutionalisation process and the medical/legal innovations that have flowed in its wake. These are people who have access to substantial financial resources and/or well organised, stable, highly educated and bureaucratically literate family or other care support network. But for many, arguably the majority of those suffering significant mental ill-health in Victoria, the promises of deinstitutionalisation in terms of better, more individually focused service provision have not materialised.

We also note that the private health system offers little to those people with complex and/or enduring mental illness who can afford it, beyond private psychiatry and in-patient services for some conditions. Consumers and families who utilise private health care for mental ill-health generally enjoy the benefits of more consistent relationships with treating clinicians. However, for the majority of people that Mind works with, access to private health is unavailable on financial grounds, or because the system simply is not able to cope with the complexity of their mental health needs.

The shift away from the provision of mental health services in institutional settings in favour of care in the home and community has resulted in a growing structural reliance on systems of unpaid care. Friends, neighbours, family members and sometimes even young children and adolescents are increasingly being called on to provide unpaid mental health care, usually within the family home. Mental health carers routinely experience diminished economic security, reduced career and employment prospects, as well as negative impacts on their own health and wellbeing. The situation of family members and carers will be examined in more detail in our response to Terms of Reference Three.

Problem

Victoria's mental health system can better be described as overlapping, complex systems of care, treatment and support, rather than the single system referred to in the Royal Commission's terms of reference. The administration of these systems is split between Commonwealth and state jurisdictions and between various geographic catchment areas and departmental bureaucratic.

No Australian state or territory currently invests enough in mental health services but Victoria lags behind the most. Mental Health Victoria (MHV) estimates Victoria is 13% below national average expenditure per capital on mental health services and 40% below national average

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[21] Vine and Judd, 17.

[22] Ibid

[23] Australian Institute of Health and Welfare figures cited in Vine and Judd, 17.

access to mental health services.[24] As the Victorian Auditor General puts it: 'Increasing demand combined with current service shortfalls are placing the whole mental health service under considerable stress.'[25]

Mind contends that the impacts of under investment are particularly severe in relation to the component that provides recovery oriented psychosocial support and rehabilitation services, with funding to acute services having outstripped resources allocated to community mental health services.[26]

Significantly exacerbating under-investment has been the NDIS transition. This has seen the removal of virtually all base funding to NGO-managed mental health services and a number of key programs discontinued or defunded, as monies were transferred into the Scheme. This process, which is expected to conclude by the end of 2019, is creating considerable uncertainty. The introduction of the NDIS has further fragmented an already complex and poorly co-ordinated landscape of Commonwealth/state mental health services, especially in areas such as housing. This submission will discuss this in greater detail in our response to Terms of Reference 2.3. It has also exacerbated differences between jurisdictions. For example, figures from the National Disability Insurance Agency (NDIA) reveal that an average NDIS plan for an individual with a psychosocial disability is $60,000 nationally, but only $40,000 in Victoria, although we are unclear exactly why this occurs.[27]

Impact

NDIS transition has exacerbated pre-existing unmet service demand, particularly at the more serious end of the spectrum. Only a very small proportion of the estimated population experiencing severe mental illness each year in Victoria are eligible for the NDIS.[28] According to MHV, Victoria currently has:

- 135,000 adults with severe mental health problems not eligible for the NDIS and accordingly will need continuing community based services and support from State Government funded services.
- 93,600 adults experiencing severe mental health issues who do not receive clinical services each year.
- 296,528 adults experiencing moderate mental health issues per annum who will find it hard to get services because of the focus on more acute presentations. [29]

Increased throughput has resulted in a shorter length of stay for patients in clinical in-patient units, down from 14.7 to 11.2 days from 2009 to 2017.[30] The higher acuity threshold in admission, combined with shorter stays, means that patients are more likely to be comparatively acutely unwell when discharged. The implications of this are highlighted by the

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[24] Mental Health Victoria, *Saving Money. Saving Lives: The case for better investment in Victorian mental health*, June 2018.

[25] *Access to Mental Health Services*, 45.

[26] Ruth Vine and Fiona Judd, 'Contextual issues and implementation of mental health legislation,' *International Journal of Law and Psychiatry*, January-February 2019, Vol.62, 16-19.

[27] These figures are sourced from two reports, the national and Victorian *NDIS, COAG Disability Reform Council Quarterly Performance Reports* for December 2018*.* The figure of $60,000 comes from page 29 of the national report. The figure of $40,000 comes can be found on page 28 of the Victoria report.

[28] *Saving Money. Saving Lives*, 4.

[29] *Saving Money. Saving Lives.*

[30] Ibid, 45.

fact that 13.8% of admissions to acute facilities reflect readmissions of patients.[31] This increased acuity has, in turn, raised the acuity in sub-acute services such as Prevention and Recovery Centres (PARCs) and other NGO run services, resulting in the NGO workforce requiring more highly skilled staff and/or having to upskill staff, both of which incur greater expense. Consequences have also flowed onto other service systems such as homelessness and justice[32] at considerable public expense.

As consumers and carers consulted in the development of this submission made clear, this situation runs totally counter to effective early intervention strategies.

> *There are so many opportunities before the crisis. A lot of chances to prevent that hurricane-like crisis.*
>
> *I had to be in very serious trouble before I could get help.*
>
> *The system really kicks in only at the point of deep crisis. I felt our intervention as parents was actually a problem in some respects. If we had been less engaged we would have been attended to sooner.*

As one service user put it, the worst aspect of interacting with the mental health system…

> *Was fighting for a bed in the public health system when I'm suicidal and being told I am not ill enough, which only made me escalate my behaviour. I was not receiving counselling because I could not afford it. It needs to be a major catastrophe before you get to the point of getting help. It has to be a totally acute situation in order to get help, because beds are so limited.*

Ruth Vine and Fiona Judd assert that 'the absence of increased capacity in community and bed based services have resulted in increased pressure on state funded health services.'[33] This is illustrated most graphically by the increase in mental health related presentations to emergency departments (ED). Approximately 3.75% of emergency department admissions in Victoria are mental health related.[34] As the Royal Australian and New Zealand College of Psychiatrists puts it: 'Too often the ED is the only option available for people who are experiencing an acute mental health crisis, especially after hours or when other services are not available.'[35] Data from the Victorian Auditor General's Office states that mental health presentations to Victorian EDs nearly doubled in the period 2004-5 to 2016-17, from nearly to 29,000 to over 54,000.[36] Mental health-related cases also take up a large proportion of Victoria's ambulance service responses.[37]

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[31] Mental Health Victoria, *Initial Submission to the Productivity Commission Inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth*, April 2019, 8.

[32] Vine and Judd, 17.

[33] Vine and Judd, 18.

[34] Australasian College For Emergency Medicine, *Waiting Times in Emergency Department for People with Acute Mental and Behavioural Conditions*, February 2018, 4.

[35] Australasian College for Emergency Surgery and The Royal Australian & New Zealand College of Psychiatrists, *Mental Health in the Emergency Department Consensus Statement*, May 2019.

[36] *Access to Mental Health Services*, 45.

[37] *Saving Lives. Saving Money*, 13.

While consumers and carers appreciate the essential service EDs can offer, they argue they are not an appropriate place for intake and response to mental health, a view backed up by Mind staff. ED staff often struggle to find appropriate care pathways for mentally unwell individuals, in no small part due to the shortage of specialist in-patient care beds, resulting in patients being stuck in ED for long periods. 'Long stays [in ED] are associated with suboptimal treatment such as restraints, seclusion and lengthy periods of sedation.'[38]
A number of consumers reported checking themselves in to an ED, itself not an easy task for someone in serious mental distress, only to be told they were not sick enough or checking themselves out without having been treated after a long delay. Data shows that people who present to an ED in mental health crisis are the group most likely to wait more than 24 hours for admission to a mental health ward, during which time people can be sedated, secluded and physically restrained.[39] Consumers also discussed what an unpleasant physical setting and environment the ED for someone in serious mental distress.

> *Clinical services are the most stigmatising area [of mental health care] and the most stigmatising staff are ED staff.*
>
> *The ED is totally the opposite environment necessary for someone in mental crisis, long wait times, chaotic environment.*

Another area of concern for consumers and their carers is the NDIS. It is recognised that there have been benefits for those individuals with mental ill-health who have been able to access the NDIS. There is also a strong feeling the Scheme has enabled a wider conversation to take place about mental health. But consumers and carers are critical of the NDIS's complexity and overly bureaucratic and transactional nature. In this quasi-market, the cost of delivery is calculated on the principle of an 'efficient price' for transacting the support provided, without counting the cost of what it means to provide that service to someone with a psychosocial disability or serious mental health issue, including the capabilities and time required to deliver the service in relationship. As a result, the Scheme is failing to deliver practical and emotional psychosocial supports that are needed by people to address day-to-day barriers to gaining/regaining a productive and meaningful life.

Mind staff are aware of clients for whom the pressure of NDIS involvement has exacerbated their mental health problems. This is also borne out by soon to be published research carried out by Deakin University academics and Mind on understanding people with psychosocial disability as choice-makers in the NDIS. While the research underlines there have been benefits for participants in the Scheme, it also emphasises the considerable 'labour of choice' facing consumers and carers at each stage of the NDIS process and how complex and often extremely difficult this can be.[40]

It is not Mind's intention to re-prosecute problems with the Scheme that are already the subject of inquiry/or remedial action in other forums. Problems, which it must be stressed, the NDIA is aware of and in many cases attempting to tackle. The key point to emphasis in the Victorian context is the shortfall in mental health service provision resulting from the bilateral

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[38] Australasian College For Emergency Medicine, *The Long Wait: An Analyse of Mental Health Presentations to Australian Emergency Departments*, October 2018, 1.

[39] *Mental Health in the Emergency Department Consensus Statement*.

[40] Erin Wilson, Robert Campaign, Sarah Pollock, Lisa Brophy, Anthony Stratford*, Understanding people with psychosocial disability as t-makers in the context of the National Disability Insurance Scheme (NDIS)*, Deakin University and Mind Australia, forthcoming.

agreements and consequent disruption of NDIS implementation on the mental health ‘ecosystem’.

This submission has already noted that only a small proportion of those Victorians with significant mental health issues will qualify for individualised support packages and many do not meet the requirements for ‘permanent disability’ due to the episodic nature of their illness. Those that do not qualify remain reliant on non-NDIS health services to meet their needs, many of which are being underfunded or funding is rolled into the NDIS. Among the services specially mentioned by consumers and carers as being valued and which have transitioned or are in the process of transitioning to the NDIS, are:

- The Victorian Psychiatric Disability Rehabilitation Support Service, which provided disability supports to people with functional impairment related to mental illness.
- The specialised community care program, Helpers and Mentors Scheme (PHaMs).
- Partners In Recovery (PiR), which provided flexible funding for a range of activities and funds to facilitate engagement and which was seen as working particularly well with people from non-English speaking backgrounds.
- The now defunct Mental Health Nurse Incentive Program, which funded community based general practices, private psychiatry practices and other appropriate organisations to employ a mental health nurse to help provide clinical care for people with severe mental disorders in a range of settings, including clinics and private homes, at little or no cost to the patient.

While some staff from these programs will be transferred to the NDIS as support workers, the end or impending end of these programs has resulted in the loss of hundreds of specialist mental health workers with major implications for service continuity. The Victorian government has started to recognise the support needs of people with mental illness who are not eligible for NDIS, or who do not want or able to apply. The Commonwealth has also attempted to meet funding shortfalls created by the NDIS through the provision of PHNs. The performance of PHNs has its own failings, discussed in more detail in our response to Terms of Reference 2.4.

Solution

Mind believes the Royal Commission must provide clarity on the question of what role the Victorian government should play in the space between what the NDIS provides to those with a psychosocial disability and what is provided by clinical and acute services. This space occupied by NGOs, a vital component of a comprehensive mental health response, is being put under major pressure due to funding cuts, tight commissioning frameworks, the over commercialisation of service provision and workforce shortages. And, put simply, if action is not taken it is in danger of largely disappearing as an effective component of the mental health system configuration.

In terms of the Commission’s deliberations on this matter, we also suggest that attention should be paid to what gaps exist or are emerging for people with high, very high and complex needs, regardless of whether they are eligible or ineligible for NDIS, and what role the state government has in meetings these:

- Services for family carers of people with high impact illness, particularly flexible respite.
- Assertive outreach for people who may find it hard to engage with services, particularly those who live in marginal accommodation and/or are homeless.

- Supported housing for people recovering from severe or prolonged episode/s of illness.
- Greater access to psychological therapies.
- The capability of existing services to provide trauma informed care.

As part of this, it is important for the Commission to attempt to put a dollar figure on the investment necessary to reverse decades of under-funding and bring Victoria up to at least the national average in terms of access to mental health services. A mid-2018 estimate by MHV put the amount of funding needed to boost mental health services at $542 million by 2022.[41] It claimed this figure, which does not include separate but necessary investment in areas such as mental health related housing, would generate an estimated $1.1 billion in savings per year, particularly to our hospital and justice systems over the long-term.[42] However the Commission will no doubt wish to calculate its own figure based on the evidence presented to it and more up to date economic forecasts.

It is also crucial that the Commission examine the significant service system and workforce needs required for Victoria's physical and mental health service system to effectively liaise, engage and intervene in a range of 'non health supports' within the state government jurisdiction. These include housing and homelessness, education, justice, disability, and policy interventions designed to achieve greater social inclusion and equity, particularly by historically marginalised groups. In line with our earlier discussion of the importance of a well-funded and conceptualised psychosocial service response, Mind maintains these supports are in fact a precursor to gaining/regaining the good health that is required on the part of many people when they are mentally unwell to be a productive and functioning member of society. For instance, it is not possible to recover from a severe or prolonged mental illness without safe and secure housing.

Longer-term system reforms to address the situation above include a clearer conceptualization of mental health need, with distinctions and interrelationships between clinical mental health treatments, rehabilitation supports and disability supports. When insufficient support is provided, or is not timely, the functional impact of mental illness is likely to increase.

Some consumers and their carers consulted by Mind as part of the development of this submission, reported being turned away from the NDIS. One possible answer to what is needed in terms of service system reform, is a tiered response that would give people access to psychosocial rehabilitation services (with an early intervention focus) first for a period of up to five years. Those with ongoing support needs beyond this time would then be automatically eligible and a 'warm transfer' to the NDIS. This is an inversion of the current arrangements, where people are asked or required to apply for the NDIS first, and only when deemed ineligible can they then be considered by other programs (for instance, those currently being commissioned through PHNs).

Whilst we recognise that some of these broader system reforms are beyond the jurisdictional purview of the state Government, Victoria has an important role to play in advocating for a more co-ordinated, integrated and targeted national system of treatment, care and support. Such reform could include a nationally consistent, standardized approach to assessment, available to anyone whose needs cannot be met through the Medicare Benefits Scheme (MBS) alone. This would, amongst other things, allow for the speedier assessment of those

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[41] *Saving Lives. Saving Money*, 13.

[42] Ibid, 5.

potentially eligible for NDIS assistance for those with psychosocial disability. Standardised assessment would comprise:

- An assessment service available to anyone with mental health issues who is also showing signs of reduced functional capacity ('red flag' or marker that a greater level and different type of assistance may be required). This would include a no 'wrong door' access to the assessment service.
- The use of standardised assessment tools implemented by multidisciplinary teams (rather like the comprehensive needs assessments undertaken in the UK, as part of the National Health Service response to frail aged people).
- Holistic assessment undertaken in the individual's regular living context and over time so that components can be built over a time frame that includes their functioning in the diverse circumstances that make up their daily life, with the flexibility to accommodate differing levels of complexity and functioning.
- The collection of standardised outcomes measures and satisfaction data.
- The development of a holistic care plan for an individual that the full range of providers then contribute to across the medical, psychosocial, social and community services sectors. The plan should take full account of their living situation and family support needs where relevant.

The process, which could also be undertaken as a Victorian initiative, would ensure that people were directed to the appropriate funded program (for instance, psychosocial rehabilitation outsides of the NDIS before being tested for NDIS eligibility). This would ensure more effective targeting of resources with less waste and duplication.

To ensure co-ordination at the individual and family level, each person/family accessing psychosocial and social supports for their mental health could be assigned a trusted worker who acts as a point of connection with services such as:

- Clinical mental health services, including in-patient services.
- Psychosocial rehabilitation.
- Social and community services (housing, education, employment, children, youth and family support).
- Disability services delivered through NDIS (if required).
- Physical health services.

The trusted worker role should combine elements of case management and facilitation, system navigation and support. Workers with a range of experience and qualifications, including peer workers, could undertake this role. In some cases, a team of workers might provide co-ordination supports in relation to mental health and non-mental health service systems.

2. How to deliver the best mental health outcomes and improve access to and the navigation of Victoria’s mental health system for all people of all ages, including through:

2.1 Best practice treatment and care models that are safe and person centred.

The following section relies on feedback from mental health service consumers and their carers and families, gathered during the face-to-face and online consultation process ran jointly by Mind and Wellways. These responses are important to explore as they provide the clearest picture of the problems in the system and what is required to deliver better mental health outcomes and improve access to care.

Problem

The consultations threw up significant issues with the Victorian mental health service system at all levels.

> *I know that in reality the system is currently doing the best it can, and I acknowledge that. I probably wouldn't still be alive unless it was for the system. But I just hope that for the future things can be done better and more effectively, so that it can help those who are experiencing mental health difficulties for the first time. The system sucks for old hands like me, but it's way worse when everything is new and terrifying. And I guess I hope that new generations don't have to go through what I went through.*

Many consumers are angry and frustrated at being made to cycle from crisis to crisis within what they describe as a confusing and poorly designed service system. Others talked about having to take up the time and resources of EDs and ambulance services, which they would not be forced to do if service responses existed that intervened before their illness reached crisis point. Many feel their views are not listened to and that they are marginalised in their own treatment – when they can get a treatment response at all. One online respondent described their experience with the system thus:

> *I have been suicidal, and then attended an emergency department in the east of Melbourne, only to be told that I wasn't suicidal enough to warrant a bed. I could not get any help at all, because my behaviours were not extreme enough. The hospital had to make a choice who got the one bed they had available. There were no services for those who didn't get the bed. So I was left out in the community without any services, and I was still suicidal.*

The person experienced further health problems.

> *Over time I was put on long waiting lists for a bulk-billing psychiatrist, but I couldn't wait the 3 months, to see one. I was still suicidal, so my behaviours deteriorated, I overdosed, I self-harmed, I was treated at the public hospital and repeatedly sent home still suicidal. They had no beds. They had no other services except ones with long waiting lists. At one stage I was in an ambulance every 72 hours.*

The individual’s health deteriorated further.

> *I was full of guilt for using ambulances like buses, but if I went in an ambulance I was taken more seriously than if I just walked in* [to an ED]*. The Public hospital system was creating an ambulance frequent flyer. I just wanted help. I would do anything to get relief from my mental health symptoms. I learned over time, how to overdose, I learned to do serious self-harm, to warrant the use of the ambulance. Just how much did Victoria spend failing to treat the cause of this which was my mental health? If I had been given a bed when I needed it, my behaviour would not have needed to get to the extreme.*

While much of the criticism was focused on clinical mental services, funding problems are also seen as impacting the quality of care provided by community providers. As this online respondent put it:

> *Community mental health organizations are operating on such tight margins that even though we are promised "choice and control", I feel like it much more a case of "frustration and disappointment"! They don't have any funding for consumer engagement anymore & it is really hard to get skilled/experienced workers even when you have lots of funding. They also often use admin staff to do bookings who don't have any understanding of how emotionally vulnerable mental health clients can be at times. And when workers ring in sick there is often no one to cover, even if you have a specialist appointment (or similar) to get to.*

Impact

The impacts discussed by consumers and their carers and families can be summarised as follows:

a) Point of entry and navigating the system

The lack of a clear entry point into the mental health system was a common concern. The dearth of easily available information about what support services exist for people with mental health issues, where these are located, and what the eligibility criteria are, were also concerns. Consumers who have been in the service system for some time commented on what a difference for the better it would have made if the knowledge they had now had been available to them when they first entered the system. As one consumer who now works as peer worker put it:

> *There are a lot of things you learn after seven years [in the system] that would have been helpful to know in the first six months.*

Some expressed a sense of alienation at being left alone to research and figure out how to navigate such a complex service system. As one person with lived experience put it:

> *It was very bumbling for me for a long time. I was not able to find the right information at first and it delayed my understanding for a long time.*

While some found the increasing emphasis on digital and phone-based services worked as a means of providing support and liked being able to self-research their own condition online, others found it difficult.

