

Response to the Productivity Commission Draft Report into Mental Health



17 January 2020

Mental health families & friends Tasmania (MHFFT) is a peak body established to support and advocate for and with families and friends caring for persons living with mental ill health in Tasmania. We use the terms 'families and friends' because, first and foremost, this is what those who care for persons with mental ill health are. Families and friends who care for persons with mental ill health often do not refer to themselves 'mental health carers.' Our vision is that families and friends of people affected by mental ill health are understood, respected, valued and supported to build their capacities and improve their quality of life. We articulate our jurisdiction's needs at a federal level through membership to our national body, Mental Health Carers Australia.

MHFFT was pleased to be able to address the Mental Health Inquiry's Commissioners at a hearing in Launceston on 9th December 2019. MHFFT welcomes the opportunity to respond to Commissioners' requests for further information and provide input into the Productivity Commission's Draft Report into Mental Health.

Below, we firstly provide some overall feedback, and then we discuss the following six specific recommendations for your consideration:

1. A relational recovery approach to mental health service delivery, with specific recognition of the role of mental health carers (relates to entire report);
2. Development and implementation of a national co-design framework for the mental health system (relates to draft recommendation 22.3);
3. Mandatory implementation of A Practical Guide for Working with Carers of People with a Mental Illness (relates to draft recommendation 13.3);
4. Establish a Mental Health Carer Peer Workforce (relates to draft recommendation 11.4);
5. Individual non-legal advocacy support for carers of persons with mental ill health (relates to draft recommendations 13.3 and 16.7);
6. Support for carers as they enter/exit the labour market, including provisions for superannuation (relates to draft recommendation 13.1 and 13.2).

MHFFT wants mental health reform to embed person-centred principles; with individuals, their families/friends and carers involved in all aspects of system design, implementation and review. We want to see services that respond to individual needs, instead of the current approach of trying to fit people into an inflexible and uncoordinated system—which appears to prioritise the needs of service providers over people living with mental ill health and their families/friends and carers.

We want to see governments at all levels genuinely respond to and address the social determinants of mental health, including access to secure housing, opportunities for education and access to meaningful employment. We want to see a system that addresses the whole person, including their most important relationships with their families, friends and communities, and their lifestyle needs and preferences. We want to see services that are responsive to the needs of mental health carers as they travel the often-convoluted journey to wellness and some form of reasonable functioning.

MHFFT views this Inquiry into mental health and wellbeing of Australians as an important opportunity for long-overdue, meaningful reform. The Inquiry presents a key chance to see real change to the way mental health services are planned, funded and delivered—from prevention and early intervention to acute care.

We know that for many people living with mental ill health, their families, friends and carers are with them as they navigate the mental health system. Carers of persons living with mental ill health deserve better, their voices need to be heard and they need to be afforded the dignity and recognition that has been lacking for so long.

MHFFT commends the Commission for highlighting key opportunities for reform in its Draft Report and supports many of the Recommendations. However, there are some important areas that we feel need to be strengthened. Firstly, we believe it is important that the issues captured in Chapter 13 need to be translated in the Summary Report and Recommendations. As it stands, the Recommendations relevant to mental health carers and families do not comprehensively pave the road for fulfilling the reform objective of increasing *'support for the wellbeing and role of carers and families of people with mental illness.'* Below we outline six key recommendations for addressing the needs of families and friends who are caring for a person with mental ill health that we believe need further consideration by the Productivity Commission.

Poor mental health and wellbeing is a growing problem in Tasmania, and has a profound impact on those with caring responsibilities. We hope that the Productivity Commission's Inquiry into Mental Health will result in genuine system reform to, not only address the mental health needs of consumers, but also specifically to ease the burden on the caring community.

Yours sincerely

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Recommendation 1

A relational recovery approach to mental health service delivery, with specific recognition of the role of mental health carers (relates to entire report)

MHFFT recommends that mental health system reform should be made through the lens of a 'relational recovery' approach. A relational approach recognises that individuals do not exist in isolation of their social worlds (Price-Robertson, Obradovic & Morgan 2017). It is an emerging framework that identifies individuals as relational beings whose lives cannot be separated from the social context in which they live.

Relational recovery is understood as a social process where recovery is interdependent on relationships with a persons' family, friends and social environments. Relational recovery moves beyond the shortcomings of individualistic recovery approaches, and Price-Robertson, Obradovic and Morgan (2017) warn that *"if the recovery approach does not grow beyond its individualistic roots it will remain unable to address the complex realities of many consumers' lives."*

In a Norwegian study involving mental health carers, researchers found that mental health and wellbeing was understood by the participants as a contextual and relational phenomenon, and this was evident both when the participants talked about themselves and when they discussed the

challenges of caring for someone with mental ill health (Berget et al. 2018). The authors wrote, “When mental health is viewed as a relational phenomenon it also connects mental health to the people working in the health care system. One can view the whole system as a body where all parts affect each other.” In this way, mental health carers are naturally engaged in the system and become an integral part of the caring team.