> *Don’t do everything by phone. How can you deal with a person in crisis on the phone?*

Online and phone based services were seen as particularly inappropriate for those from non-English speaking backgrounds. One service worker who deals extensively with the Chinese community commented that face-to-face interaction was the best means of contact with that cohort. This is due to language issues and the fact that:

> *A lot of people don’t understand community services in Australia. It takes a lot of time to explain what they do. Also, many people are suspicious of government authority. Once they understand it is not a government investigation they will start to accept the service.*

Others mentioned something as simple as not having enough mobile phone data as a major impediment to accessing services.

b) Service responses only occurring at the point of crisis

As already noted, for many, the mental health service system only responds when an individual has reached the point of crisis instead of supporting them to avoid becoming more unwell and having to seek a clinical admission.

Consumers are clear that the shortage of beds in in-patient units, CCUs and PARCs has meant an increased level of acuity to qualify for admission and shorter stays for those who are admitted. Several consumers reported being turned away from EDs for not being sick enough, which creates a sense of desperation and encourages people to behave in more extreme manners in order to get admitted.

> *The biggest challenge that I have faced with mental health services has been getting a bed in a public hospital Psych unit. So that I could access services for my mental health, get a diagnosis and start treatment.*
>
> *Trying to get an emergency appointment with a psychologist. Waiting times are a killer. Even the CAT Team often does not answer the phone in person. That's deadly for someone who is suicidal. It would be good to have a place at a hospital or facility, where people are given support but not 'locked up'. That is any person who suffers from mental health issues worst nightmare*

c) Quality of mental health care in the mainstream medical system

Consumers and carers understand the pressure clinical and community mental health and staff are under and value the service they provide.

> *It was difficult to get my son into hospital, but once he was there it was such a relief to have him in there with trained psychiatric staff who were very helpful.*

They raised many issues, however, particularly in regard to the inappropriateness of EDs as a response for someone in severe mental distress. As one online response expressed it:

> *Recently I was feeling suicidal and was in a public hospital in Melbourne. I waited several hours in the emergency room to see a doctor because for obvious reasons I*

> *was not as emergency (sic) as those with a physical condition. But waiting so long made the overall experience even worse and I frequently thought of leaving the hospital to go and overdose. I stayed because it was an unknown hospital, area, and it was the middle of the night. By the time I was seen in the ward it was 3am, and not seen by the treating psychiatrist until 4pm the following day. This experience has been quite traumatic and I would avoid the public system at all costs now. This places an additional burden on my private psychiatrist who for obvious reasons cannot be there all the time.*

Consumers reported poorly treatment by ED staff, including being sedated and restrained against their will and kept waiting in a secluded area for long periods of time.

> *I also support a close friend who has serious mental health issues and trying to navigate the public mental health system with her the past year has been an absolute nightmare! She has been handcuffed by police (despite not being violent), transported to hospital by ambulance on a section 351, tied to a trolley in ED, forcibly medicated, locked in HDU [High Dependency Unit –a hospital unit for patients that need a high level of monitoring and care] overnight where I am not allowed to see her, then discharged home the next morning in a worse state than when she went in. Once she was discharged home on a Friday afternoon, straight from a 3 night admission in HDU, with no safety plan, no support and still acutely suicidal. I am not in a position to provide the level of support she needs, but I also can't just sit back & watch her kill herself!*

A number of consumers reported being labelled as hostile, angry or non-compliant when they questioned medical staff about their treatment. One case involved an individual admitted to hospital for a mental health problem, who had to stay for a long period while the staff got the dosage of new medication right. The high caseload for the community team attached to the Area Mental Health Service meant it could not be done in the home. When the person questioned why they had to stay in hospital for so long (against the principle of least restrictive practice set out in the Mental Health Act 2014), they were told that they would be chemically restrained if they continued to question the clinician’s decision.

d) Service fragmentation

The service system is seen by most as completely fragmented.

> *Gaps? These aren’t gaps. These are great big holes. Craters. Huge. Where people get stuck and forgotten. We keep talking about how people need to link better to services. There aren’t any services! Or if there are, they are full.*

Poor linkages occur at a number of points:

- Between different types of service delivered by different parts of the overall health and social care system: the ED and acute in-patient services, specialists and GPs, clinical mental health services, and NGO services.
- Between different approaches to reduce or remove symptoms and psychosocial wellbeing and interventions to enhance life in the home and community.
- Between mental health and other service systems, such as homelessness, justice, education and employment.

- Across geographical catchment areas, particularly the regions that govern the provision of Department of Health and Human Services (DHHS) housing, homelessness services, and family violence services.
- At various life stages, for example, transferring from youth services to adult mental health services, then exiting this system into aged care.

One carer described the impact of his long-term mother who had enduring mental ill-health turning 65 in particularly stark terms:

> *We went from having good support to zero. Once you hit 65 you move into the aged care system. A lot of services for aged care don't provide supports for mental ill-health. You wouldn't cut off service to someone with a heart problem but that is what happens to people with mental illness. This happens for a lot of reasons, a key aspect of which is that they can't advocate for themselves.'*

A number of consumers and carers reported the task of linking to and between services has become harder with the transitioning into the NDIS of support programs such as PHaMs and PiR. Consumers and carers were also concerned about constant changes in the staffing. The resulting lack of continuity of care is exemplified most clearly in consumers having to retell their stories with each presentation to a new service or change of worker.

> *I personally have had multiple case managers and support workers over recent years, which then requires me to have to relive traumas again to start the process again.'*
>
> *The worst therapeutic thing is to have to keep telling your story over and over again.*
>
> *There is a huge turnover of carers. We would just start developing a relationship and they would disappear.*
>
> *By the time he opened up to a support worker, there was a new one. My son would say 'mum, why do I have to keep telling my story over and over to new people'.*

e) Issues relating to service configuration

Problems with the fact that many services operate within certain time periods were raised in the face-to-face and on-line consultations. Services are mostly delivered on a weekday 9am to 5pm basis when support was often required out of hours or on the weekend. Public holidays and long weekends were dreaded as a particularly bad time to experience a mental health crisis

> *Mental health services operate on a 9-5pm basis. Whatever you do, don't have a mental health problem on a long weekend.*
>
> *My mental health problems are 24/7, whereas the people I am dealing with [in the service system] are part time. I appreciate employment diversity but where is the care?*

The location of mental services was another issue. Consumers and carers argued strongly for the importance of clinical and community mental health services based in their local areas.
Service location was particularly important for people in regional and rural Victoria. Respondents from rural and regional areas reported a major shortage of mental health

services, leaving them with less choice and forcing them to travel large distances to access care and support.

> *[We need] more mental health facilities in the country. More counselling services for people so that can address their issues before it can get too serious.*
>
> *There is not enough funding for regional areas. No venues provided or supervised group for high functioning mentally ill within 10kms.*

According to MHV, low access rates in rural and regional parts of the state occur because there is a lack of available primary health and mental health services.[43] The erosion of services in regional and rural Victoria relates not just to clinical and community mental health but associated service systems such as homelessness and aged care.

f) The cost of accessing the service system

The financial costs associated with accessing Victoria's mental health system is seen by many as an important issue that is seldom discussed in the reform context.

> *I'm a 57-year woman on my own but coming from a professional background there is an assumption I don't need bulk billing services or a broad range of services. I struggle every day but cannot afford the money or the waiting periods to access services. Mental health crosses all groups in society. Specialist GPs would be a start. I fall in the middle, can't afford private care but not eligible for concession rate care, so I drift on, getting more unwell, less able to support myself and a future of possibly homelessness and poverty. Help the ones in the middle too.*

This issue also needs to be viewed in the context of NDIS implementation which is resulting in people having lost or in the process of losing support services with the result that they either had to make do with nothing or seek alternatives. This sometimes comes at significant financial cost, particularly for those on a Disability Support Pension (DSP). Other consumers said they had had to maintain private health insurance to meet support needs, despite the significant financial cost of doing so.

While respondents understood it was a Commonwealth matter, the most commonly raised cost issue related to limitations around the 10 publicly funded consultations with a psychologist provided under Medicare. Ten sessions were viewed as not providing enough time for consumers to develop a relationship with their psychologist. Additional support is also required for those preparing to enter the labour market and for serious mental health conditions. Several people discussed the difficulties of trying to find a psychologist that bulk billed at the conclusion of their 10 sessions and being forced to pay full cost to access counselling.

> *Psychiatry needs to be made more readily available locally and bulk billed. The 10-visit health plan for psychology should be extended to 15-20 visits per year.*

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[43] For more information see, Mental Health Victoria, *Accessibility and quality of mental health services in rural and remote Australia*, May 2018.

> *Financial pressure when you need to see a counsellor frequently and run out of subsidized sessions mid-way through the year - more sessions should be given to people with complex mental health issues!*
>
> *My consultant psychiatrist is amazing (and life-saving) but I have no idea how I will find another specialist who only charges the schedule fee & who specialises in trauma & dissociation if/when she retires.*

Other issues related to the financial cost of accessing mental health services included:
- Access to drugs that are not on the Pharmaceutical Benefits Scheme.
- Travel to access services, especially for people from outer suburban, regional and rural areas.
- The difficulty of seeing appropriate individuals without private health insurance, especially for those with rare or unusual diagnoses. Some consumers maintained private health insurance to access services such as trauma therapists despite the cost, which was particularly significant on a fixed income.

It is not just strictly defined clinical treatments for people when they are mentally unwell that are difficult to access. As one on-line respondent put it.

> *One of the best activities for mental health recovery is exercise. The cost to attend is out of the range for people on disability support pension. More funding for activities of which participant is interested in. Music lessons, art lessons, gardening, walking groups, social outings.*

Solution

We have already discussed the need for a single point of entry and standardised, comprehensive assessment described on pages 16-17 and 19 of this submission. We now draw attention to what a ‘person-centred’ system of care might look like. While the importance of ‘person centred’ treatment and care is raised by the Royal Commission, what does this actually mean in the context of the mental health service system? Consumers and their carers and families did not use the term person centred care, but their responses capture what needs to be changed in order for it to be delivered.

a) Being treated with respect and being consulted about their care

> *Feeling mentally well means a sense of connection, belonging and place, and having power over your life. Not living in shame for your lack of competencies.*
>
> *GPs and psychologists (and other allied health workers) need to be funded for the time it takes to do good multi-disciplinary care so that workers can communicate properly, not just pro-forma letters written in a hurry to tick the box for Medicare referrals.*
>
> *A trusting, respectful relationship with your specialist is vital.*

A respectful relationship between the person experiencing mental ill-health and their clinical provider or GP is vital. This means being consulted about treatment and the recognition by clinical staff that the consumer is an ‘expert by experience’. It also means not being belittled or having their condition made light of by medical staff, as some consumers reported had happened. As part of this, some consumers mentioned the importance of being allowed to try something new, take risks and not worry about setbacks.

> *[What we are after] It is progress, not perfection. It is never going to be perfect.*

Having a GP with a good knowledge and referral base, who takes the time to get to know their patient and does not jump to conclusions about the patient's physical and mental health, was also seen as vital. As is access to a good psychiatric nurse, someone in the system but who understands how it works from a mental health perspective and can explain and decode it for a person in mental distress. It is also important to consumers that GPs and medical staff made carers and family members feel like they are included in their treatment.

b) The value of a psychosocial and social response

While consumers did not use the terminology of psychosocial and social responses, the importance of these is implicit in their emphasis on the need to treat the 'whole' person and not just the mental illness in a narrow clinical sense. People wanted services that enabled them to develop a life outside of the narrow clinical definition of their illness. They wanted help with what was happening in their everyday experience, what they felt was important rather than what the system proscribed in terms of a treatment or, as one consultation participant expressed it, the 'need to find a hook back into life'.

> *Focus on the person and what they need now. Focus on the future rather than going over and over what has happened.*
>
> *My diagnosis is only one dimension of what is happening to me. I need safe housing. I want to find things I can do. I would like some friends. I worry about money.*

This assistance can take many forms, from looking after a pet, to singing in a choir, to learning how to cook. For some it was getting the skills to engage with the wider world, such as financial advice or a housing advocate. Relationship skills were also seen as important to fight social isolation and loneliness, reconnect with family and friends, or repair relationships which may have been damaged during an episode of illness.

Some expressed the need for structured social groups that were not related to their context as someone with mental health.

> *It is important that you have access to social groups that do not take place within a therapeutic environment. Sometimes you just want a book club that is a book club.*

Several people mentioned the importance of getting help to gain employment.

> *I just want to work. I liked getting up and having something to do. I didn't think so much. I wasn't alone in my head so much.*

c) The value of a good support or service worker

Consumers and carers talked a lot about what they wanted in a good support or service worker, often as a proxy for the changes they would like to see in the broader system.

These competencies are explored in greater detail in our response to Terms of Reference 2.2. For now, what is important to emphasise is that what consumers most wanted from a service or support worker is continuity, whether it is clinical, community or crisis services. Long-term relationships between consumers and service workers build a sense of trust and stability, which can be vital in helping recovery.

> *Routine [is vital]. I have been in the system for more than 20 years. Routine is so important to help you recover. You can get lost in the whole structure of the mental health system. When you are in the right pattern it is easier to build on this and make yourself better.*

Consumers particularly value the sense of someone they can trust, who knows them and their story. Consumers and carers also discussed the importance of staff that 'go the extra mile to help', as one put it. This might involve accompanying them to a GP, making connections to services, or following up with a consumer after a stay in an in-patient unit. Consumers and carers realised that this level of service would only happen if staff were better remunerated.

Consumers also expressed a desire to have something in common with their support workers.

> *It is important to pair workers with clients who have similar experiences. I need something in common with a person to make me feel comfortable spending time with them. Why would I want to spend so much time with a person who I have nothing in common with?'*
>
> *'Being able to connect is fundamental. People who have mental health issues will be labelled for turning away from someone they have nothing in common with, where it is in fact a very normal thing to do.'*

Many consumers also stressed the value of having someone with lived experience of mental illness involved in their care.

d) Having a safe space to recover

One topic, discussed at length by those taking part in the consultations, was the value of a safe space to recover from mental illness. The value of PARCs, in particular, was mentioned and it was argued more of these were needed. Jointly run between area mental health services and community providers such as Mind, PARCs offer 24/7 sub-acute short-term accommodation (28 days maximum) and clinical and psychosocial supports for people stepping down from a hospital stay or as a step up to avoid hospital admittance. PARCs were described as a safe and nurturing environment that allowed people the time and space to get better and build their skills and confidence, as well as taking the pressure off families and carers.

> *PARC was great, relaxing and I had my own space. The CATT team visiting was good, I felt cared for, a more holistic approach than the [hospital] ward.*
>
> *You have the opportunity to reintegrate life skills in a PARC…if you are having a bad day there is someone to talk to.*
>
> *They look after mental health stuff but they also teach you everyday stuff. Like cooking, looking after a place, sharing responsibility for things, how to live with people again.*

Not all the feedback was positive, however. The flow on effects to sub-acute services from the increasing demand and level of acuity in Victoria mental health system was viewed by some as having had a negative impact on the ability of PARCs to provide quality care. Pressure for greater patient throughput is resulting in people leaving who are still very unwell. There were also reports of high staff turnover and that PARCs can sometimes feel neglected and uncared for, with one carer observing that the neglect of the person is reflected in the neglect of the spaces within the services provided. This person stressed that this was not the fault of the people working at the service but the lack of money in the service to cover cleaning and to enable staff to spend time to help clients look after the spaces they shared and lived in.

> *My daughter was going into PARC [and] her room was really messy, dirty. I went in and cleaned it for her before she got out. I thought to myself when I was cleaning it [her allocated room] this isn't fair. This is someone's home.*

One consumer reported PARC staff getting annoyed with her for not sleeping and feeling suicidal. After repeated requests to go to hospital, she reported that PARC staff drove her to hospital and dropped her in the car park.

> *I just got dropped off on the way back from dinner. I spent 15 minutes just staring at the traffic, thinking bad thoughts before I managed to get myself to the hospital. This was several years ago.*

e) Increasing the number of publicly funded sessions with a psychologist under Medicare

Consumers and carers agreed there was an urgent need for the Victorian government to lobby the Commonwealth to increase the number of publicly funded consultations with a psychologist under Medicare.

Mind would argue that at least 15-20 sessions per year should be funded. We would add that those experiencing particularly serious mental health problems should be able to access up to 40 sessions.

The Victorian government could also take a more proactive stance on two related issues:

- Introducing a scheme to pay the gap fee in health services for those on low incomes.
- Pressing for those with a psychosocial disability to be able to access psychological therapy as part of their support needs under the NDIS.

2.2a Strategies to attract, train, develop and retain a highly skilled mental workforce, including peer support workers

Problem

Victoria faces a looming crisis in relation to its mental health workforce, both retaining the current workforce and attracting new entrants into the mental health related professions to meet future population needs. According to the Victorian Auditor General's Office, many of the factors underpinning this situation are common to mental health services generally across the state.[44] Mind's comments, however, will focus on its concerns regarding the skilled psychosocial workforce leaving the NGO sector and the difficulty of finding suitably trained replacements.

As previously stated, an effective mental health response not only focuses on interventions to meet people's clinical needs, in the form of treatments and therapies delivered by doctors (GPs and psychiatrists), psychologists, and mental health nurses, but psychosocial and social supports. These supports include care, service coordination and navigation, as well as a range of 'non-health' supports, such as housing, social inclusion, assistance with undertaking education and training and gaining employment.

These supports, which are particularly important in relation to 'high' and 'complex' needs consumers, are mainly provided by the NGO sector. To undertake them, Mind employs a diverse workforce that brings together specialist (i.e., trained to undertake assessments, deliver and oversee technical interventions), and specialised (i.e., trained to work with a particular cohort, delivering more generic skills sets) staff. This workforce, which at times also operates in partnership with clinical services to deliver integrated clinical and psychosocial care, includes:

- Certificate-qualified mental health practitioners who provide step-by-step practical and emotional assistance to help people get back on their feet after a period of illness.
- Degree-qualified practitioners to provide complex care co-ordination and support facilitation, behavioural supports and other complex interventions.
- Registered allied health professionals (occupational therapists, psychologists, and mental health social workers).

Mind is concerned by the significant workplace challenges facing NGOSs working in the community mental health space, which threaten the provision of vital psychosocial and social support services. These are the result of:

- Increasing levels of stress and burnout related to the growing complexity of service provision and greater acuity of the NGO sector is being called on to deal with. Related to this are issues arising from mental health workers experiencing trauma vicariously through their work with high needs clients.
- The combination of tight service delivery timeframes and commissioning models, underfunding, delays in contracts being announced and significant problems resulting from the increasingly transactional nature of service delivery.
- Uncertain funding arrangements that see short-term funding contracts, insecure work, and pay that does not reflect the specialised nature of the work undertaken, all of which result in significant recruiting challenges.

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[44] *Access to Mental Health Services*, 35.

Impact

> *Mental health workers get burnt out. They don't know it until they get to the point where their attitude changes for the worse. They need more support to do their jobs.*

The current configuration of short-term funding contracts, delays in contracting, and short notice periods for contract end dates, is combining to create uncertainty for workers. This is evident in rising sick leave, turnover rates and difficulties attracting, recruiting and retaining staff.

Mind’s annualised turnover rate (based on resignations) has run at around 22% for a number of years. However, in the last year, we have seen this increase to as much as 29% in some parts of our business where the impact of NDIS transition has been strongly felt. It costs Mind around $30,000 to replace a frontline worker, in recruitment, training, getting up to speed etc. There is also substantial impact on worker wellbeing, with role insecurity, insecurity about employment, and the stress of carrying the burden of uncounted emotional labour compounding each other.

Across the community-managed sector it is becoming harder to attract, recruit and retain people with the appropriate specialism. We are at risk of losing a whole segment of the workforce with the capabilities to address the social determinants of mental health and assist people to connect and reconnect with meaningful and productive activity. These issues are impacting the NGO sector across the board but are particularly pronounced in regional Victoria, where isolation, limited access to professional development, inadequate management and professional support structures, make finding appropriately qualified staff even more difficult, often resulting in a reliance on casual staff that makes continuity of care difficult.

In short, the current system configuration threatens the viability of NGO mental health providers. Increasing commercialisation favours providers that adopt a lean business model based on rapid throughput, with staffing profiles below the minimum certificate 4 skill level qualifications and on lesser pay and conditions that those in the Social Community Home Care and Disability Services Industry Award (SCHADS) preferred by Mind. We consider that Certificate 4 is the entry-level qualification, and SCHADS the most appropriate industrial framework for the specialised psychosocial workforce to deliver the recovery outcomes sought by consumers, their families and carers, and by government. We have chosen to continue to

Related to this are the problems resulting from the increasingly transactional nature of service delivery. This is where the cost of delivery is calculated on the principle of an ‘efficient price’ for transacting the support provided without counting the true cost of what it means to provide that service to someone with a psychosocial disability or serious mental health issue, including the capabilities and time required to deliver the service. The true cost of a service that can deliver recovery outcomes needs to take account of the service delivery relationship between a person needing assistance, and a person providing it. This is particularly important in the light of feedback from consumers and their carers and families about the skills and aptitudes they value in service workers. These include:

- Deep listening and empathy.
- Compassion.

- Understanding of the interplay of different clinical and social service domains, and the ability to understand what is going on in the clinical but respond with psychosocial interventions.
- Understanding of contextual factors such as economic and social disadvantage, or the needs of particular cohorts such as Indigenous or LGBTIQ+ people, and how this might apply to their mental ill-health.
- Understanding of how the various symptoms of mental ill-health manifest in functional impairment and the ability to work with the person to improve that function and not just assess it.

These capabilities are a mix of generic social services skills and the ability to work effectively with people with serious mental health challenges. Examples of how these skills manifest in service provision that emerged during the consumer consultations for this submission include:

- A skilled community mental health worker will identify that the client may want to develop skills around self-catering, and work with the person on small steps to improve their functional ability in this area. This may include the steps necessary for someone to leave the house, shop, and cook. In contrast, under the NDIS meals may be delivered.
- An NDIS support worker may ring a consumer up and ask to visit them. That consumer may say they do not want the visit, in which case the worker will not do it. An experienced psychosocial worker, who, ideally, through having cared for the consumer over a period of time, will know that the consumer in question may need the visit and may even want it to a degree, will find a way to visit. For example, they will use the excuse, 'I was passing by and wanted to drop in'. The value of this assertive outreach was mentioned by a number of people.

Under the current service configuration, the emotional and mental labour, and the time, to provide this level of psychosocial support are no longer a funded component of the work. They still occur but are unfunded, adding to service staff's workloads and emotional burden. This is also true of the kinds of liaison necessary between workers within a service and between different service systems and organisations, to ensure that support for any given individual was effective and contributed to positive outcomes. Although it is not always articulated as such by consumers and carers, the constraints imposed on service workers by low funding levels, 'efficiency' prices, and tight commissioning frameworks, etc, are often what is behind many of their negative experiences with the mental health service system.

As the NDIS is bedded down, a better understanding is emerging of what service gaps exist; particularly those focused on mental health rehabilitation and addressing social determinants, across the system. However, it is likely to take at least another five years before the system configuration implications of the NDIS are fully understood. But if the capabilities of the NGO workforce are inadvertently eroded in the interim period, there will be a significant human and financial cost to rebuilding them.

The loss of the NGO managed workforce will adversely impact on hospital avoidance, the service provided by PARCs, and where psychiatric rehabilitation requires a partnership of clinical and psychosocial team based care, delivered as an integrated response and allowing the various professionals to work at the top of their scope of practice. Funding pressure and diminishing capabilities in this workforce will also impact on our ability to invest in new, innovative programs and approaches, such as mainstreaming the peer or lived experience workforce and training new and existing staff to deal with the increasing level of complexity and acuity in those seeking its services.

The impact of stress on the paid mental health workforce is also replicated amongst unpaid carers. Any shortfall in service coverage or other system failure impacts on unpaid family carers in much the same ways as it impacts on the paid workforce. Yet unpaid carers lack the protections offered by paid employment contracts. They do not routinely access training to support the changing nature of the care work as the systems around them change. They generally are not consulted in change processes. Yet when system fails, it is often the unpaid carers who are left to pick up the pieces.

Solution

The mismatch between needs (particularly in relation to psychosocial rehabilitation) and the current capability of mental health services must be addressed in future workforce planning.

Victoria has a *Mental Health Workforce Strategy* published by DHHS in 2016. This covers the estimated 5000 workers in clinical mental health workers across the state and the approximately 1300 NGO staff working. While we acknowledge the 2018/19 state budget contained $34.2 to implement this strategy, mainly through reducing occupational violence against mental health work force in in-patient units, the improved service delivery principles in the *Mental Health Workforce Strategy* remain aspirational. It contains little in the way of hard thinking about the skill, aptitudes and staff numbers that Victoria's future mental health workforce will require. The Auditor General's Office makes the same point:

> Despite this range of workforce activities, it is not clear what DHHS aims to achieve through its workforce strategy and initiatives, as it has not set quantifiable performance indicators or targets, and there are no plans for a formal evaluation…. DHHS requires a clear understanding of the numbers and types of staff needed, and where and when they are needed, to enable its broader service reforms to occur. This in turn would inform specific targets. Without such ways to measure progress, DHHS cannot track whether its investment in mental the workforce strategy and initiatives is growing and supporting the mental health workforce. The strategy also does not directly address the identified issues of higher workforce gaps in regional and rural areas.[45]

It is also important to note that the *Mental Health Workforce Strategy* contains no mention the question of wage growth for the overwhelming female community mental health workforce, to make it a more attractive career option, in the face what is an increasingly difficult, complex and, at times, dangerous profession.

A comprehensive workforce strategy should consider arrangements to support a mixed community-managed mental health sector workforce, covering allied health (including some clinical components), rehabilitation and disability support. We contend that the NGO sector is well placed to deliver appropriately governed psychosocial and clinical services (i.e., clinical case management, mental health nursing) more efficiently and economically than in the current model that separates out clinical and medical and NGO psychosocial support. As part of this, Mind would like to see more opportunities for more services that are delivered through NGO/clinical partnerships and NGO partnerships with private psychiatrists. We would argue that such partnerships are valuable not only in terms of cost effectiveness but because recovery oriented practice is far more effectively delivered via the NGO sector than through clinical providers.

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[45] *Mental Health Workforce Strategy*, 37.

In the shorter term, Mind would encourage the Royal Commission to examine a range of additional measures that could be undertaken by the state government:

1. Examining opportunities to streamline arrangements and reduce the burden of responding to tenders, as well as contractual compliance. Mind's current compliance and accreditation costs sit at over one million dollars on an $80 million turnover.
2. Considering where block grants, rather than competitive tendering, is more likely to lead to better services, as well as improved outcomes for staff. These include a greater sense of employment security and flexibility to renumerate high performing staff above the award and keep them in the sector, either in terms of pay, development or additional leave entitlements.
3. Support for advanced training to cope with the increasingly complex and, at times, dangerous nature of sub-acute care being provided by the community sector, including advanced communication and de-escalation strategies.
4. The development of service models for people with psychosocial disability and for people who require rehabilitation following mental illness that take full account of the specialised capabilities required to deliver effective and safe services to these cohorts of people. In other words, ensure that the emotional labour is captured in the efficient price.
5. Innovative strategies to build a sense of a diverse, long-term career path within the community mental health sector. These could include:
    - The creation of clearer pathways from TAFE/VET into community mental health providers.
    - Industry partnership and projects to offer work experience in a variety of settings - sub acute, outreach, individual living facilities, rotations in a clinical setting, etc.
    - Partnerships with TAFE/VET and higher education providers that would see Certificate 4 qualification plus workplace experience offered as credit towards a degree in psychology.

In relation to this point we would also urge the Royal Commission consider the 2012 Australian Health Workforce Institute report on the role of carers and volunteers in the health workforce.[46] This contained a number of recommendations on how to better support and link carers into the health system. We urge the Commission to consider the needs of family carers in the same manner as the needs of a paid workforce might be considered.

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[46] Peter Brookes, *The Role of Carers and Volunteers in the Australian Health Workforce: Caring in Partnership*, the Australian Health Workforce Institute, November 2012.

2.2b Improved training and professional development for the lived experience workforce

Problem

> *Any organisation that doesn't believe in consumer voices having input will fail because you are not going to have good service outcomes.*

Consumers and their carers consulted in the writing of this submission frequently mentioned the peer workforce as a vital component in the delivery of mental health services. The dominance of the clinical care model, among other factors, however, has stifled the development of a greater role for peers as a viable mental health service modality.

Victoria's *Mental Health Workforce Strategy* puts the number of individuals employed specifically for a lived experience of mental illness within what it says is the 1300 strong MHCSS workforce at just 6%. It claims 'a smaller number of peer staff, consumer/carer consultants' are employed in the clinical mental health work force.[47] While the *Mental Health Workforce Strategy* includes a commitment to 'Further develop and expand the lived-experience workforce',[48] no detailed workforce strategy or numbers are attached to it. While the NDIA has an in-principle commitment to incorporate peer work, the Agency has failed to clearly conceptualise how peers fit into the Scheme including its outreach and community work.

More research needs to be done on why, in an emerging choice based market for disability services, more participants aren't choosing to incorporate peer workers into their individual plans. We believe part of the reason relates to a much wider lack of understanding about the role of peer workers in the disability sector generally. Anecdotal evidence indicates there is a widespread perception that peer workers can only provide one-on-one support to people experiencing mental ill-health, whereas, as Mind conceptualises their role, they can do everything that a non-peer does but from a peer perspective.

Indeed, a 2014 Mind Australia evidence review set out a broad range of models that could be informed by peer work approaches, including community based interventions, group based mutual support, peer education, coaching and telephone based support.[49] However, new roles for the peer workforce are emerging, such as a possible role in helping to deal with the increasing number of mental health presentations to hospital EDs, which came out of consultations for this submission, on which more detail will be provided below.

Impact

Through its failure to pay more attention to peer work the mental health sector is missing out on a crucial service innovation and the improved services outcomes and financial savings it could bring about.

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[47] *Mental Health Workforce Strategy*, 5.

[48] Ibid, 23.

[49] Tori Bell, Graham Panther, Sarah Pollock, *Establishing an effective peer workforce: A literature review*, May 2914.

Mind's commitment to peer work originated in the 1990s as part of a shift in its practice from what might be called 'professional led paternalism' towards peer led partnerships.[50] Mind currently employs 65 people in designated peer/lived experience roles. These individuals are employed at all levels of the organisation, and include consumer and carer peers. We note that our peer workforce has a lower annualised turnover rate than non-peer workforce (14% compared to 21%), and they take less personal leave (including sick leave). We argue that this indicates that, when appropriately funded and supported, a peer workforce can reduce costs as well as deliver improved outcomes.

There is an emerging evidence base pointing to the outcomes and cost effectiveness of peer work. In addition to the findings of the 2014 Mind report,[51] a 2013 report by the UK Centre for Mental Health found that peer workers brought about significant reductions in bed use among the patients they supported, leading to financial savings well in excess of what it cost to employ them.[52] Other research has shown that not only can staff with lived experience function at the same level as non-peer workers, but that they can achieve a range of other positive benefits and outcomes for the people they work with. Examples include the successful use of peer mentors in working with people with serious mental ill-health to cease smoking,[53] a variation on which Mind is currently trialling utilising telephone support services, and the success of an on-line peer support program to reduce stigma, promote social connectedness and improve the wellbeing of individuals with mental health.[54]

Among the outcomes noted in a 2017 review of academic studies on peer work in mental health, were reduced hospital admission/re-admission rates, a reduction of alcohol and drug use, and increased community integration and social inclusion.[55] The review also noted better outcomes for carers, such as an improvement in relationships and support when carers were feeling excluded by services. There was also evidence of benefits from the bidirectional sharing of knowledge between clinicians and peer workers. Other benefits identified in the literature include:

- Greater rates of success working with 'difficult to reach' clients.
- Instillation of hope and the demonstration to the patient that it is possible to move from being controlled by an illness to gaining some control over it.
- Role modelling and use of self-knowledge to better negotiate day-to-day life, including with mainstream human and social service providers.
- Creating relationships based on trust, acceptance, understanding and the use of empathy, better ability to 'read' a client.

Mind's experience is that the use of peer approaches has led to improvements in client independence and empowerment, reflected in increased stability in work, education and

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[50] Erandathie Jayakody and Anthony Stratford, 'Peer work in Mind Australia,' in *Peer Work in Australia*, 71.

[51] Bell et al, op cit.

[52] Janet Meagher, Gerry Naughtin, 'Scope, role and contribution of peer work: derived, synthesised and analysed from selected peer work literature,' in *Peer Work in Australia: a new future for mental health*, 24.

[53] Faith B. Dickerson, Christina L.G. Savage, Lucy A.B. Schweinfurth, Deborah R. Medoff, Richard W. Goldberg, Melanie Bennett, Alicia Lucksted, Matthew Chinman, Gail Daumit, Lisa Dixon, and Carlo DiClemente, 'The Use of Peer mentors to Enhance a Smoking Cessation Intervention with Persons with Serious Mental Illness,' *Psychiatr Rehabil*, Vol. 39, No. 1 (2016), 5-13.

[54] 'Online peer-to-peer support in youth mental health: seizing the opportunity,' *Epidemiology and Psychiatric Sciences* (2016), 25, 123–126.

[55] Frances Dark, Murray Patton, Richard Newton, 'A substantial peer workforce in a psychiatric service will improve patient outcomes: the case for,' *Australian Psychiatry*, Vol.25, No. 5 (2017), 441-444.

training. It has also played a major role in breaking down the stigma around mental illness, which continues to be a major issue in relation to the employment of peer workers.

> *A lot of people with mental health issues who used the system find it hard to go back into a role working within it. Stigma is rife. You are almost seen as damaged goods. I have had to sort out a lot of my own health issues because I want to work within the system.*

Consumers involved in peer support activities have higher levels of community integration and enhanced social functioning. Within the organisation it has resulted in important conversations related to job configuration and training, not just for peer workers but all staff. In addition, peers model good behaviour to staff in terms of management of mental health generally and make others comfortable to discuss issues involved in stress and burn out, etc.

Mind continues to develop in relation to its peer workforce. Nor are we the only organisation that is attempting to shift practice and organisational structure to accommodate this emerging and important service modality. Some of the issues we have faced and continue to face, which may provide useful background for the Royal Commission in its deliberations on how to better to incorporate peer work into mental health responses, include:

- The need for change at all levels of the organisation, including human resources and the configuration of position descriptions and jobs tasks.
- The challenge of configuring IT systems in such a way as to ensure peer workers exercise control over the disclosure of their mental health condition.
- Role clarity and position description drift. For example, there have been instances where someone with lived experience has created a peer position but it has only remained so while that particular individual is in the job and after they have moved on it has ceased to be filled by a person with lived experience. There have also been examples of people with lived experience moving into leadership positions but the management role not adequately incorporating the peer perspective and framework.
- Stress, isolation and burnout for peer workers (although we would stress this is an issue for mental health workers generally).

One of the most serious issues we have identified is the lack of professional development, training and career path options for peer workers. There is only one specialised qualification, a Certificate IV in Mental Health Peer Work, offered through the TAFE/VET sector, specifically designed for people with a lived experience of mental illness to equip them to assist others in recover of mental illness.

Mind has partnered with Swinburne University of Technology TAFE to support some clients and residents in its independent living facilities to undertake this course and the Certificate 4 in Mental Health and to count placement activities with Mind as part of the assessment. There is still a lack of employment options upon graduation. The transitioning of PHaMS funding into the NDIS has exacerbated the situation. Introduced by the Commonwealth in 2006, Mind was one of the organisations that successfully tendered for PHaMS and it played a major role in the evolution of our peer workforce. PHaMS consisted of five person teams, one of which had to have lived experience of mental health and recovery. This was the only government program that specifically mandated the employment of peer workers.

Solution

As a starting point, the Royal Commission should examine the successes and failures experienced by Mind and other community managed mental health in incorporating peer workers and perspectives. These are a number of detailed case studies in the previously cited book by Jayakody et al.[56] In addition to the *Mental Health Workforce Strategy*, the 2011 *Victorian Framework for Recovery Oriented Practice* specifically recognises the value of a peer workforce and principles to underpin its creation. However, like the workforce strategy, it has not been supported to have any measureable impact.

We believe there would also be value in the Commission examining the operations of the Mind Recovery College. Based on a UK model, the College is designed to advance Mind's recovery orientation focus and provide education-based mental health services achieved through the provision of education by people with and without a lived experience of mental illness. Among the positive outcomes identified in a 2016 evaluation of the College by the University of Melbourne was expanding the conceptualisation of employment possibilities for people with mental ill-health, including greater knowledge of career options in peer support.[57] Mind is happy to provide the Commission with more details about the College.

In line with our point earlier about the need to conceptualise the elements of peer work activity as a developing service modality, Mind believes there are innovative ways in which peers could be play an expanded role in the wider mental health system. An example that came at several points in the face to face in consultations is in relation to the increasing number of mental health presentations to hospital emergency departments (EDs).

While measures need to be taken to reduce mental health ED presentations, the current reality is that as the 'front door' to the health system,[58] they will continue to occur. But many of the negative impacts on both patients and the staff could be considerably ameliorated by the insertion of mixed teams of peer/community mental health workers into the ED. The role of peers within these teams could include:

- Playing a role in reducing patient stress, de-escalating potentially difficult situations, conflict resolution and liaising between patients and staff.
- Explaining to patients what is going on and what is available in terms of treatment.
- Minimising the traumatic aspects of ED treatment for the patient.
- Reduce stigma and educating ED staff about mental health.
- Assisting with admission to in-patient care or referrals to other services.

While such blended peer/community mental health workers teams would obviously need to be supported by ED and work closely with staff, entailing changes in hospital procedures and clinical culture, the benefits could be considerable given, as one consumer put it: 'The sense that everyone [presenting to ED] with mental is an involuntary patient to some degree.'

We would also recommend the Royal Commission examine the following specific proposals.

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[56] In addition to the two chapters previously cited in Jayakody et al, the Commission should examine Fay Jackson, Tim Fong 'Changing Culture and growing peer work', 43-68. The book also includes a number of contributions on the experience of peer work by states and territories.

[57] Teresa Hall, Lisa Brophy and Helen Jordan, *A report on the early outcomes of the Mind Recovery College*, University of Melbourne and Mind Australia, 2016.

[58] Ibid.

- Increase funding for the Victorian Mental Illness Awareness Council in relation to its ability to support and take advocacy on behalf of consumers who are dealing with aspects of the mental health service system that do not work for them.
- Funding for a state based lived experience advisory body and secretariat, separate from MHV, which can advise government on mental health policy, strategy, and workforce issues.
- Examine how DHHS might improve the opportunities for ongoing professional development for people with lived experience who seek to work as peers in the mental health sector. This could also assist with preventing burn out and make a longer-term career feasible for mental health peer workers.
- Consider developing a graduate program that could place new graduates from relevant degree courses in a series of rotations in different components of the mental health system, over a two or three-year period. The Future Social Services Institute in Victoria is a good example of an initiative that combines research and workforce development across multiple community services sectors (disability, aged care, mental health) and recognizes the commonality of some capabilities, transportability of qualifications and possibilities for shared or pooled training. It also has PhD scholarships and bursaries aimed at up skilling the existing workforce

2.3 Strengthened pathways and interfaces between Victoria's mental health system and other services

Having a safe and secure place to live was a major issue for those consulted as part of this submission. The maintenance of stable housing and the confidence that comes with the security of tenure and associated feelings of safety, are critical for recovery from mental ill-health.

> *When I have a home a whole lot of stress is lifted. This stress makes my health a lot worse. I can't think about recovery when I don't have a safe place to live.*
>
> *Because I had some assets, I was not eligible for public supported accommodation. I could not get what I needed and the entire onus on advocacy was on me. It was better for me to stay with friends or at my ex-boyfriends or with family or even in a motel, than to rely on public or emergency accommodation.*

The following section will focus on improved pathways between mental health and housing and homelessness services for people with complex and/or enduring mental illness. Mind believes this issue needs to be seen in terms of the missing middle of service provision, noted earlier in this submission. Particularly important is how to meet the long-term accommodation needs of those with significant mental health issues who fall between clinical service provision and the NDIS, and what is the best configuration of mental health and housing supports for them.

Mind's service provision intersects with the issues of housing and homelessness for people with complex and severe mental illness in several ways:

- Supported residential rehabilitation programs across Victoria, with a strong focus on early intervention.
- Supported accommodation for those with a mental and intellectual disability.
- The Haven Foundation, an innovative, family-inclusive model of supporting independent long-term accommodation for people with a significant mental illness.
- Supported independent living in a mixture of self-contained units, stand-alone houses and boarding house style accommodation.
- The management of eleven PARCs, in cooperation with the area mental health services across the state.
- A Community Recovery Program (CRP), in partnership with the Austin Hospital. This provides 24-hour support and an accommodation stay of between six months to two years. This is a rehabilitation program for people with enduring and serious mental health issue who may be exiting a secure extended care service or forensic hospital, to assist them transitioning back to the community. It provides assistance with mental health issues, social and vocational life skills and other needs, including housing needs post-discharge. As these services are partnered with a health service, the staffing configuration includes psychiatrists, mental health nurses, and allied health staff, as well as Mind's community mental health nurses.