A relational recovery approach provides us with the opportunity to create a mental health system that recognises the interpersonal contexts of recovery, to address the underlying determinants of mental ill health and achieving more sustainable solutions. We urge the Productivity Commission to embed the concept of relational recovery into the recommendations for mental health reform in Australia.

Recommendation 2

Development and implementation of a national co-design framework for the mental health system (relates to draft recommendation 22.3)

Following on from the vision for a mental health system that embraces relationality, MHFFT calls on the Australian Government to develop a national co-design framework to be applied across all service settings, where the development of any new mental health-related services and products is undertaken in conjunction with consumers and their carers, as appropriate. Such a framework should include information about the continuum of consultation, guiding principles on how to establish governance mechanisms, how to identify and engage key stakeholders and provide funding to ensure effective engagement.

There needs to be more attention to the involvement of families and friends caring for persons with mental ill health in all aspects of mental health system development and implementation. Co-design is a truly inclusive method that brings stakeholders together to plan, design and produce services. It is a process that operates around principles of equal partnership, shared decision making, innovation and respect; and moves beyond traditional models of consultation, towards seeking community leadership from the outset so that people can be involved in defining problems and designing solutions collaboratively (Co-design Initiative 2016).

Too often, family and friends caring for persons living with mental ill health are excluded from the mental health system. In a study involving 119 mental health carers in Tasmania in 2015, we

uncovered some harrowing stories of experiences of caring for someone with mental ill health and we can't help but feel that some of these situations could have been prevented with early intervention and more holistic care (Vandenberg 2015). Families and friends caring for persons living with mental ill health have knowledge, skills and expertise that can help make the system better for everyone. It is critical that mental health carers are enveloped in a person-centred approach to the care and treatment of their loved ones and themselves, supported with information, assisted to identify their boundaries so they can maintain their own health and wellbeing, and that they are listened to and genuinely involved in system improvement. Together, developing a holistic, integrated and equitable mental health system can mean that the road to treatment, support and recovery need not be so fraught.

Recommendation 3

Mandatory implementation of A Practical Guide for Working with Carers of People with a Mental Illness (relates to draft recommendation 13.3)

MHFFT recommends that the Australian Government mandate the implementation of *A Practical Guide for Working with Carers of People with a Mental Illness* (Mind Australia et al. 2016) into the health and social services sector. This Guide provides practical steps for organisations to involve carers in partnership approaches to service delivery. It can be used in a wide-range of service settings to assist staff to recognise and support mental health carers in their role as partners in recovery. In 2017, MHFFT worked in partnership with Headspace Hobart (a community service for young people aged between 12 and 25 with mild to moderate mental ill health) to implement the Guide and found promising positive outcomes across all areas (MHCT 2018).

Through six partnership standards (refer to **Figure 1**), the Guide provides practical self-assessment tools for staff and organisations to identify opportunities for improvement to better engage, support and work with families and friends of persons suffering mental ill health in all areas of their care. It also specifically supports service providers to navigate issues of consent and confidentiality (a common barrier to involving carers). The Guide can support organisations to create better outcomes for persons with lived experiences of mental ill health and provide guidance for system change.

Figure 1: Six Partnership Standards in the Guide for Working with Carers of People with a Mental Illness (Mind Australia et al. 2016)

Six Partnership Standards
1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.
2. Staff are carer aware and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for carers in all service settings.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of carer support services is available.

Recommendation 4

Establish a mental health carer peer workforce (relates to draft recommendation 11.4)

MHCA supports the Commission’s recommendations in relation to strengthening the peer workforce, with a specific focus on the role of those with caring responsibilities; and endorses the need for a program to build support among clinicians for the role and value of peer workers. A carer peer workforce harnesses and validates the lived experience of carers, and uses their unique skill set can be used to complement the clinical staff skill set, allowing for a stronger caring team (Bourke et al. 2015).

Most of mental health carers’ time is spent on providing emotional support and psychosocial care for the person they care for (Diminic et al. 2017), which takes an enormous toll on the health and wellbeing of carers themselves. When we asked mental health carers as part of our research what physical or emotional effects they had experienced as a result of their caring role, two-thirds of participants said they frequently felt worried or depressed, and more than a third had been diagnosed with a stress-related illness (Vandenberg 2015). When asked what they needed to assist them in their caring roles, 60% said they needed more emotional support. A peer workforce could help fill this important need. Current government expenditure on mental health carers support services is

relatively modest in comparison to the enormous economic contribution carers make (Diminic et al. 2017), and further investment in this area is warranted.

Within any mental health peer workforce program there needs to be recognition that the roles of peers for persons with mental ill health (consumers) and mental health carer peer workers are distinctly different as consumers and carers have different needs and experiences of the mental health diagnosis and recovery process. A national carer peer workforce should be developed in co-design with mental health carers. The peer worker needs to be recognised as a professional role that is distinguished from other forms of peer support by the intentionality, skills, knowledge and experience that peer workers bring to their role, and should be clearly articulated in role descriptions.