Housing and homelessness issues are also a key focus of Mind's research including working with AHURI on a major program of research, '*Trajectories: the interplay between mental health and housing pathways*', which examines the intersections, over time, between mental ill-health and housing insecurity for people with complex and/or enduring mental illness. The study includes in-depth service mapping and analysis of data contained in the Melbourne Institute's Household, Income and Labour Dynamics in Australia (HILDA) Survey and Journey's

Home (JH) longitudinal study of factors affecting housing stability. IN addition, the research has involved interviews with more than eighty consumers, and a smaller number of family carers, in fifteen locations across Australia, and service provider workshops in each capital city. Mind is happy to pass the full study to the Royal Commission after it is finalised.

Problem

There is substantial data pointing the links between mental illness and housing problems and homelessness. Australian Institute of Health and Welfare (AIHW) specialist homelessness services figures state that mental health services were the second highest services required for those who accessed homelessness support, after general health and medical services,[59] and an estimated one third of the homeless have a severe mental illness.[60] There are several levels to this problem.

a) Poor service configuration on the part of both mental health and the housing and homeless.

MHV quotes recent AIHW figures that more than 500 of the people that presented at Victorian homelessness services did so after discharge from state psychiatric services.[61] There is also an increase in homelessness rates amongst those exiting custodial institutional, of which a large number also experience significant mental health issues.[62]The Mind/AHURI study underlines numerous problems with the lack of integration and coordination between homelessness, housing and mental health services. Examples include:

- Insecure housing means people may be forced to move to access housing, with the result that they may no longer be located in their current mental health catchment area, thus disrupting continuity of care. Clinical services attached to hospitals do not work across regions.
- Homelessness workers not knowing how to work with local area mental health services, nor trained to see the signs of a client’s mental deterioration or ill-health until the situation is so far advanced that it is in the critical stages of impacting on their housing. Many clinical workers, in turn, will not accept the assessment of a housing worker.
- Further compounding this is the lack of knowledge and recognition of housing issues facing specific groups experiencing mental ill-health.

A particularly serious issue highlighted by both the Mind/AHURI study and reinforced by feedback from the consultation process is the increasing risk of discharge from acute and sub-acute mental health services into insecure accommodation or homelessness. This is the result of a combination of factors, many of which have already been mentioned, including:

- Increased demand on services, which has resulted in pressure to move people through quickly.

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[59] Australian Institute of Health and Welfare, *Specialist Homelessness Services Annual Report 2017-2018*, February 2009, 16.

[60] Nicola Brackertz, Alex Wilkinson, Jim Davidson, 2018. *Housing, homelessness and mental health: towards systems change,* AHURI Research Paper, Australian Housing and Urban Research Institute Limited, Melbourne, available at https://www.ahuri.edu.au/__data/assets/pdf_file/0023/29381/Housing-homelessness-and-mental-health-towards-systems-change.pdf

[61] *Saving Money, Saving Lives*, 11.

[62] *Specialist Homelessness Services Annual Report 2017-2018*, 69.

- The lack of exit points into appropriate and stable housing and constraints within the health system to undertake appropriate discharge assessments, planning and follow up post-discharge.

Mind staff are aware of examples where facilities have sometimes had little choice but to discharge clients into unsuitable accommodation such as rooming houses or a Supported Residential Services. This can be re-traumatising for the individual concerned and/or expose them to drug use or other behaviour that may lead to relapse and see them back in hospital, at considerable cost to the public purse. Some PARC services will not accept individuals experiencing housing problems because they do not want to risk discharging individuals into homelessness or being left with the responsibility to source accommodation. As is the case with other sections of this submission, the issues involved in preventing discharge into homelessness are more serious in rural and regional Victoria where there are far fewer housing options.

b) Macro level shifts in the housing market

The issue of homelessness and mental health must also be viewed within the context of well-documented changes to the Australian housing system, including the falling rate of home ownership and the growth of the private rental market. This is captured in an AHURI presentation to the NMHC, which details falling rates of home ownership and the extent of downward pressure this is exercising on the private rental market whereby housing previously accessed by people in the fifth income quintile is now accessed by those in the fourth and even third quintiles.[63] This is squeezing disadvantaged individuals and families, forcing them into more marginal and insecure forms of accommodation. Mind service staff also report seeing more women in their fifties who may have rented or owned for a long time but now face significant housing insecurity. Some have had mental health issues in the past but have coped well, but the lack of security they now face is often enough to unravel what progress they may have made.

c) Declining investment in social housing

Government policies that have seen declining public housing stock, traditionally viewed as an option for the cohort with issues such as mental ill-health. Victoria's per person spend on social housing, a figure that includes public housing, has fallen each year since 2014/15.[64] Despite rapid population growth, Victoria now has less units of social housing than it did in 2014, meaning that the proportion of social housing stock has significantly declined to just 3.2% of all housing stock (down from 3.6% in 2010-11).[65]

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[63] AHURI, Housing, Homeless and Mental Health, presentation to the National Mental Health Commission

[64] Luke Henriques-Gomes, 'Victoria spends less than half the national average on social housing, report shows,' *The Guardian*, January 22, 2019 https://www.theguardian.com/australia-news/2019/jan/22/victoria-spends-less-than-half-what-nsw-does-on-social-housing-report-shows

[65] Council to Homeless Persons, 'Homelessness will grow if state budget doesn't deliver change,' March 13, 2019 https://chp.org.au/homelessness-will-grow-if-the-state-budget-doesnt-deliver-change/

d) Failure to look at housing as a health intervention

While achieving better housing outcomes for people with severe and persistent and/or complex mental health illness by necessity involves the provision of more stock, i.e., looking at it as an infrastructure issue, it also involves questions around what the best accommodation and support models are for people dealing with mental illness, i.e., looking at it as a health intervention. Failure to effectively conceptualise housing for people when they are mentally unwell dates back to de-institutionalisation and the insufficient attention and resourcing given to the question of where people should live whilst they are recovering and rehabilitating from serious illness, and what accommodation should be provided for those who need specific forms of housing support to lead productive lives in the community. As is the case with other areas, the issues relating to housing outcomes for people with complex and/or enduring mental health conditions have been considerably complicated by NDIS implementation.

Impact

The aforementioned The Mind/AHURI study found that poor mental health could lead to housing instability and homelessness. Deteriorating mental health also significantly increases the likelihood of subsequent forced moves.[66] Interestingly, the diagnosis of a mental health condition can offer a protection from entering homelessness, because there is more likelihood it will ensure the individual is engaged with the necessary supports to keep them housed. Indigenous Australians, those with longer histories of unemployment and lower levels of education, those born in non-English-speaking countries, and people opting out of responding to questions on violence, whom we hypothesise are much more likely to be currently experiencing particularly traumatic events, are less likely to access health services and, hence, diagnosis. This emphasises our earlier point about the need to not lose focus on those people who are most severely impacted by mental illness and whom systems are least well equipped to respond to in humane and effective ways.

Perhaps the most pertinent finding of the *Trajectories* study, from the Inquiry's point of view, relates to what is the most suitable form of accommodation tenure for those dealing with mental ill-health. Private home ownership is a significant protective factor from housing instability and homelessness compared to private rental. Public housing has a similar protective effect on reducing risks of housing instability and homelessness to home ownership. Community housing, traditionally seen as a secure housing option, does not offer the same level of protection. According to the study this is because community-housing providers are more dependent on rent revenue and therefore less tolerant of rental arrears, and do not adequately monitor the mental health of their tenants, missing opportunities for early intervention before their tenancy gets to the crisis stage. Mind would also speculate the lack of protection offered by social housing is also related to downward pressure on the rental market. This has shifted the cohort accessing community housing to include many who would previously have found accommodation in private rental but who have effectively been priced out of that market. The findings of the Mind/AHURI study are particularly important given Victorian government policy of transferring public stock to the community-housing sector.

Another example of how state government policy can potentially undercut sustainable housing outcomes for those with mental ill-health is reforms in Victoria aimed at bringing

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[66] Rosanna Scutella, *Analysis of Mental Health and Housing Instability Utilising HILDA and Journey's Home Surveys: Final Report for Australian and Urban Research Institute*, Mind Australia and AHURI, forthcoming.

public and social housing into a single register. This has a number of potential positives. These include simplifying the process of applying for housing by ensuring individuals only need to apply once for eligibility and allowing those providers that register with the single entry point to access a wider pool of tenants. But there are many potential problems. It makes the process of housing referral for clinical and community mental health services considerably less flexible. There are no KPIs to ensure that social housing providers source a diverse range of tenants and we are concerned providers may discriminate against certain groups, including those with current or past mental ill-health. This impacts their access to secure housing and reinforces the problems they already experience in the private rental market. There is also the issue of how individuals, including those with mental ill-health, find out about the central register and apply to be on it, especially if they are not engaged with support services.

It is also important to note issues arising from the interface between NDIS and the housing activities of NGOs such as Mind. In Victoria, funding for supported accommodation for those with mental ill-health has been completely subsumed into the NDIS, with the result that it now takes two to three months to house an individual in one of Mind's supported independent living units. It has to be part of the individual's NDIS package. The consumer has to be assessed as eligible, and the assessment quote has to be approved by the NDIA. While the NDIA has shown a preparedness to accept Mind's recommendations regarding eligibility and, to their credit, is trying to streamline this process, it is nonetheless time consuming and bureaucratic. To give a snap shot of the impact from this, Mind currently has 15 vacancies – out of a total stock of 120 residential accommodation opportunities across 13 different sites across Victoria – currently waiting on NDIA sign off. We are aware of people who need independent supported living but who have opted out or disengaged from the process, or for whom it has resulted in a relapse of health.

Solution

a) Increased investment in public/social housing

While expanding public housing is a politically unpalatable policy option, Mind would nonetheless stress the evidence from our AHURI collaboration that it is one of the most effective long-term policy interventions for people dealing with mental ill-health. While we note the most recent Victorian state budget included initiatives to increase social housing, even with these there will still be a reduction in the proportion of social housing in Victoria, from 3.44% in 2018/19 to 3.42% in 2019/20.[67] A more ambitious investment is needed.

It is also important that safeguards are implemented around the Victorian single housing register. Mind, which has made the decision to sign up to the register, is concerned that challenges in relation to maintaining stable tenancy and the wider issue of stigma from neighbours, community housing providers and real estate agents, could negatively impact the outcomes from this initiative for people with complex and/or enduring mental health conditions. We would urge the Royal Commission to recommend to the Victoria government setting aside a portion of properties on the register for those in mental ill-health. Funding also

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[67] Council to Homeless Persons, 'Homelessness initiatives welcome, but more action needed to deliver social housing', May 27, 2019.

needs to be allocated towards short-term crisis intervention and support for these people to ensure their tenancies are not at risk.

b) A greater focus on Housing First and its various iterations

While increased investment in public/social housing is one part of the solution, some people with significant mental health problems will not want to go into public housing and, viewed as a health intervention, for some it will not work. A suite of responses is thus needed. In terms of specific housing models for people with complex and/or enduring mental illness, Mind would advocate greater investment in 'Housing First' (HF) models. Several examples that align with the majority of the HF principles already operate in Victoria.

HF is based on the notion that secure and appropriate housing is fundamental to recover from mental illness. Its core components include:

- Rapid access to secure housing with no readiness conditions
- Consumer choice
- Separation of housing and services
- Recovery as an ongoing process
- Community integration

A $110 million HF trial operated from October 2009 to June 2013 in five Canadian cities, involving a randomised control trial of people with high needs, including severe mental ill-health that compared HF to existed homelessness interventions.[68] While both groups experienced improved outcomes, the results were particularly good for the HF cohort. A number of factors specific to the context in Victoria make the Canadian experience hard to replicate,

- The lack of affordable housing stock.
- The implementation of the NDIS.
- The lack of connectivity between different service systems. A high level of service interconnectedness made the Canadian project possible, including partnerships and buy in from not for profits, and government agencies and departments. The involvement of Ministry of Social Development in one site saw substantially reduced wait times for housing. There were also innovative partnerships with landlords and landlord associations.

There could also be potential disadvantages in the HF model for people on the public housing waiting list, as their priority listing is downgraded when they secure a property through a HF program even though the accommodation may not be long term. Despite these problems, Mind believes the HF concept is useful, not only as a model, but as a central organising framework to conceptualise how Victoria might better facilitate access by those with mental ill-health, to affordable, stable accommodation and achieve greater service sector connectivity.

A modified version of HF run by Mind is the Haven Program, which provides housing for people who live with the enduring and severe impacts of mental ill-health. The program recognises that secure, affordable housing is a critical aspect of recovery for many people. In order to maintain housing people with mental ill-health often look for support and the opportunity to learn new skills, as well as working towards other goals that support their own personal

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[68] *National Final Report: Cross-Site: At Home/Chez Soi Project*, Mental Health Commission of Canada, 2014.

recovery. The Haven program, therefore, includes support as part of its design with particular emphasis on family-inclusive practice. The program is run by the Haven Foundation, a registered community housing provider, which merged with Mind in mid-2018 and is now a controlled entity within the organisation. Tenancy and property management services are run by Housing Choices Australia, and the 24/7 support services are provided by Mind, funded through the NDIS as supported independent living.

In addition to long-term affordable and secure accommodation the service model includes:

- Extensive on site psychosocial support and recovery services.
- As part of supported independent living packages through the NDIS, clients receive services that are tailored specifically around their wishes and needs, and that support their recovery, with them taking the lead in deciding what supports they want. Each client develops a *My Better Life Plan* where they state their own recovery goals. Where these goals relate to clients accessing the broader community outside of their housing, Mind staff assist them to find possibilities which match them. Clients may also choose shared supports, including shared meal planning and cleaning, shared access to sleep over staff and shared group activities.

In the past, referral pathways have included MIND and other community mental health providers and clinical services. Assessment criteria include that clients can:

- Meet Housing Association asset and income limits.
- Be over 18 with no dependents.
- Be seriously affected by a severe mental illness and have an associated level of disability that cannot be met by alternative housing and support options.
- Want to live in an independent home environment and are assessed as having the potential to achieve a level of daily living skills and social function that can be successfully managed in a community setting.

The involvement of family members and carers, while not mandatory, is integral to the model and highly valued. Family members and carers are also involved in the practice governance of the Haven Foundation.

The first Haven site in South Yarra has 14 units. With capital funding from the Victoria State Government, the model has subsequently been established in Frankston (18 units), and Geelong and Wyndham (16 units each, to be completed in 2020), with expansion to Whittlesea in the pipeline. While the model does not suit everyone, we would recommend it to the Commission for serious consideration as an accommodation solution for those experiencing severe mental ill-health. With the support of Mind, the Haven model has the ability to be up scaled quickly, if well-located land is available for purpose-built accommodation. It is also relatively cost effective compared to other models. One year of 24/7 supported accommodation for an individual at Haven's Frankston facility costs approximately $100,000. This is compared to the annual cost per client of accommodation in a CCU ($123,735), secure extended care unit ($179,215) and hospital care ($208,780).[69] Mind is happy to provide more details to the Royal Commission about the Haven model.

Mind would stress that the Haven model is only one possible HF style model for those living with a mental ill-health. Accommodation does not have to be purpose built, for example, but could utilise repurposed public stock, with support provided by NGOs such as Mind. Another option is to move away from congregate models in favour of co-located individual

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[69] Provided by the Haven Foundation on the basis of figures obtained for the 2012-2014 period.

accommodation, again with NGO support services provided. Mind would encourage the Victorian government to examine the applicability of such programs for those who do not qualify for the NDIS but nonetheless require some housing/mental interventions to ensure their condition does not worsen, resulting in significant problems for them and their carers and family and an increased draw on the resources of the health and other service system.

We also wish to draw the Commission's attention to the question of available land and suitable infrastructure for such HF models. One factor impeding the development of appropriate infrastructure is the lack of land available for new builds. We recommend that a proportion of land releases into the future are preserved for this kind of HF housing. We also note that it is much easier to accommodate people in new build housing, purpose designed for the specific needs of people with complex and/or enduring mental illness. We have noted the possibility of repurposing government owned legacy stock, including stock that is beyond repair, which can then be redeveloped/rebuilt as part of the HF infrastructure.

c) Introducing measures to improve the operation of the NDIA in relation to housing

Mind also encourages the Victorian government advocate at a national level to ensure a psychosocial stream of Specialist Disability Accommodation (SDA) funding. SDA is funding for specialist capital supports for participants with high and complex needs that require specially designed accommodation. This is perceived as only being only suitable NDIS participants with a physical disability, and currently there are no examples of SDA being provided for people with a psychosocial disability.

Mind believes this demonstrates the lack of understanding around what is the most appropriate configuration of health and housing supports for people with a psychosocial disability. Part of the data collected in the Trajectories program of research includes interviews with individuals who have experienced poor mental health and housing instability. This has highlighted a number of housing needs for people with a psychosocial disability that are not met in their current housing and are not likely to be met by current social housing models in the future. These include:

- Soundproofing: difficulty controlling emotions means that those with mental ill-health can be very loud when upset, which leads to complaints by neighbours and possible police involvement which can further impact mental health. Additionally, hearing others, such as neighbours, arguing can be extremely distressing for those with a psychosocial disability and can trigger their own mental health issues.
- Women only properties for women with mental ill-health who have experienced sexual violence and require an area where they feel safe with other women
- The provision of sensory rooms, which can beneficial for those with psychosocial disability and contribute to well-being.
- Space for support persons and carers to visit and stay.
- Modifications to enable people with a psychosocial disability to sleep better, including automatic blinds and the set-up of bedrooms.
- The provision of garden space as the connection with nature can be important to recovery and can support physical and mental health.

As noted earlier, the NDIS has also complicated the process of supported accommodation for those with a psychosocial disability and made it impossible for Mind to provide respite accommodation, for which there remains an urgent need. While the NDIA attempts to streamline its processes in relation to housing, we think there is a role for the Victorian government to introduce a program that provides up to three months supported accommodation while an individual waits for the Scheme to approve their housing and provide it.

d) Short-term interventions

There are a number of additional short-term interventions the Victorian government can make.

1. Implementing strategies that would result in housing/homelessness and mental health services working better. Of particular importance is the need for more effective hospital and mental health institution discharge processes.
2. Examining how the Victorian government can assist the process of engaging the private rental market with NGOs in HF programs. There is a considerable gap in the market for adult residential accommodation for individuals who are sub-acute but have long term needs that community mental health services such as Mind could help to fill with some assistance from the state government. This could include:
   - Public stock managed by Mind on a two to three-year residential model.
   - Programs where organisations 'head-lease' properties on the private rental market and provide support and financial assistance to tenants to ensure whatever problems they may experience they are dealt with before the tenancy is threatened, thus providing a safety net for real estate agents prepared to engaged with complex clients as renters.
   - The wider application of the Doorway program trialled by Wellways, which works with clinical services and real estate agents to provide support for people with complex and/or enduring mental illness to access private rental.[70] Participants pay 30% of income and Commonwealth Rent Assistance towards the cost of private rental and Doorway pays the remainder for 18 months and provides a range of other supports to ensure the tenancy is stable.

3. In relation to the issue of stigma, Mind would encourage the Royal Commission to examine:
   - The issue of who can access records relating to a person's actions while they were mentally unwell, including unpaid fines and court appearances, and the conditions under which this can be done. Not only do these records hang over someone's head for years they can also present problems in terms of trying to get a private rental property.
   - The possibility of providing training to property managers and community housing providers around mental health issues to improve the way in which they deal with the mental unwell.

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[70] For more information see: https://www.wellways.org/our-services/doorway

2.4 Better service and infrastructure planning, governance, accountability, funding, commissioning and information sharing arrangements.

Mind has already raised a number of issues related to better infrastructure planning, governance, and accountability. However, we would take the opportunity to re-emphasise some or our arguments and make additional points. The issues around better information sharing arrangements will be discussed in our response to Terms of Reference 2.5.

Problem

The shortcomings in relation to the planning, funding and governance of Victoria's mental health service are well known and many of these have been raised in this submission, including:

- A lack of targets for funding investment in relation to population growth.
- No forward plans for capital infrastructure in relation to mental health services.
- The lack of a detailed workforce strategy that contains targets to meet the future employment requirements of the mental health sector, relative to need and population growth and address personnel and skill shortages, especially non-metropolitan areas of the state.
- The lack of any plan to address the myriad of issues in terms of the provision of mental health services.
- No plan for improving the interface between mental health and other service systems.

While these issues are system wide, they are being particularly felt by NGOs that occupy the space in-between what the NDIS provides those with psychosocial disability and what is provided by clinical and acute services. As we have stressed, this vital component of a comprehensive mental health response is now under threat due to policy and funding pressures and is in danger of disappearing.

The removal of virtually all base funding to community managed mental health services and its transition into the NDIS, has removed vital support services from a large number of mental health consumers and their carers and created considerable uncertainty. The Victorian government appears to have no plan in terms of how to deal with the shortfalls in service provision created by its approach to NDIS implementation.

In addition to the feedback of consumers and carers detailed in this submission, there is evidence of benefits in a system in which more funding is directed to NGOs delivering the bulk of social and psychosocial services. This is set out in the KPMG modelling for the National Mental Health Council mentioned at the beginning of this submission.[71] KPMG modelled a number of what it described as more optimal service system models, more focused on 'upstream service provision', that is, one that placed greater emphasis on primary and community care and interventions aimed at improved outcomes in areas such as employment, housing, welfare and justice. It stated 'that upstream service provision delivers better outcomes at lower cost over time that those [systems] with a higher focus on downstream acute services.'[72] It also reported lower costs associated with better service system responses related to housing and justice.

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[71] KPMG, *Paving the way for mental health: The economics of optimal pathways to care*, National Mental Health Commission, November 2014

[72] Ibid, 12.

In addition to our commentary elsewhere in this submission on the lack of, and opportunities for better integration between mental health and housing, and mental health and justice, we wish to draw the Commission's attention to the interfaces with education and employment. Improvement of these interfaces is vital for improved quality of life for Victorians impacted by mental ill-health. Ian Hickie's widely publicised critique of the headspace model centres on its failure to deliver enhanced education and employment outcomes for young people, remaining fundamentally as a clinical service for young people. Notwithstanding the enormous benefits provided by headspace to young people, we believe that adaptations to current and future models that explicitly require partnerships between providers in different service sectors would go a long way to addressing the current shortcomings of otherwise accessible models such as headspace. We also believe that partnerships are an effective way of increasing accessibility in remote and rural areas where service provision may be thin on the ground.

Impact

While Mind recognises the considerable opportunities arising from individualised service provision for consumers, its ability to innovate and provide individualised care on a day-to-day basis is being hampered by several factors:

- Multiple funding streams, often with short-term, insecure contracts.
- Uncertainty around when tenders will be announced.
- Short notice on contracts and dates.
- Commissioning bodies that don't have a good understanding of the systems they are commissioning into.
- Poor coordination within and across different levels of government.
- Overly burdensome regulation and reporting regimes that are not focused on improving person centred care but rather the acquittal of funding and narrow, transactionally focused service outcomes.

While the NDIA recognises that the drive for greater efficiency prices is a problem, this is not reflected in commissioning by health services. These problems are epitomised by the operation of PHNs, six of which operate in Victoria. Along with bulk billing fees for counselling and GP visits, etc, PHNs provide the bulk of Commonwealth funding to state based mental health services. Introduced to replace Medicare Locals, PHNs have been funded to cover the gap created as services were rolled into the NDIS for those not in the Scheme but who continue to need psychosocial support and stepped care. They are also supposed to perform a significant regional planning function. In short, they are a major component of the Victorian mental health service system, making it is impossible to discuss meaningful reform at the state level without reference to them.

The administration of the PHN scheme, the small amounts of funding dispersed over relatively tight time frames (one to two years initially although this has since been expanded), with very tight KPIs has had several detrimental impacts on service providers. The small amount of money, spread across the entire PHN network, combined with unrealistic expectations, has made the job of providing a sound service, in Mind's view, unviable. The low funding level, combined with the short time frame of contracts, has also made it impossible to recruit and train the qualified staff. Further complicating this situation, there is a lack of coordination, resulting in a plethora of service models and no continuity of care. A recent review of PHN operations also pointed to a number of significant problems, including:

- The short term nature of PHN funding contracts, and the uncertainties and difficulties this creates in terms of service provision and workforce retention.
- The assumption there is regional market for suitable, qualified service providers in every region.
- Variations in PHN capacity in relation to mental health service provision.
- Lack of a consistent approach to service provision and the collection of data for evaluation and benchmarking.[73]

The current focus on 'efficient overheads' is placing undue pressure on providers, away from a focus on quality and safety of service and the outcomes delivered for individuals, families and communities.

Solution

A number of recommendations for change in relation terms of reference 2.4 have been or will be made elsewhere in this submission. In addition to these, Mind recommends the Royal Commission support:

- A greater focus on commissioning service models that rely on partnerships between different sectors of the mental health system, and between mental health services and providers in other sectors.
- Funding that covers the full cost of service provision to someone with mental ill-health, including the time and emotional labour involved in servicing relationships with clients and carers, liaison between workers and between different organisations and service systems. Two decades of under investment has put Victoria's mental health system under considerable strain and it is neither fair nor possible to expect it to react in an innovative and effective manner to the commercialisation of mental health services, by doing more with less.
- Longer contractual time frames for government funding, ideally up to five years.
- A move to outcomes-based contracts based on population estimates, supported by significant government investment in provider systems and capabilities.
- The Victorian government lobbying other states and the Commonwealth for changes to the PHN commission model, as per the recommendations of the 2018 review.

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[73] *Report of the PHN Advisory Panel on Mental Health*, September 2018, https://www.health.gov.au/internet/main/publishing.nsf/Content/mental-health-advisory-panel

2.5 Improved data collection and research strategies to advance continuity of care and monitor the impact of any reforms.

Problem

Victoria's mental health system needs better data to enable more effective monitoring of performance and planning in response to current and future mental health service needs. In an increasingly dynamic and individualised funding and service environment, improved data and easier access to it is also required by service providers to respond to shifts in consumer need and map outcomes (or the lack of them), and for consumers to hold government, institutions and service providers to account.

Impact

Problems in data collection and monitoring, as well as the quality of data collected occur at all levels of the mental health service system. University of Sydney academics, Sebastian Rosenberg and Ian Hickie maintain past Commonwealth reform efforts have faltered, in part, because of the limited data available to make comparisons and measure progress, with the result that we are, they contend, 'largely outcomes blind'.[74] One of many ways in which this manifests in the Victoria is in the operations of PHNs, which lack a common commissioning framework and way of operating, making it impossible to develop a coherent set of data around their effectiveness or not.

A recent report by the Victorian Auditor-General's Office found significant shortcomings in DHHS data systems related to mental health, which seriously impact its ability to calculate and respond to current demand for services, including gaps in service provision, and future service needs.[75] The Auditor-General's Office also found DHHS has not developed indicators or measures to monitor outcomes in four areas that relate to the wellbeing of children and young people with severe mental health problems: participation in learning and education, economic participation, financial security and social engagement.[76]

Improved data collection is also a major issue facing NGOs, which more than any other part of the mental health system suffers from a lack of evidence to support the outcomes it achieves, a fact also noted by Rosenberg and Hickie.[77] With its roots in localised and voluntary services the sector has not been required nor, it is vital to add, funded to build an evidence base for its practice in the same way as occurs in 'mainstream' health service delivery. Comprehensive data entry can be a burden for service staff struggling with heavy caseloads.

Mind staff have also raised concerns in relation to:

- The type of data they are mandated to collect as part of DHHS and other service reporting.
- Data fields being configured against disbursement of funds and contractual obligations, rather than improved consumer experience and better outcomes for individuals.

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[74] Sebastian Rosenberg and Ian Hickie, 'No gold medals: Assessing Australia's international mental health performance,' *Australian Psychiatry*, Vol. 27, No. 1 (2019), 36-40.

[75] See *Access to Mental Health Services*, 42-48.

[76] Victorian Auditor General's Office, Child and Youth Mental Health, 2019, 71.

[77] Rosenberg and Hickie, op sit,

- NGOs do not have any access to data reported to government in an aggregate form to improve service provision.

The overwhelmingly contractual nature of reporting has been reinforced by the introduction of the NDIS.

Solution

The Royal Commission should examine ways to simplify as well as improve mental health service data collection.

First, there is a need to be clear about the principles underlying the data collected. Monitoring and reporting needs to be tied to a clear strategy that distinguishes between whole of population mental health, the needs of the majority who become unwell, and the needs of those with high and very high levels of need. In turn, the adoption of clearly defined targets would help governments, service providers and the public to track outcomes and identify service provision gaps and failings.

Second, what type of data should be collected? Mind suggests it needs to be:

- Outcomes focused. In addition to improving results for consumers, this would also assist the workforce to realise the importance of capturing the information concerned rather than seeing it as yet another of the tasks they are asked to do.
- Consistent across providers and able to reach across geographic and service systems boundaries.
- As much as possible, collected and able to be viewed in real time.
- Able to be shared between NGOs.

Third, what role the Victorian government could play in terms of improving its own data collection? Mind would suggest that this include consideration of:

- Options for improved portable technology for mobile members of the workforce.
- The possibility of the state government playing a role in developing an improved data system that could be licensed to the NGOs and utilised across the sector. Mind is currently developing a new data system, at considerable expense, but has no major IT expertise and believes it would be far more effective for the state government to do this on behalf of the sector. The system could include the provision for shared client data with strong privacy provisions built in, similar to what is on the desktops of GPs.
- Funding for innovative research projects to overcome the lack of detailed research on the outcomes delivered by community mental health services. As part of this, funding provided to community mental health providers needs to include sufficient administrative costs to collect, analyse and report on outcomes data.

3. How best to support the needs of family members and carers living with mental illness.

Currently, policies concerned with mental health carers in Australia present an inconsistent array of priorities. On the one hand, the unpaid work of mental health carers and families is relied upon to deliver care that would cost the state billions to replace.[78] On the other, government is concerned with the loss of workforce participation by carers (particularly women). Governments are keen to see the workforce participation of this group improved, to avoid carer cohort reliance on welfare income and health services into the future. Legislatively, the *Carer Recognition Act* (2010), and the *Victorian Carer Recognition Act* (2012) acknowledge the need for better supports and recognition of carers.

Concurrently, research on mental health caring reveals that carers are experiencing burnout, stress, and carer fatigue in ever-increasing numbers. Through research and outreach, mental health carer organisations are pushing for greater and more explicit supports for mental health carers and families, alongside recognition that mental health carers and families have their own needs and lives beyond their caring role. Carer's rights are being promoted as a legislative priority though campaigns such as the Caring Fairly Campaign in response to the lack of action and coherent policy responses to mental health carers' and families' needs.[79]

As a result of these contradictory positions, governments at both the Commonwealth and State levels walk a conflicting policy line. On the one hand, they attempt to sustain and enrol carers to continue to provide their unpaid work. On the other, as the population and the cohort providing care also age, there are growing concerns about the sustainability of the caring role. Research has shown that long term informal caring leads to economic vulnerability and precarity in old age.[80] Moreover this reality raises the fraught question of who will care for the consumer when carers and families are no longer able or around to care.

One of the results of the failure of the mental health system in Victoria is that families and mental health carers are stepping in and attempting to support people who are struggling with mental illness and unable to get adequate and timely supports. Amidst this complex policy landscape, many families and carers supporting people with mental illness in Victoria are in crisis. Crisis does not just mean police and ambulances; crisis means that the day to day is overwhelming. Crisis means constant vigilance. Crisis means that families and carers are unable to manage their own lives. Crisis means that families and carers are dealing with high levels of distress and behaviours of concern without any support, a plan, or skills or knowledge about what they are attempting to navigate. Crisis means trying to support someone – sometimes for decades – without ever being recognised by the mental health system. Crisis

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[78] Deloitte Access Economics and Carers Australia, *The economic value of informal carer in Australia*, June 2015 http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf; Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess, Jan Kealton, Harvey Whiteford, *The economic value of informal mental health caring in Australia: technical report*, University of Queensland School of Public Health, 2016

[79] http://www.caringfairly.org.au/

[80] Tristan Durie and Edward Cavanough, *Guaranteeing Women's Super: How to Close the Gender Gap in Superannuation*, The McKell Institute, 2017; Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care, Volume 1*, 2013; Trish Hill, Cathy Thomson, Bettina Cass, *The costs of caring and the living standards of carers Social Policy Research Paper No. 43* Social Policy Research Centre, University of New South Wales, 2011; Australian Human Rights Commission *Accumulating poverty? Women's experience of inequality over the life cycle*, 2011.

leads to mental health carers having some of the poorest levels of health and wellbeing across the Australian community. Crisis leaves families fragmented and dislocated. Evidence of this crisis can be found in the insights from the consultations held by Mind Australia for this Royal Commission. It can also be found in current research on mental health caring as well as in the outreach and advocacy work of carer and mental health carer organisations.[81]

> *Carers are tired of filling in the gap of the shortfall in services*

The reasons for this crisis are multilayered and include:

- Ineffectual legislative and policy responses to the position of carers and families within the mental health system.
- Inconsistent application of best practice approaches to working with families and carers in mental health settings.
- Inadequate responses to families and carer concerns in relation to the person they support, particularly when the consumer lacks insight about how unwell they are.
- Patchy involvement of carer and family support staff across mental health settings
- Loss of carer respite and supports and uncertainty about supports as a consequence of the transition to the NDIS.
- Under-investment in community mental health services and places of safety outside clinical settings.
- Tensions between consumers and carers regarding the interpretation of consumer rights by mental health staff working in the system.

Carers also feel stigma and marginalisation.

> *I feel invisible. Nobody listens to me. They think I am interfering, yet they expect me to be there when [the person I support] comes home and supervise their medication, get them to appointments keep them safe, keep them alive.*

More critically there is an assumption underpinning the mental health system that informal supports in the form of carers and family are a foundational pillar of the system – an unpaid modality that functions as an adjunct to the paid treatment and support provided in formal services. Yet this informal workforce is not equipped with rights, conditions, education and training, on the job supports, annual leave, or choices about the work they do and the extent of that work.

Mind would argue that one of the key questions the Royal Commission needs to address in relation to the needs of families and carers is: what are the long- term consequences for families and carers (and for consumers) of this reliance?

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[81] Mental Health Council of Australia, *Consumer and Carer experiences of stigma from mental health and other health professional*s, Canberra, 2011; Ben Edwards, Daryl J. Higgins, Matthew Gray, Norbet Zmijewski, Marcia Kingston, *The nature and impact of caring for family members in Australia: Research report 16,* Australian Institute of Family Studies, Melbourne, 2008; Claudia Jardim and Kenneth I. Pakenham, 'Carers' views on respite care for adults with mental disorders,' *Advances in Mental Health*, Vol. 9, No. 1 (2010), 84-97; Royal Australian and New Zealand College of Psychiatrists, Submission to the inquiry into better support for carers, June 2008; Robert A Cummins, Joan Hughes, Adrian Tomyn, Adele Gibson, Jacqueline Woerner, Lufanna Lai, *The Wellbeing of Australians – Carer Health and Wellbeing*, Deakin University, October 2007; Tandem Inc., Submission to the Productivity Commission Inquiry into Mental Health, April 2019

> *I would like to see a wrap-around support to my family member that frees me up to just enjoy their company as any other family might do. Our conversations shouldn't all centre on health and survival.*

a) Definition of a mental health carer

For the purposes of this submission mental health carers will be defined as:

> A person or people who provides regular and sustained informal care to a care recipient whose main health condition is a mental illness, where the care recipient is aged 16 years or over. Carers of people with a mental health issue may include family members, partners, friends, neighbours or anyone whose primary relationship with the person concerned is a personal, supportive and caring one. We recognise families and carers may not live with the person they care for.[82]

This definition acknowledges that many people that provide support for a person with a mental illness do not identify as carers. There is a range of reasons for non-identification, from a conscious decision taken on the basis of stigma and the fear of discrimination through to a realisation that one has become 'a carer' by stealth, by being in relationship (of some sort) with someone who needs support initially during a period of illness, and then over months, years and decades. 'Carers' may not realise they are such because their 'caring role' has crept up on them over many years of unpaid work supporting someone with enduring mental ill-health.

This lack of self-identification however does not preclude them from the need for support. It is also important to identify that, so often when the mental health system interfaces with carers, it assumes that there is a carer dyad – one person who does the majority of the support. Although this is often the case, one of the recommendations of research on family inclusive practices, is to broaden out the notion of the 'carer' to include other family members and relationships. These relationships (such as siblings and friends) are also significant sources of support but can be seriously impacted by the mental illness.[83] Cultural inclusivity is also essential in the identification of who is a carer in order to accommodate extended family relationships, families of choice, identity communities and definitions of family such as those found in indigenous communities where broad intergenerational and intragenerational relationships are identified as family.

On the national level, there are an estimated 2.7 million unpaid carers in Australia, of whom some 850,000 have an intensive primary care responsibility that extends far beyond what has been 'traditionally expected', or outside of contemporary family norms.[84] Research commissioned by Mind, and undertaken by the University of Queensland's (UQ) School of

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[82] Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess, Jan Kealton, Harvey Whiteford, The economic value of informal mental health Caring in Australia: Summary Report University of Queensland School of Public Health, March 2017, 2.

[83] *Family relationships and mental illness: Impacts and service responses*, AFRC Issues, No. 4, June 2008.

[84] Australian Bureau of Statistics, *Survey of Disability, Aging and Caring*, 2015.

Public Health from 2016[85] to 2018[86] has revealed new insights into the extent, replacement costs, and opportunity costs of Australia's structural reliance on systems of unpaid care in the mental health space.[87]

Specifically, these two interconnected studies found:

- There are, by conservative estimates, at least 240,000 mental health carers in Australia, including approximately 54,000 primary mental health carers.
- Mental health carers provide an estimated 208 million hours of informal care per year. The total annual replacement cost for all informal mental health carers was $14.3 billion, as at 2015.
- Over 40% of working age mental health carers are either unemployed or not in the labour force.
- 47% of primary mental health carers who are not currently employed were working prior to commencing their caring role. This rate is similar across primary carers for all types of conditions.
- Over half (54.3%) of employed primary mental health carers aged 15-64 years have a possible need for more employment related support to either: maintain; improve; or, re-enter employment, based on the available indicators.
- Over half (57.1%) of primary mental health carers who are not employed have a possible need for employment related support based on having left employment to commence caring, or wanting to work while caring.
- Young mental health carers may be disadvantaged in terms of participation in education and employment compared to other young people of the same age. School attendance for mental health carers aged 5-14 is significantly lower (87.2%) than for other young carers (100%) and all young people in general (97%).

b) What do carers do?

The majority of mental health carers identified emotional support and psychosocial care as the two main areas of support they provide. Emotional support is described as involving companionship, motivation and encouragement, sustaining relationships, maintaining or encouraging wider social connections and working to prevent loneliness. Psychosocial care involves managing distress and swings in mood, self- harming behaviours, prompting action, keeping the consumer occupied, mapping out the week, transporting to appointments, responding to behaviours of concern (managing crisis, preventing wandering) as well as assistance with practical tasks around the home, health care coordination, helping with communication and finances (the paperwork around social supports and Centrelink for instance) and finally, assistance with daily life, nourishment, sleep, prompting to self-care, exercise and shopping for food and clothing.

Mental health caring is challenging for a number of reasons. Carers and families of people with mental illness have particular experiences and stresses amplified by stigma, misinformation, isolation and the unevenness, and indeterminacy of treatment and diagnosis,

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[85] Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess, Jan Kealton, Harvey Whiteford, *The economic value of informal mental health caring in Australia: technical report*, University of Queensland School of Public Health, 2016.

[86] Sandra Diminic, Emily Hielscher, Meredith Harris, *Understanding factors associated with Australian mental health carers' employment: technical report*, University of Queensland, School of Public Health, 2016.

[87] Diminic et al, *The economic value of informal mental health caring in Australia: technical report*.

as well as the poor servicing of the mental health sector more broadly.[88] Mental health carers speak about being on alert and vigilant all the time, even when the person they support is managing okay. They effectively have to put their entire life on hold. Conversely, at times of highest need, people suffering from mental illness are often unable to recognise they require support. Sometimes, consumers never have full insight. They may be experiencing 'lack of insight' or 'lack of awareness', a medical condition known as 'anosognosia'.