Recommendation 5

*Individual non-legal advocacy support for carers of persons with mental ill health
(relates to draft recommendations 13.3 and 16.7)*

MHFFT recommends that the Australian Government invest in advocacy support for families and friends who care for persons with mental ill health when it is needed. Support for carers should be timely, responsive, appropriate and accessible.

Our research has shown that Tasmanian families and friends caring for someone with mental ill health often feel that they are not recognised as part of the caring team by health and social service professionals (Vandenberg 2015). We found that mental health carers often felt unrecognised, unheard and disrespected. Mental health carers felt that their concerns were dismissed, and their contribution to and valuable insights into the specific needs of the person they cared for were often ignored by service providers. Wilkinson and McAndrew (2008) argue that in order to care effectively, greater recognition of the expertise that family carers hold is required, as *“they are a source of knowledge, and experts in knowing the loved one and the person behind the illness”* (Rowe 2012).

Despite such concerning findings, it is also important to recognise that the carer/services interface is amenable to change and there is enormous potential for more responsive and enhanced service delivery (McPherson et al. 2014). A possible solution that could help address the ‘constant struggle’ associated with interactions with health and social services and systems, which is often described by mental health carers, is to provide advocacy support.

Advocacy support could help overcome current barriers to engaging with health and social services, understanding processes, which services were responsible for what, ‘navigating the pathway’ through a web of services and understanding carers’ rights. A New Zealand study identified how specially trained advocates can play a key role in care-coordination across the caring life-course (McPherson et al. 2014). **Figure 2** illustrates the key points of care coordination where a skilled advocate could provide valuable assistance to carers as they navigate the caring journey. For example, advocates could support carers to understand their rights or entitlements, to identify which services are available and what they offer, to access the various services as they undertake the caring journey, to liaise with service providers, to aid in transitioning between different caring environments, and to plan for the future. Importantly, advocates would need to have specific skills and attributes including having a passion for the role, being a good negotiator, and having had personal experience of ‘navigating the pathway’.

Figure 2: An ‘optimum’ interface: engaging with the carer (McPherson et al. 2014)



Recommendation 6

Support for carers as they enter/exit the labour market, including provisions for superannuation (relates to draft recommendation 13.1 and 13.2)

MHFFT recommends that the Australian Government provide further support for carers as they enter and exit the labour market, and make provisions for superannuation.

Australian data reveals that Tasmanian primary carers have a lower labour force participation rate (60.5%) than people who were not carers (78.5%) (ABS 2015). In 2018, in Tasmania, around 70% of primary carers were female (ABS 2018). Labour force participation among women primary carers has

been shown to be lower than for non-carers, and has substantial financial consequences across the life course (Nepal et al. 2011).

Our 2015 research involving mental health carers in Tasmania found that labour force participation isn't simply a matter of choice (Vandenberg 2015). Those who did work, said they did so because they had to – to meet financial needs; however, many carers said they also wanted to work for the social and personal benefits associated with employment. To be able to work, carers identified that they needed to be able to create space in their lives to participate in paid work, find a job with sufficient flexibility, have some sense of the need for 'self-care' and personal growth, as well as the capacity and resilience to take on dual roles. When these enablers are not enacted, the choice to work is increasingly diminished.

For many carers, labour force participation is altered as a result of their caring responsibilities. It is not uncommon for people to step away from the workforce or reduce their participation when they commence caring responsibilities. Further, caring responsibilities may terminate at a later stage, paving the way for a person's return to the workforce. At these key transition times, carers need additional support and advocacy—as such decisions are inherently complex and stressful.

In an Australian study, Nepal et al. (2011) examined the earnings prospects of women over their working life between 30 and 64 years of age, comparing women who are primary carers with women who are not carers. They found that compared to non-carers, female primary carers earn less income over their working years than non-carers with similar socio-demographic profiles and are subject to a greater financial stress. The primary carers most vulnerable in terms of lifetime financial prospects are single mothers with poorer health and lower level of education. Government income support payments for carers only partly compensate for the income foregone from reduced ability to participate in paid employment.

In addition to reduced income from employment, foregone superannuation savings are another major consequence for primary carers. As they become unable to participate in the paid employment, carers lose the opportunity to contribute to superannuation for the future.

Currently in Australia there is no provision to compensate for foregone retirement savings. It would therefore be appropriate to include a superannuation contribution as part of income support payments for carers of working age. As argued by Nepal et al. (2011), *"This is justifiable because in the*

absence of informal carers, the Government would have to arrange formal care by paying at least minimum wages and superannuation to the providers.” Without families and friends who care for persons with mental ill health, care needs would either go unmet or would need to be picked up by the formal health and social care systems, at additional cost to the government. It is estimated that it would cost \$13.2 billion to replace informal mental health care with formal support services (Diminic et al. 2017).

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