Currently, many mental health carers and families have to equip themselves (for better or worse) to navigate this complexity. Just as significantly, the aetiology of mental illness can disrupt families and the relationships between mental health carers and those they support. This creates particular difficulties that add to the challenges in accessing support and managing the ongoing relationships that are involved in supporting someone. The causes of mental illness can also create fundamental divisions between mental health carers and treatment teams, as these disruptions can be readily pathologised.

> *When he was admitted [to a Psychiatric Unit], he was so angry at me, he blamed me for calling the ambulance. He said he didn't need to go. He told me not to visit, he said he would never forgive me. Of course when he was a bit calmer (got some sleep, some medication) he said he needed help. That he'd gone off the rails big time. But at the time it was really hard. It made me cry*.

Documenting and understanding the intensity of mental health caring is critical to considering the supports mental health carers and families require so that they can provide support and live their own lives. The roll out of the NDIS has made the situation worse for many carers as existing supports for families and mental health carers that were working well have disappeared or transitioned into the Scheme, leaving mental health carers and families without any backup.

Mental health carers and families need to feel safe and supported. They need to be seen, respected acknowledged and listened to. They need advocacy, information and education in culturally appropriate ways, they need supports where they live whether regional, urban or rural and choices in supports. They need real choices about how much they can or want to do. They need key relationships to be nurtured and sustained. They need to be able to think about and plan for their future.

The following section identifies five key problems highlighted in the research and consultations for this submission that create or exacerbate the crisis for families and mental health carers in Victoria. Some of these are tied to the lack of responsive, proactive and preventative measures available to consumers with mental health issues discussed elsewhere in this submission. Others relate more directly to families and mental health carers themselves, to assumptions about their role, and the way they are viewed and treated within the mental health system.

Whilst the section describes the problems and impacts separately, it offers a set of solutions which, if taken together, provide a framework for a more holistic and humane approach to how carers are understood, recognised and supported. Some of these require new ways of

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[88] Jennifer A. A. Lavoie, 'Relative invisibility: an integrative review of carers' lived experiences of a family member's emergency mental health crisis, Social Work in Mental Health,' Vol. 16. No. 5 (2008), 601-626.

working with families and carers and the people they support, others require more effective application of existing policies and processes. Mind believes that these solutions, taken together, will deliver better outcomes for consumers, for families and carers and for the Victorian community as a whole.

Problem 1: Mental health carers and families feel and are unsafe.

> *There is a reluctance by clinicians to include considerations regarding carers & family, particularly aging carers who have experienced trauma as a result of behaviours of the person they care for.*

Too many mental health carers and families feel unsafe in the mental health system. Lack of safety takes can take many forms:

- The intensity of what they are left to manage when consumers are discharged and are still very unwell.
- Where behaviours of concern are present but the consumer is 'not sick enough' to be admitted for treatment or where the consumer does not have insight into their intense behaviours.
- Where cultural expectation about privacy and the role of family means that families and carers are dealing with unpredictable behaviours and emotions and are not equipped with culturally appropriate supports.

Although it remains largely undisclosed or undiscussed, family violence is a problem for some mental health carers. Research is emerging that suggests that between 10% and 30% of families experience violence as a consequence of behaviours of a person with mental illness.[89] Behaviours of high distress, of 'fight and flight' can result in highly charged incidents that consumers, families and mental health carers struggle to manage within the home.

Impact

The impact of the feelings around safety mean that mental health carers and families can experience trauma and develop anxiety and stress related illnesses. Mental health carers and families experience the lack of safety in their own poorer mental health outcomes.

High levels of expressed emotion can also occur when families and mental health carers are attempting to navigate complex moods, behaviours and unpredictable emotions. This can create charged situations where a sense of safety is lost for all. Guidelines and practice resources have been developed that begin to take account of the issues of safety for families, mental health carers and consumers. Safety for all is a key guiding principle of these resources

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[89] For more information about family violence in the mental health space, see: Jo Howard, *Adolescent violence in the home: the missing link in family violence prevention and response*, Australian Domestic, Family Violence Clearinghouse, University of New South Wales, 2011; Michel Stewart, Leslie M. Wilkes, Debra Jackson, Judy Mannix, 'Child-to-mother violence: a pilot study', *Contemporary Nurse*, Vol. 21, No. 2 (2006), 297–310; Seena Fazel, Gautam Gulati, Louise Linsell, John R. Geddes, Martin Grann, 'Schizophrenia and violence: systematic review and meta-analysis', *PLoS Medicine*, Vol.6, No. 8, (2009); E.B. Elbogen, S.C. Johnson 'The intricate link between violence and mental disorder: results from the National Epidemiologic Survey on Alcohol and Related Conditions', *Archives of General Psychiatry*, Vol. 66, No. 2 (2009), 152–161.

but more work needs to be done on the hidden dimensions of family violence and mental health.[90]

Aged carers are particularly vulnerable to being unsafe because often they have been caring on their own for a long time and adapting to the persons' illness by altering their own behaviours.

> *She would get upset when strangers came to the house or people she didn't know. Even friends she would be afraid of, so I stopped having people over.*

The other dimension of feeling unsafe relates to the safety of the person they are supporting. Where mental health carers and families are concerned about how the consumer is being treated in the system, on the streets, in EDs, by first responders, then their own feelings of safety are compromised. Mental health carers and families hear the stories about mentally unwell homeless people and the distressing ways consumers are treated in some in-patient settings, including the lack of safety due to the behaviours of other consumers. These realistic fears can mean that families and carers are reluctant to engage with the system even when their own safety can be compromised. In a relational sense it is hard for families and carers to feel safe when they are anxious and stressed about the safety of someone they care about.

Family violence in a mental health context needs to be sensitively dealt with but it does need to be acknowledged. Families may not disclose violence because they see it as a result of the illness, not a deliberate act. In consultations within mental health carer organisations, carers often share that they don't want to use the word 'violent' in talking about the person they support. Carers can also feel terrible shame that they are not managing the illness in ways that prevent violence. Consumers can also feel this shame, aware of how their behaviours when they are unwell have been confronting and intense. This shame is silencing and does not allow for an open conversation about the impacts of the illness on all parties involved. Families and mental health carers may also be concerned about the consequences for the consumer and the family if they do make disclosure and do not want the person that they care about to get into trouble for something that they see as not their fault, but as a consequence of illness.

Problem 2: Mental health carers and families feel, and are, invisible.

> *I was a young carer completely unsupported. Schools need to be more on board in recognising young carers and providing first level support*
>
> *When my daughter had her first psychotic episode at school, we had no idea what was happening, no one told us anything, there was police, ambulance, the hospital, we were just left sitting.*

Many mental health carers and families feel, and are, invisible in the system. Sometimes, they are invisible because the person they support is not engaged with treatment. Sometimes it is because, even though the consumer is engaged, services do not actively include the people that provide support. Young carers and older carers are especially invisible in the system because, on the one hand, there are no requirements to identify them and on the other, they have become isolated and disconnected. They feel protective of the person they support and so down play the significance of what is occurring and their role in it.

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[90] *Chief Psychiatrist guideline and practice resource family violence*, Department of Health and Human Services, 2018.

Impact

Not being 'seen' means that families and mental health carers are not equipped with ways to provide support. It can mean that their own needs are not considered. It can lead to families and relationships breaking down or families and carers burning out. Mental health carers and families often feel the contradiction of their position; that they are expected to just be there without being included in any meaningful way. Furthermore, sometimes when they are 'seen,' when they speak up or ask for information, or argue that what is happening is not working (for themselves and/or the consumer), they are viewed as problematic, a nuisance, or pathologised. Yet, they are still expected to be there, even when they have been undermined and disempowered by the system.

Problem 3: Mental health carers and families feel unsupported in the mental health system.

> *I have used the Carer helpline and it has literally saved me. These appear to have disappeared - money is going away from carer supports.*
>
> *I worry about my carer who is aging and not going to be able to continue to support me for much longer, but there are virtually no funded supports available for her.*

Mental health carers and families feel unsupported in a number of crucial ways. They feel unsupported because mental illness still has so much stigma and misinformation in the community, they feel unsupported because they are not seen or remain invisible. They feel unsupported because the system focuses on the individual – the consumer – not on their context or relationships.

Mind notes that the Commonwealth Government's new Integrated Carer Support System (ICSS) is yet to be fully rolled out. Nevertheless, existing state and federally funded service – in particular, respite – have been defunded as resources are rolled into the NDIS. The failure to align the implementation of the ICSS with the transition of services to the NDIS has exacerbated the lack of support in existing coverage. The uncertainty has also caused carers a great deal of anxiety, as they wonder what will be available for them in future.

Impact

There are a number of layers to the support needs for families and mental health carers. Firstly, there is the need for initial supports that help them to navigate mentally; supports that help to address the questions they have. These questions can include:

- What is it?
- How does it express itself?
- What are they ways forward?
- What kinds of support are helpful?
- What supports are available?
- What does diagnosis mean?
- How does medication work?

- What are reasonable and unreasonable side effects?
- How do they deal with lack of insight, behaviours of concern?
- What are the processes for getting help?
- What does a crisis look like?
- What is the future with this?

Secondly, there is the need for supports in the caring role: information, strategies, and education.

Thirdly, there are supports that are needed for mental health carers and families to be able to consider their own needs outside the caring relationship. Often, when there are supports available, they focus on equipping the carer in their caring role. A number of the consultation participants argued there needs to be a lot more attention on supports that address the needs of families and mental health carers in their own right. Carers spoke about the need to know what supports were available. The expectation was that carers would seek them out whereas most mental health carers spoke about the need for the supports to come to them, or to be informed about them through the health system such as GPs, clinics and other settings.

The transition to the NDIS is exacerbating uncertainty around carer supports. Critical funding that was previously available to support carers to sustain their own wellbeing is ceasing as it is transferred to the NDIS. This means that all of the crucial carer support programs and services for those supporting the vast majority of Victorians living with severe mental illness will no longer exist. As a consequence, mental health carers and families, who have been disconnected from existing supports, feel a level of uncertainty and cynicism about what is going to replace it and have seen the loss of skilled carer support and advocacy staff who have built up a community of practice at the local level.

This shift has particular consequences for mental health carers and families in rural and regional areas where carer outreach and advocacy were identified as critically important for isolated older carers. These, defunded, primarily federally initiated carer programs, were established on the strong evidence that investing in family and carers reaps both systemic benefits and benefits for mental health carers' and family's well-being. The decommissioned services also include services and supports for children carers of parents living with mental illness.

Problem 4: Mental health carers don't feel they are consulted or listened within the mental health service system.

Through the consultation, mental health carers and families expressed the view that the system would rather not bother with them. As one online respondent put it:

> *There are barriers to accessing good services, barriers in being understood by workforce, barriers in a lack of connected up approaches, and very limited therapeutic or counselling support to people with mental health issues. Families break down waiting for help and people are dying. I live and work and manage this in my personal life and my life has become consumed by managing the myriad gaps that exist, the stigma such that I would say our family lives as part of an underclass not well understood by the rest of society.*

If they are not viewed with suspicion, they are seen as a nuisance or as part of the problem. When they present to the system, families can appear dysfunctional, anxious, over emotional and frustrated. But these characteristics are often the consequence of the impacts that mental illness can have on the everyday capacity of families to navigate ordinary lives. Some families are disorganised and messy. But as carers observe, if they have turned to seeking help, then that is a good sign that they care and would like to be able to help; to be part of the solutions and part of the supports.

> *My son presented at emergency four times this month; including being ambulances from a psychologist appointment in regards to attempts to suicide. Each time he said he was okay as he did not want to go to hospital - no-one seemed to gather his prior history; and he has lost his relationship, housing, friends, income, food and ultimately nearly his life as he spiralled down.*

Impact

Key areas where mental health carers and families identify they are not being listened to or consulted include:

- When they are supporting a person who may lack insight, who has had traumatic experiences of treatment, or who has complex needs such as dual diagnosis, all of which may require admission to acute clinical settings and the process of stepping up and stepping down from these settings.
- In relation to post discharge; mental health carers feel the system does not ask for any information or insights that they may possess in a consistent way. Not only does this mean that important information can be missed, but also that families and mental health carers are left with the consequences of decisions that are made without their input.

Although privacy and confidentiality are important principles in any therapeutic relationship, and the rights of the consumer to privacy are essential, there do exist guidelines regarding how to obtain consent for information to be shared. And if consent is not given, it is unclear what critical information mental health carers and families can obtain so that they can make reasonable decisions about their capacity to provide support (and alternatives to their support) once the consumer is discharged into the community. Too many carers spoke about the lack of communication around discharge, assumptions about where the consumer was going to be living and assumptions about how much support families and mental health carers were able and equipped to supply.

Mental health carers and families also flagged how their knowledge of the consumer, particularly when they were not so acute, was not solicited even though such information provides ways into the therapeutic space.

> *They liked music, I told them to talk to them about music and that they might open up more readily if they did. They looked at me like I was a bit of an idiot.*

The Practical guide to working with carers of people with mental illness[91], provides an evidence-based set of partnership standards for carer engagement. The approach, based on the UK Triangle of Care, sets up a framework for collaborative working that enhances recovery outcomes for consumers, the wellbeing of families and job satisfaction of the service staff the

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[91] A practical guide for working with carers of people with mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Australia and Mental Health Australia

interact with. The Guide, which is supported by Mental Health Carers Australia comes with a set of publically available online resources, and has been trialled and tested in a range of mental health service settings. The website can be accessed here: https://www.carerguide.com.au/

Problem 5: Mental health carers and families feel the work they are doing is unsustainable.

> *Carers can't work, and when we try to juggle it all we are absolutely spent. We are absolutely exploited by government systems who did away with institutional care but replaced it with absolutely nothing therapeutic. To better support me, I need a break from talking to nurses, NDIS, support staff, answering emails, people expecting me to fill gaps when people don't show up, dropping money in when it's run out, buying things for family members because their own resources can't cover their costs.*
>
> *All I do is this. I can't work because they need me, I don't get out. I've lost friends. Family even stays away.*

The UQ research demonstrates that the amount of work mental health carers and families currently undertake is unsustainable[92]. They either lose their ability to undertake paid work, lose their health and well-being, lose their connections to other people because of the intensity of what they do, or lose their security in retirement or the idea of retirement is foreign to them.

Impact

While the impact on women in particular is well understood in terms of things such as their ability to participate in the labour market, little is being done to adequately address the gendered aspects of providing long-term support and care (although, disturbingly, in this regard, the UQ report notes that whether or not female carers get formal respite support does not impact on their employment prospects[93]).

The overall impact of this lack of sustainability is that mental health carers and families can lose sight of a future. Carers and families become accustomed to the new 'normal', adjusting to the person with the illness and accommodating them as best they can to the point where any sense of what is reasonable to expect is lost. They manage day-to-day but cannot plan ahead or think about the future being any different to the present.

> *You know I haven't had a holiday in years, [two decades] not even a weekend away. I don't really think about it. I just accept it, I guess. If I didn't it would be worse.*

Often, when mental health carers and families are thinking about the future, it is with anxiety and fear. They know what they do is unsustainable, but they can't see any way out of it. They acknowledge that if something were to happen to them, the person they support would be

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[92] Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess, Jan Kealton, Harvey Whiteford, *The economic value of informal mental health caring in Australia: technical report*, University of Queensland School of Public Health, 2016.

[93] Diminic et al, *Technical Report*, 18

left with no one. Many mental health carers, particularly older carers, sit with this anxiety all the time.

> *I can’t think about the future, but really the worry is there all the time about what is going to happen when I’m not here or if I get sick.*

Solutions

> *Mental health policies should be a priority of a healthy, civil society and politicians could contribute by providing more than slogans and lip service. It is essential to include carers… still!*

The Royal Commission provides an opportunity to rethink the role of families and carers and to position safe, supported and sustainable relationships at the centre of the system. A vital part of this is understanding the problem as relational phenomenon that is experienced socially and not just by the individual. This necessitates a stronger emphasis on relational and family focused practices in mental health treatment and recovery supports.

As part of this, legislation changes should be focused on mandating the rights of families and carers within the system. A ‘Families and Carers Rights Act’ would frame rather than suggest appropriate responses, turning guidelines into policy. Giving mental health families and carers rights does not mean that they are then competing with the consumer in the ‘rights space’. Rather, it opens the possibility of talking about relational rights and how the rights of families, carers and consumers can be respected and negotiated.

The ‘Caring Fairly’ Campaign speaks to the need for a rights approach with a cascading effect, not just through the mental health system, but also into workplaces, education and training, and the broader community. In the *Carers Strategic Framework*, the Victorian Government speaks to the need for better supports for carers, but they are still framed in a way that emphasises the recognition of their contribution to the economy.[94] Mind would argue that this recognition is hollow if mental health carers’ and families’ contributions come at a cost to their health and well-being, economic security, community engagement and other relationships. As one online responses put it:

> *Take it seriously. Fund it seriously. Stop leaving families to pick up the slack, which isn't evidence-based treatment and abandons the need of the individual with mental health issues.*
>
> *There is a need for flexible home-based services including carer advocates, something like district health nurses for mental health…*

Many mental health carers live from day-to-day, dealing with and managing issues as they arise as best they can, in the midst of all their concerns and responsibilities. Because of this there is little opportunity to plan or to think of the future. Techniques that assist carers and families to think about where they are and where they would like to be considering the needs and desires of all members are critical to helping them identify the sustainability of what they do and what supports they need to initiate change. This could be done as a whole of family process including the consumer. Mind has developed its own approach to this, the ‘My Better

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[94] Department of Health and Human Services*, Recognising and supporting Victoria’s carers: Victorian carer strategy 2018–22*, 2018.

Life' plan, based on extensive research with our own consumers, families and carers as well as the research literature. Across the NGO sector, providers use tools such as Carer Star or the CHIME,[95] are in widespread use across to help people chart their own lives. Most importantly these tools can help to identify what services can do to help to facilitate change for families, carers and consumers.

Mind believes there are a number of areas in which the Victorian government could play a greater role:

1. As a matter of **immediate priority**, mapping current mental health carer supports in the community sector. Identify where they are located, who uses them and the extent of the carer support workforce that currently exists to ensure that no carer supports are lost in the transition to the NDIS and that there is a commitment to ensuring the continuity of support and level of support. This needs to be undertaken as a matter of urgency, given the defunding of carer support programs ahead of the implementation of the ICSS.

2. Apply this mapping, also as an **immediate priority**, to urgently address gaps in the supports available, and to ensure there are sufficient funded supports in place to enable carers to maintain their caring role whilst achieving an acceptable quality of life.

3. Applying approaches to mental health carer & family support that emphasise safety. This should entail safety planning, assertive outreach to assess issues of concern in family centred ways, methods to assess crisis that are responsive and sensitive to the high levels of stress and trauma families and consumers may be experiencing and links to appropriate community supports before the consumer becomes too ill to benefit. Suggestions from mental health carers have included mental health nurses that operate like district health nurses, CAT teams that are able to respond in a timely way across geographies (metropolitan, rural, regional) and better access to safe alternative accommodation for those experiencing mental ill-health, such as PARCs.

4. Identifying clear and proactive ways to fill the gap in mental health supports so that families and mental health carers are not left as the space between acute/clinical and NGOs services. These might include more supported accommodation solutions with inbuilt therapeutic supports that provide an alternative for consumers and mental health carers and families.

5. Developing policy responses to the need for carer inclusive workplaces and to address the issue of the vulnerability and precarity of women due to their often life-long caring responsibilities.

6. Developing mechanisms that assist in identifying 'hidden' mental health carers and families that do not rely on self-identification. This could be through GPs, community health centres, myAged Care, primary health networks, schools and other educational settings and workplaces. It might take the form of:

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[95] Mary Leamy, Victoria Bird, Clair Le Boutiller, Julie Wells, Mike Slade, 'CHIME: Conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis,' *The British Journal of Psychiatry*, No. 199 (2018), 445–452.

- A carer checklist or a carer assessment tool.
- A flyer listing current and relevant mental health carer supports.
- A series of question that don't use the word 'carer' at all, but talk about supports and what their rights to support might be.

Assessment tools and information needs to be available in a range of different forms and formats, and able reach culturally diverse families and carers, as well as carers who do not access online material.

7. Develop and implement a system of quality assurance for family inclusive practice for all mental health service providers, in much the same way as the Rainbow Tick is applied to LGBTIQ+ inclusion. *The practical guide to working with carers of people with mental illness* provides an immediate framework and set of partnership standards for mental health services to engage and work productively with families and carers.

8. Ensuring that there are skilled workers from diverse cultural backgrounds working with families and carers as mental illness may be viewed very differently in different cultures and create further barriers to seeking support or receiving supports that are relevant and helpful.

9. Increasing home based and outreach supports. This includes face-to-face conversations that provide a chance to talk about experience, to find supports (for both the carer and the consumer if relevant) and to receive advocacy and ways of navigating the system. It was unanimously argued that these approaches should not be replaced with online options.

10. Building the paid carer lived experience workforce that can provide support to families and carers in all therapeutic and service settings, recognising that families and carers benefit from the support of others 'who get it' in the same way that consumers do. As with our recommendations on the consumer peer workforce, this workforce must be adequately renumerated and skilled appropriately, and embedded properly in the setting they work within, so that they can act with authority on family and mental health carer concerns. Without appropriate remuneration and support, like their consumers peers, this workforce can become disillusioned, frustrated and burnt out.

11. Embedding family focused or inclusive practice across all sectors of the mental health system. Guidelines already exist that have been collaboratively developed, trialled and evaluated between the clinical, community mental health providers such as Mind but these are inconsistently adhered to in service practice.[96] Current research internationally evidences the adoption of family inclusive or family focused practices in mental health recovery. Research shows that family (of blood or choice) support is critical in an individuals' recovery journey.[97] Mind believes that working in family

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[96] Department of Health and Human Services*, Working together with families and carers Chief Psychiatrist's Guidelines*, Victorian State Government, 2018; Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia, *A practical guide for working with carers of people with mental illness*, March 2016.

[97] Kim Foster, Darryl Maybery, Andrea Reupert, Brenda Gladstone, Anne Grant, Torleif Ruud, Adrian Falkov, Nick Kowalenko, 'Family-focused practice in mental health care: An integrative review,' Child & Youth Services, Vol. 37, No. 2 (2016), 129-155.

inclusive ways creates better outcomes for families, mental health carers and consumers. Initial guidelines have been developed that identify how to do this across the system but a whole of system 'buy-in' is required to embed these processes. [98]

12. Developing methods of acknowledging family trauma. Attitudinal change in staff could occur through drawing on the skills of carer consultants and paid peer workers to educate and illuminate the intensity of the on-the-ground experiences for those working in the sector who see mental health families and carers at best as a nuisance and at worst as part of the problem. Awareness training that promotes a 'no shame, no blame' approach to families as they present for support would help both mental health staff and families to work more collaboratively.

13. Providing greater support with the changes that occur when mental illness becomes a part of the fabric of everyday life within families and relationships. How to manage difficult behaviours and high levels of distress such as suicidal ideations and self-harming, anosognosia and how to feel safe and navigate crisis situations. Support to link into accommodation and housing services for the consumer so that mental health carers and families have age and relationship appropriate choices about whom they live with and how.

14. Improving understanding that the clear demarcation between mental health carers and consumer is often blurred. Many mental health carers are also consumers. Whilst the intensity of the consumers' needs and vulnerabilities can obscure this fact it is important (as part of an inclusive approach) to identify mental health carers own health needs and to respond appropriately and support appropriately.

15. Utilising tools that identify mental health carers at risk and tools that also recognise that the high levels of stress created by the level of informal support that many mental health carers and families carry makes mental health carers vulnerable to their own health issues.[99] Research has shown this, across the board and yet mental health carers and families are still treated in a policy neutral way when it comes to how much unpaid work they do and the complexity of that work. Respond to these risk indicators with appropriate supports.

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[98] Department of Health and Human Services*, Working together with families and carers Chief Psychiatrist's Guidelines*, Victorian State Government, 2018.

[99] The Draft *Carer Support Framework Integrated Carer Support Service* (ICSS) DRAFT Version 0.1, 26 October 2018, discusses carer assessment, however no such tools for immediate and quick risk assessment are widely available. There are other examples in development in the UK. For example: Mary R. O'Brien, Katherine Knighting, Barbara A. Jack, Hilary Fairfield, Neil Drinkwater, *The Carers' Alert Thermometer (CAT): Identifying The Support Needs Of Family Carers Of People Living With MND*, Edge Hill University, 2019;

4. How to improve mental health outcomes taking into account best practice and person-centred treatment and care models, for those in the Victorian community, especially those at greater risk of experiencing poor mental health.

As the Commission notes, certain population cohorts in the Victorian community are at greater risk of experiencing poor mental health. Mind will focus its comments in relation to terms of reference 4 on a group that the organisation has direct experience in working with, the LGBTIQ+ people and communities. For clarity, this submission will use this term 'LGBTIQ+', whilst understanding that it contains several distinct and overlapping demographic groups, each with their own distinct histories, experiences and mental health needs.

Our main interaction with Victorian LGBTIQ+ communities is via the operation of the Mind Equality Centre. This is a specific counselling service run by the organisation for LGBTIQ+ identified people. It provides a range of targeted allied health supports inclusive of, but not limited to, group and individual mental health counselling, skewed towards high risk and complex mental illness, for LGBTIQ+ people from 15 to 80 years of age, on a face-to-face and e-counselling basis, on a bulk billed and full fee basis. The Centre, which has been running now for three years, was established in recognition of the unique challenges to mental health faced by LGBTIQ+ communities and the prevalence and vulnerability of many LGBTIQ+ people to the issues examined by Mind.

Problem

Mind believes the question of how to improve mental health outcomes and provide best practice treatment and care to members of the LGBTIQ+ communities, has three dimensions:

- The broader societal level, including attitudes, stigma, government policies and decision-making regarding those with diverse sex, sexuality and gender identity , play out in terms of the LGBTIQ+ people's mental health.
- The experience LGBTIQ+ people have in relation to the mainstream mental health system – from the lower to acute to and how this can be improved, and;
- The issue of what tailored service responses exist to deal with the specific mental health issues faced by LGBTIQ+ people, how to better support these and create safe pathways into them.

Mind believes that on each of these levels the system is failing LGBTIQ+ people. How to remedy this without further fragmenting the service system and further marginalising the perspectives of LGBTIQ+ people is a major challenge.

Impact

While there are significant differences in mental health and wellbeing experiences across Lesbian, Gay, Bisexual, Transgender, Intersex and Queer people and communities, there is significant evidence that as group, they experience poorer mental health and wellbeing outcomes than their heterosexual, cis-gendered counterparts. Data compiled by the National LGBTI Health Alliance points to higher rates of suicide, or thoughts of suicide, and self-harm, and being more likely to have experienced and be diagnosed with a mental health condition.[100] Stigma and discrimination are a major reason behind these higher rates of mental illness and distress. American psychiatrist, Ilan H. Meyer's term 'minority stress' is a useful analytical tool to discuss the way in which stigma and discrimination create a hostile and stressful environment that can cause significant mental health problems.[101]

As an example of the way in which this manifests in poorer health outcomes, Equality Centre staff report a trebling of demand for their services during the 2017 marriage equality plebiscite, with a very long tail after the vote to change the law from people who were exhausted by the campaign and traumatised by social stigma and inter family conflict it generated. Another example of how broader government decision-making can impact the work of LGBTIQ+ people is the current legal environment in Victoria that stigmatises that sex workers and makes their work more dangerous, often putting them at significant physical risk. Over half of sex workers in Australia identify as other than heterosexual, including many who are bisexual or queer. Some Equality Centre clients are either currently doing sex work, or have done in the past, and suffer poor mental health consequences due to the conditions which the legal system here force them into.

Members of the LGBTIQ+ communities also experience poorer outcomes in housing and employment, to name just two areas. There is evidence LGBTIQ+ clients experience discrimination at all stages of the housing cycle and homelessness services are not always LGBTIQ+ friendly, especially to transgender clients. A 2017 university study noted evidence that housing/homelessness issues are heighted for LGBTIQ people.[102] They are at least twice as likely to have experienced homelessness as those who identify as heterosexual and face a range of specific structural factors associated with homelessness, including violence, harassment and explicit and implicit forms of discrimination, arising from homophobia, biphobia and/or transphobia, on top of personal vulnerability arising from mental ill-health. Mind staff report that LGBTIQ+ people also face additional barriers in the job market, including discrimination in selection processes and on the job by managers, clients and co-workers. This is supported by the findings of a 2015 New South Wales Council of South Services report into poverty and disadvantage faced by LGBTI people.[103]

Importantly, LGBTIQ+ identified people report negative experiences of the health and mental health service system and medical professionals, ranging from ignorance to outright prejudice and discrimination. Equality Centre staff maintain that many members of LGBTIQ+ communities often have to educate mainstream health professionals as part of getting a service, which can be exhausting and, in some cases, re-traumatising for the individual seeking help.

There are also significant gaps in LGBTIQ+ specific mental health service delivery in Victoria. There are five LGBTIQ+ specific organisations that offer mental health services all of which are

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[100] National LGBTI Health Alliance, *Snapshot of mental health and suicide prevention statistics for LGBTI people*, July 2016, https://lgbtihealth.org.au/resources/snapshot-mental-health-suicide-prevention-statistics-lgbti-people/

[101] Ilan H. Meyer, 'Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence,' *Psychological Bulletin*, Vol. 129, No. 5 (2003), 674-697.

[102] Ruth McNair, Cal Andews, Sharon Parkinson, Deborah Dempsey, *LGBTQ Homelessness: Risks, Resilience and Access to Services in Victoria*, University of Melbourne Faculty of Medicine, dentistry and Health Sciences and Swinburne University of Technology, September 2017.

[103] New South Wales Council of Social Services, *Beyond the Myth of 'pink privilege': Poverty, disadvantage and LGBTI people in NSW*, 2015

located in metropolitan Melbourne (although some PHNs have queer specific programs). The Equality Centre has a waiting list of several months and staff report that consumers travel from large distances to attend. There have even been inquiries from interstate. Many of these clients report poor experiences at mainstream acute and sub-acute mental health services.

Another issue relating to the lack of specialist mental health support for LGBTIQ+ identified people is the lack of available information on inclusive psychiatrists and social workers, and the main referral channel continues to be word of mouth from other LGBTIQ+ specific services.

Solution

Mind believes that the optimal policy solution in this area is a better standard of mainstream mental health service provision to LGBTIQ+ people, including improvements in one-on-one clinical practice, coupled with an improved set of LGBTIQ+ operated and specific services, with better referral pathways between the two.

Indeed, although the focus of Mind's contribution is LGBTIQ+ consumers, we would argue that the same general principle applies to all groups in Victoria at greater risk of experiencing poor mental health.

While everyone experiences mental health differently, there are obviously particular cohorts who may require services and supports that are sensitive to specific aspects of that groups culture, identity or social situation. In this respect Mind would point the Royal Commission's deliberations to the notion of 'cultural safety'. The phrase, originally formulated by Maori nurses in the 1990s was first used in the Australian context in relation to Indigenous service provision.[104] The underlining principles, that services operate in such a way as to not assault a person's identity, and the people best equipped to provide this culturally safe environment are people of the same culture or identity, has been used more widely in relation to more effective service delivery for marginalised groups.

Mind would urge the Commission to support increased investment in specialist community controlled LGBTIQ+ mental health services, including person-to-person and phone counselling, and bed-based services. The state government also has an important role to play in funding research on knowledge gaps in relation to LGBTIQ+ mental health, especially population level longitudinal studies, and innovative service delivery.

Significant changes also need to be made to improve the level of mainstream mental health service provision to LGBTIQ+ consumers. LGBTIQ+ consumers have the same spectrum of mental health issues as the general population and are entitled to be able to access safe, appropriate, mainstream services on the same basis as their heterosexual counterparts, without being discriminated against or traumatised/re-traumatised. In addition, the reality is that we cannot put the onus to cater to an entire population group on already tightly stretched specialist services, no matter how good they may be. And for many LGBTIQ+ people, for example those in rural areas currently, there will be little choice but to rely mainstream mental health services at some point in their illness.

Changes need to be mainstream clinical and sub-acute and community run mental health services to ensure they deliver a good generalist service that understands the basic situation

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[104] Robyn Williams, 'Cultural safety – what does it mean for our practice?' *Australian and New Zealand Journal of Public Health*, Vol. 23, No, 2 (1999), 213-214.

and needs of LGBTIQ+ consumers, including what, if any appropriate referral options to LGBTIQ+ specific services are available. Crucial to this, mental health staff, including clinical staff and GPs, need a basic education – 'LGBTIQ+ 101' as one Equality Centre worker put it – to ensure there is a no harm approach and a basic level of cultural safety is provided.

In this respect, Mind believes the Royal Commission should support the wider roll out of the Rainbow Tick national accreditation program, owned and developed by Rainbow Health Victoria, across mental health services. The program supports organisations to understand and implement LGBTIQ+ safe and inclusive delivery in the areas of organisational capacity, workforce, consumer participation, access, disclosure and documentation and culturally safe and accessible service provision.[105] The Equality Centre Achieved Rainbow Tick accreditation in early 2018 and Mind is now in the process of applying for it for the entire organisation. We are committed to this, including recruiting a part time Diversity and Inclusion Project Coordinator who will develop a plan and readiness processes, because we believe the Rainbow Tick is the most effective way for a health provider to demonstrate commitment to the LGBTIQ+ communities and provide assurance of quality and safety of our services.

Other changes that could be made to mainstream Victorian mental health services include:

- Funding provisions and requirements for mainstream mental health providers in meeting LGBTIQ+ inclusive practice standards.
- An explicit focus on the employment of LGBTIQ+ peer workers in any mental health workforce planning undertaken as part of the Commission's recommendations.
- Assistance to create a searchable register of LGBTIQ+ trained and inclusive psychologists, including the feasibility of lobbying and funding the Australian Psychological Society to update its 'Find a Psychologist' service.
- The introduction of minimum administration form requirements for state based and funded services to ask questions in relation to gender, sexuality and sex characteristics in an LGBTIQ+ inclusive way.
- LGBTIQ+ awareness and competencies built into tertiary qualifications in health care and continuing professional development to be LGBTIQ+ for GPs, psychologists and social workers.
- Include seven hours continuing professional development to be LGBTIQ+ specific for GPs, psychologists and social workers.
- A comprehensive review of data gathering infrastructure, including coronial data, to better capture rates of mental health outcomes and suicide for LGBTIQ+ communities.

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[105] More information on the Rainbow Tick, including *The Rainbow Tick Guide to LGBTI-inclusive practice*, can be found at https://www.qip.com.au/standards/rainbow-tick-standards/

4.4 In contact with, or at greater risk of contact with forensic the mental system and the justice system.

Problem

Much of the discussion around mental health and the justice system takes place at the forensic end of the intersection: individuals with complex mental health problems, often from socioeconomically disadvantaged backgrounds, who have experienced repeated contact with the justice system, occasionally resulting in incarceration.

There is certainly a clear correlation between being mental unwell and interaction with the justice system. One third of the Australian adults in their twenties and thirties with a psychiatric illness had been arrested during a 10-year period, with the first arrest often occurring before any contact with mental health services.[106] Surveys of prisoner health reveal that 60% of Victorian prison entrants report being diagnosed with a mental health problem prior to their imprisonment. [107] Gooding argues that the combination of the rapid implementation of state government deinstitutionalisation policies and the restructuring of Victoria's welfare state in the 1990s resulted in increased encounters between people living with mental ill-health and the police, including a series of police shootings in the early 1990s, a large percentage of which involved the people living with mental ill-health.[108] Vine and Judd cite evidence that increased pressures on state mental health services, along with changes in sentencing practices, had contributed to a substantial increase in the prison population.[109]

Consumer and carer feedback for this submission was mixed in terms of their experience of police and the justice system. Some reported very negative experiences. Others provided positive feedback about the attitudes and behaviour of individual police. One consumer who had had repeated psychotic episodes, echoed the views of several who took part in the consultations about the calm and professional manner in which the police acted.

> *They [the police] were extremely respectful with how they treated me. They talked to me respectfully. They didn't handcuff me and they drove me to hospital and just treated me like a normal person. This was the case with all three of my encounters with the police.*

Mind agrees there are serious issues in terms of the inadequate resources to adequately deal with mental health in the prison system and the problems of assisting these people to transition back to society. However, Mind wants to reframe the discussion around justice and mental health and discuss the work we are doing in the area of health-justice partnerships. This involves taking legal services into a specialist medical or health setting, and in doing so bringing healthcare and legal professionals together to address the social determinants of health and their legal interface and overcome the disconnect that often occurs between the health and legal/judicial systems.

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[106] Australian Institute of Health and Welfare, *The Health of Australian's Prisoners 2015*, 2015, 36.

[107] Australian Institute of Health and Welfare, *The health of Australia's prisoners 2015, Data tables: Mental health s30-s55*, 2015, https://www.aihw.gov.au/reports/prisoners/health-of-australias-prisoners-2015/data

[108] Gooding, 2017.

[109] Vince and Judd, 19.

Impact

There is a significant unmet demand for legal services on the part of people with poor mental health. Evidence from the UK, mainly in the area of welfare rights, shows that mental health problems both follow on from and increase vulnerability to legal problems.[110] People with complex and/or enduring mental illness can experience fear of disclosure, real and perceived communication problems and other capability issues. These can make even relatively simple legal problems appear overwhelming.

The key finding focused on the importance of integrating legal services into mental illness and other support services. Local research by the Law and Justice Foundation confirms the nexus between disability and illness, including mental illness, and the increased experience of legal problems. 'Not only do people with illness/disability have high legal and health needs, but it is well documented that they can face a range of obstacles in accessing services.'[111] In particular, people with complex and/or enduring mental illness experience both individual and systemic barriers to accessing legal advice and their sense of the problem being overwhelming can result in them avoiding addressing the issue, leading it to increasing in seriousness and consequences for the individual concerned. Research has also noted the importance of providing legal services to young people who are experiencing mental ill-health as they often experience a range of interrelated personal, practical, emotional, health, social welfare, and legal problems simultaneously.[112]

Solution

Recognising the patterns of structural inequality in terms of access to legal advice experienced by people with complex and/or enduring mental illness, Mind began a small scale health/justice partnership with a community legal centre in the western suburbs of Melbourne, WEstJustice, in 2017. This involved embedding a WEstustice lawyer in one of Mind's community services in the Western suburbs, two days a week, to provide general advice and assistance, build trust, and create a space where conversations could be held around legal issues. To date, a total of 38 clients have been assisted and advised on multiple legal matters over a period of 22 months, with an average of three issues per client, with some clients referred to other services. There was a striking degree of commonality regarding the issues dealt with over this period:

- Infringements/fines.
- Consumer debt, mainly credit card debt and people being upsold on products when they have been on medication or, in one case, put into a 'lock in' contract when they were in a psychiatric ward.
- Family violence.
- Superannuation/insurance, including enforcing disability insurance components of superannuation policies. This has secured over $1.5 million in payouts for three clients.
- Social service inquiries, mainly advocacy relating to people being transferred from DSP to Newstart, and assistance with how to word applications to go on the DSP.
- Matters to do with power of attorney and wills for carers with adult children with complex and/or enduring mental illness.

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[110] Linda Gyorki, *Breaking down the silos: Overcoming the Practical and Ethical Barriers of Integrating Legal Assistance into a Healthcare Setting*, Churchill Fellowship and Inner Melbourne Community Legal, 2014, 28.

[111] Ibid, 29.

[112] Ibid, 30.

With funding from the Victorian Legal Services Board, over the next two and a half years Mind is working to expand this work to take in partnerships between Mind’s frontline community mental health services and at least six community legal services. Mind services will be the contact point, and the scope of services covered will be focused, initially, on the six issues identified above.

Mind believes that this is an exciting and innovative model that will deliver pragmatic legal services to a community that has been structurally disadvantaged in accessing it. In addition to providing legal advice and representation to individuals experiencing mental ill-health, the model aims to:

- Collect data from casework to develop an evidence-based platform to develop pragmatic policy solutions to improve health, social and economic outcomes for the target community, as well as advocate for system wide reform.
- Provide training to Mind staff on issues relating to access to justice and the law.
- Develop a best practice model for how to deliver legal services to a hard to reach community and to scale it up beyond Mind. The aim is to contribute to the development of integrated and collaborative service models in the area of health/justice partnerships, as a way of providing innovative and practical solutions to bear to close the gap in terms of access to legal assistance for people with complex and/or enduring mental illness.

An independent evaluation of this model, conducted by researchers from La Trobe University, is underway.

Mind would argue that there is compelling evidence that intervening early in the life cycle of many legal problems experienced by people with mental ill-health can have significant benefits. This includes:

- Integrating legal advice, information and representation into a model of recovery oriented care, with improved legal outcomes for individuals, often accompanied by beneficial impacts for their mental health.
- Diverting individuals from a deeper engagement from the justice system.
- Financial savings in terms of reduced interaction with legal and other service systems, in terms of preventing indebtedness, and homelessness. Mind is in the process of building a comprehensive database of these savings.

Mind is happy to provide more information on its model of health-legal partnerships, should the Royal Commission require it.

5. How to best support those in the Victorian community who are living with both mental illness and problematic drug and alcohol use, including through evidence based harm minimisation measures.

People who suffer from mental health disorders that are complicated by alcohol and or other drug use disorders are defined as having a dual diagnosis. It is estimated that anywhere between 40% and 80% of service users who experience mental illness in Victoria, also have issues with substance use. One definition of dual diagnosis refers to it as:

> The co-occurrence of mental illness and alcohol and other drug use problems. 'Dual' suggests the existence of two disorders; however, it more commonly refers to those who have multiple complex needs. The term dual diagnosis does not indicate a secondary condition but instead identifies that a person has concurrent or co-occurring condition.[113]

Victoria's 2014 *Mental Health Act* is the first such legislation to embody the principle that people receiving mental health services should have their medical and other health needs, including any alcohol and other drug problems, recognised and responded to.[114] Although the proportion of people with dual diagnosis is high, substance use problems are often not the focus of mental health policies, processes, and practice or integrated as a matter of course into mainstream services. Up until recently in Victoria, drug and alcohol treatment was a specialism with its own areas of practice and staff.[115] At the same time, not all drug use is viewed problematically, and therefore not always associated with the risk or experience of mental illness. It is often assumed that people with mental health issues use drugs to self-medicate, but research reveals that this is not always the case.

In youth and adolescent mental health services there is concern about the way substance use can trigger mental health crisis in certain individuals with a vulnerability to mental illness. At a time when prevention policies are strengthening in relation to mental illness, examining the vulnerability of young people to dual diagnosis is emerging as a priority policy area. There has been and there still is tension, however, within the therapeutic and community health sector around how drug use should be viewed and treated. Is it a pathology, a social process, part of experimentation and risk- taking behaviours, and/or a way to intensify moods and feelings that lead to positive experiences?

> People with mental health problems and disorders may use alcohol and/or other drugs intermittently or continuously and for reasons that are similar to people in the broader community, that is, to socialise, for enjoyment or to alter their mood. They also sometimes use substances to reduce symptoms of their illness or the unwanted effects of their medication. Self-medication, however, is usually not reported as the main reason.[116]

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[113] M, Tesson and L, Burns, *National co-morbidity project, Department of Health and Ageing*, Australian Government, 2001

[114] *Mental Health Act* 2014, Objectives and Principles 2:11 (g) 'persons receiving mental health services should have their medical and other health needs, including any alcohol and other drug problems, recognised and responded to …'

[115] *Dual diagnosis: Key directions and priorities for service development*, Department of Human Services, Victoria 2007

[116] Kenneth Minkoff, 'Developing standards of care for individuals with co-occurring psychiatric and substance use disorders,' *Psychiatric Services,* Vol. 52, No. 55 (2001), 597-599*.*

Drug and alcohol use is problematic when it disrupts the lives of users to such an extent that they cannot manage everyday life, or when illegal behaviours interface with the criminal justice system and community safety concerns. How to approach and support people with dual diagnosis in ways that are inclusive and non-judgmental whilst ensuring safety for all, is an ongoing challenge for the sector and the system overall. It is widely acknowledged, however, that the high percentage of people with dual diagnosis requires a proactive response in government policy and guidelines,[117] and there is a strong impetus to improve the lives of people with dual diagnosis who may be living on the margins.

In consultations for this submission, consumers and carers rarely discussed dual diagnosis. Where comments were made, they suggested consumers and mental health carers viewed people with dual diagnosis as somewhat problematic. Ice addiction, in particular, was mentioned as an issue of concern in in-patient and treatment settings due to the potential violence or view of violence embedded in the pathology of ice addiction.

> *Getting a bed. Now many are taken up by ice addicts. It would be good if they had their own specialized wards to help them and all the beds they take up were free again for people who are suicidal and really need it.*
>
> *Hospital wards seem too clinical and people fear the ice addicts they may have to share a room and ward with.*

Problem

Dual diagnosis is understood in a range of different ways across services and treatment areas. The Victorian system still struggles to work in an integrated way.

There is a general agreement that drug and alcohol use can worsen mental health issues, even when the use is not at the level to be classified as a substance use disorder. How drug use interacts and intensifies the mental illness is key to identifying the extent of the problem. While there is no shortage of up to date research in this area, there are problems in relation to appropriate training, program design guidelines and protocols in relation to individuals who are living with both mental illness and problematic alcohol and drug use.

Impact

Working with people with dual diagnosis can be a delicate and complex process. How consumers are engaged without the taint of paternalism or judgment requires insight and skill. There is a view that people with addiction are more likely to engage in problematic behaviours and behaviours of concern. Staff can find themselves working against community opinion or in contradictory policy settings. How and in what ways services work with people who may be ambivalent about change or completely resistant to dealing with change in one part of their diagnosis, creates challenges for services and workers and can create tensions with other consumers who are working on mental health recovery in shared settings.

Consumers suffering from mental health issues often suffer from physical ill-health. With substance use the severity of impacts on physical, mental and psychosocial wellbeing are only

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[117] *Youth Dual Diagnosis Resource Guide*, Victorian Dual Diagnosis Initiative, 2015

intensified. Substance abuse often results in poor self-care, and compromised diet and sleep. Drug use places a range of systems in the body under stress including the nervous system, circulatory system, endocrine system and gastro-intestinal system. Compromised physical health can lead to negative impacts on the mental health of the person that can make treatment more complicated.

As well as having a complex presentation, a dual diagnosis can have a detrimental impact on a person's life and on their families and friends. It is not uncommon for a person with dual diagnosis to lose their social networks because of the stress on families and friends of trying to support a person with addiction as well as mental illness. For many family members it is difficult to understand where the addiction ends and the mental illness begins, and what is the relationship between the two. What to do to help can become fraught. Do you set firm boundaries, such as a zero tolerance to substance use? Or do you acknowledge the addiction is part of their mental illness and attempt to provide them with support despite the addiction or with the addiction?

> *I had a friend whose daughter had addiction and mental illness. They used to buy her daughters' heroin because they figured that their daughter was going to use anyway and at least this way she was off the street and the heroin was safer…*

There is an increased risk of anti-social behaviours that can accompany addiction including violence, increased suicidal ideation, self-harm, and high-risk behaviours. The subsequent loss of family and community support as a consequence of these behaviours of concern can lead to people with dual diagnosis experiencing homelessness or coming in contact with the criminal justice system.

Changes in the workforce are creating gaps in the system for appropriate training, qualified staff and service approaches that are able to integrate dual diagnosis. In Victoria, unlike other parts of Australia, drug and alcohol services were handed to non-government services. This meant that the drug and alcohol workforce was trained in delivering drug and alcohol services in social contexts. While this is vital, there is often a need for this to be informed by addiction psychiatry or therapeutic approaches to mental health. In these settings there is a danger of the mental health dimension of the diagnosis not receiving the integrated treatment attention required.

This also impacts on our worn workforce. Many of Mind's consumers, particularly those who have been taking psychiatric medications for many years, experience complex and chronic physical health issues. As noted above, these are further exacerbated when significant drug and/or alcohol use is in the mix. Responding to this situation has required Mind to invest in developing workforce capability to manage physical health as well as drug and alcohol use. We have found multidisciplinary approaches, delivered through various forms of partnership, of great benefit when working with people with complex physical health and drug/alcohol use.

Harm minimisation policies are applied inconsistently across Australia. The Victorian government both supports and doesn't support such initiatives. Safe injecting rooms, pill testing at music festivals, and more contextual responses to sentencing in the juvenile justice system have all been applied but are also challenged by the broader community and within government. The tension between zero tolerance and harm minimisation played out recently in the Victorian government's rejection of pill testing at music festivals despite evidence that it can prevent deaths.[118] The inconsistent message around harm minimisation and zero tolerance reflects conflicts within the community about drug use despite evidence- based research highlighting that harm minimisation does keep people alive and reduce anti-social behaviours.[119]

Solution

Understanding and responding to dual diagnosis should be core business for the community mental health sector and for the mental health system more broadly as research shows this is not a marginal issue but one that effects a high proportion of mental health consumers. Mind would argue that the integrative approach recognises the high rates of substance use and dual diagnosis across the population of mental health consumers.

Just as there are resources for families and mental health carers to help them to understand mental illness, there needs to be parallel and related information for families and mental health carers that demystifies dual diagnosis and points them to relevant supports and information. Evidence from alcohol and drug research suggests that supporting a person with dual diagnosis requires a different way of viewing the consumer. As one Victorian government document put it:

> We are moving to a focus on complex needs rather than just mental health and substance use… looking at people's plethora of needs [with] no-wrong-door service systems, much more effective models of early recognition and intervention with youth.[120]

Consumers consulted as part of this submission commented on the problems of people with addiction in the PARC services and in-patient settings. Concerns were also expressed about how behaviours associated with a dual diagnosis are managed. It is of great concern if consumers are loath to engage in services because they are afraid of other consumers in a service space. There are also concerns around consumers with dual diagnosis disengaging form services because of stigma. Ensuring staff are trained, equipped and resourced with appropriate protocols to manage such behaviours is essential.

Mind would encourage the Royal Commission to focus measures to better integrate dual diagnosis and mental health services, including:

- Greater integration between the mental health and alcohol and other drugs (AOD) sectors would be beneficial. Historically in Victoria, AOD services have been handed to non-government services in less medicalised settings. This means that the AOD workforce is trained to deliver in a social context approach, but without addiction psychiatry or therapeutic supports.
- Support and treatment for dual diagnosis is still very much an evolving field, both in terms of understanding causal relationships as well as in developing effective strategies for prevention, treatment and recovery. Mind believes that the concept of

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[118] Andrew Groves, '"Worth the test?" Pragmatism, pill testing and drug policy in Australia,' *Journal of Harm Reduction*, Vol. 15, No. 1 (2018), 1-13.

[119] David Ryder, Noni Walker, Alison Salmon, 'Drug use and drug-related harm: A delicate balance (2006), IP Communications, 13.

[120] *No Wrong Door*, Department of Education and Early Childhood Development, State Government of Victoria, 2014 www.nowrongdoor.com.au

psychosocial disability is useful in assessing the impact of substance abuse and addiction on functional capacity so that the necessary supports can be initiated.

- Dual diagnosis is often identified and experienced in young adults. There is an urgent need to resolve some of the territorial and practice boundaries to ensure consumers receive the supports they need and are not hand-balled from one community service to the next.
- Greater consistency regarding harm minimisation measures based on evidence and research. Mind would argue that harm minimisation is not just about reducing deaths from overdoses and drug related crime. Harm minimisation programs and services provide an opportunity to link people to other services. For example, the safe injecting room in Richmond provides pathways to mental health supports. Harm minimisation policies can also facilitate connections between youth and young adults and mental health services that can assist in supports to navigate dual diagnosis.[121]
- The provision of education materials regarding mental health and substance use disorders at key health interface such as GPs, community health settings and community providers.
- Services designed to combine detox with mental health supports, as detox can often intensify mental health symptoms creating a disincentive to undergo detox.
- More community education around harm minimisation drawing on evidence-based research and lived experience research to counter assumptions about the permissiveness of such approaches

Following on from earlier comments in this submission about the importance of better integrating lived experience into mental health interventions, Mind believes more attention needs to be paid to research that draws on the experiences of people with dual diagnosis and their families and mental health carers. Mind sees building an evidence base in lived experience dual diagnosis research as an important step in better understanding and resourcing this significant part of the mental health community.[122] There is also a need to build a peer workforce with insights and experience of dual diagnosis to encourage, support, and coach consumers to follow through the process of recovery.

It is also important to build dual diagnosis capacity building in services. As one Victorian government document puts it:

> Dual diagnosis capability refers to the evolving capacity and orientation of workers, agencies and sectors to routinely identify, welcome and respond effectively to a range of co-occurring mental health and substance use concerns. It does this with an integrated treatment, recovery-oriented focus with the person and their family or carers driving their recovery[123]

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[121] For more information see, Harm reduction Victoria, https://www.hrvic.org.au/

[122] 'Time for a change: a training resource for lived experience of dual diagnosis'. A one-day workshop that is an introduction to dual diagnosis, 28th May 2019, Mental Health Inter-professional Leadership Network.

[123] CORE Study Community Report 3, December 2016. The CORE Study involves collaboration between Mental Health Community Support Services, The University of Melbourne, VMIAC and Tandem. The CORE Study is funded by the Victorian State Government Mental Illness Research Fund.

Managing the complex relationship between mental health, physical health and drug/alcohol use is also well served by partnership models for service delivery that can enable multidisciplinary teams to work with people across organisational boundaries.

Concluding remarks

Victorian mental health services have been severely underfunded for a number of years. Currently, Victoria has one of the lowest per person expenditures on specialised mental health services in Australia. The Victorian system has been under further strain due to the introduction of the NDIS with many mental health supports dismantled or only available to NDIS participants.

This has led to major gaps, particularly in the "missing middle" – namely services for people with significant psychosocial disability, who need long term support to enable their recovery but are not in acute clinical need. We believe that services for people living with mental illness must address the social and economic factors that can precipitate or prolong mental health problems. This can lead to profound increases in quality of life for people living with mental illness and their families.

The validity of our response is strong, being based on the reports of people with lived experience which have been collected systematically, and combined with the best available research evidence.

The solutions we have proposed and our major recommendations are re-iterated below and linked to the Terms of Reference:

Terms of Reference 1. How to most effectively prevent mental illness and suicide and support people to recover from mental illness, early in life, early in illness and early in episode, through Victoria's mental health system, and in close partnership with other services.

Recommendation 1: Mind believes the Royal Commission must provide clarity on the question of what role the Victorian government should play in the space between what the NDIS provides to those with a psychosocial disability and what is provided by clinical and acute services. In terms of the Commission's deliberations on this matter, we also suggest that attention should be paid to what gaps exist or are emerging for people with complex and/or enduring needs, regardless of whether they are eligible or ineligible for NDIS.

It is also crucial that the Commission examine the significant service system and workforce needs required for Victoria's physical and mental health service system to effectively liaise, engage and intervene in a range of 'non health supports' within the state government jurisdiction. Consideration of a tiered response that would give people access to psychosocial rehabilitation services (with an early intervention focus) first for a period of up to five years is desirable. Those with ongoing support needs beyond this time would then be automatically eligible for a 'warm transfer' to the NDIS.

Recommendation 2: Early in life, early in illness and early in episode: we recommend that high quality standardised assessments are conducted and linked to a holistic care plan. We recommend the introduction of a single entry point into the mental health service system. This should incorporate a standardised and comprehensive approach to assessment that can be undertaken at multiple points in diverse systems. This should be available to anyone whose needs cannot be met through treatments provided under the Medicare Benefits Scheme alone. The Victorian government should also advocate that this approach be adopted nationally.

Terms of Reference 2. How to deliver the best mental health outcomes and improve access to and the navigation of Victoria's mental health system for all people of all ages, including through:

Terms of Reference 2.1 Best practice treatment and care models that are safe and person centred.

We have evidence that the service system is complex to navigate, fragmented, and only available at crisis points. Many touch points with the health system are not helpful to people with mental ill health (such as EDs).

A respectful relationship between the person experiencing mental ill-health and their clinical provider or GP is vital. Consumers also emphasise the need to treat the 'whole' person and not just the mental illness in a narrow clinical sense. Long-term relationships between consumers and service workers build a sense of trust and stability, which can be vital in helping recovery. Consumers and carers agreed there was an urgent need for the Victorian government to lobby the Commonwealth to increase the number of publicly funded consultations with a psychologist under Medicare.

<u>Recommendation 3:</u> Strengthen recovery outcomes by extending the range of services delivered through clinical-NGO partnerships, and introducing new models delivered through partnership across the continuum of need from acute care through to longer term rehabilitation and support.

Terms of Reference 2.2a Strategies to attract, train, develop and retain a highly skilled mental workforce, including peer support workers

<u>Recommendation 4:</u> Develop and implement a comprehensive workforce strategy to meet current and future demand, and which recognises the essential contribution of a specialised NGO workforce that provides important psychosocial and social supports.

Terms of Reference 2.2b Improved training and professional development for lived experience workforce

<u>Recommendation 5:</u> Fund innovative approaches, backed up by concrete workforce planning measures, to encourage the greater development of a lived experience or peer workforce. For instance, many of the negative impacts of ED presentations on both patients and the staff could be considerably ameliorated by the insertion of mixed teams of peer/community mental health workers into the ED.

Terms of Reference 2.3 Strengthened pathways and interfaces between Victoria's mental health system and other services

One of the most effective long-term policy interventions for people dealing with mental ill-health is providing access to appropriate housing. There a number of evidence-based models that demonstrate positive outcomes for people living with mental ill health. There is a need for more flexible supports that strengthen pathways and interfaces between the mental health system and the NDIS in relation to housing provision.

Recommendation 6: Determine the best configuration of mental health and housing support for people with complex and/or severe mental illness who are not eligible for the NDIS, and introduce targeted initiatives to meet their long-term accommodation needs.

Recommendation 7: Introduce a program that that provides up to three months' supported accommodation to NDIS participants while they wait for the Scheme to approve and provide their housing.

Terms of Reference 2.4 Better service and infrastructure planning, governance, accountability, funding, commissioning and information sharing arrangements.

Recommendation 8: Reform the governance, funding and commissioning of mental health services, including a reduction in regulatory burden, longer contracts, and funding that covers the full cost of service provision, including the time and emotional labour involved in servicing relationships and liaison between workers, different organisations and service systems.

Terms of Reference 2.5 Improved data collection and research strategies to advance continuity of care and monitor the impact of any reforms.

Recommendation 9: Construct a greater role for the Victorian government in supporting NGOs to improve data collection, assessment, benchmarking and outcomes, including examination of the feasibility of government developing an improved data collection and reporting system that can be licensed to the NGOs and utilised across the sector.

Terms of Reference 3. How best to support the needs of family members and carers living with mental illness.

Our submission has highlighted the significant challenges for carers and families. Firstly, mental health caring can be extremely stressful, amplified by stigma, misinformation, isolation and the unevenness, and indeterminacy of treatment and diagnosis, as well as the poor servicing of the mental health sector more broadly. Secondly, the mental health system does not support the unpaid work of carers, even as it relies on their labour to fill service gaps. Services do not actively include the people that provide support and may actively exclude them from important aspects of treatment and planning. Thirdly, the supports that have been provided to carers are insufficient, inadequate or being reduced. Respite, carer outreach and advocacy are all getting harder to access.

Recommendation 10: Demonstrate greater recognition of the important role that families and carers play in supporting people with mental illness by increasing the level and variety of supports and funding to help them do their job, based on the principles of control and choice that underpin many contemporary service delivery systems.

Terms of Reference 4. How to improve mental health outcomes taking into account best practice and person-centred treatment and care models, for those in the Victorian community, especially those at greater risk of experiencing poor mental health.

This current submission has mainly focussed on the mental health issues for the LGBTIQ+ community. Mind would urge the Commission to support increased investment in specialist community controlled LGBTIQ+ mental health services, including person-to-person and phone counselling, and bed-based services. The state government also has an important role to play in funding research on knowledge gaps in relation to LGBTIQ+ mental health, especially population level longitudinal studies, and innovative service delivery.

Terms of Reference 4.4 In contact with, or at greater risk of contact with forensic the mental system and the justice system.

Mind would argue that there is compelling evidence that intervening early in the life cycle of many legal problems experienced by people with mental ill-health can have significant benefits. Mind is piloting an exciting and innovative model that will deliver pragmatic legal services to a community that has been structurally disadvantaged in accessing it and is happy to provide more information on its model of health-legal partnerships, should the Royal Commission require it.

Terms of Reference 5: How to best support those in the Victorian community who are living with both mental illness and problematic drug and alcohol use, including through evidence based harm minimisation measures.

Understanding and responding to dual diagnosis should be core business for the community mental health sector and for the mental health system more broadly as research shows this is not a marginal issue but one that affects a high proportion of mental health consumers. Mind would encourage the Royal Commission to focus measures to better integrate dual diagnosis and mental health services, provide education to the community and health practitioners and improve engagement with young people with dual diagnosis. Mind believes more attention needs to be paid to research that draws on the experiences of people with dual diagnosis and their families and mental health carers.

Mind appreciates the opportunity to make this submission on behalf of consumers, carers, families and concerned workers in the sector. We welcome the prospect of groundbreaking improvements in the mental health services that will improve the mental health and quality of life for all Victorians.

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