



**SUBMISSION TO THE PRODUCTIVITY COMMISSION INQUIRY INTO THE
SOCIAL AND ECONOMIC BENEFITS OF IMPROVING MENTAL HEALTH**

Mental Health Carers Australia
April 2019



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Introduction

Mental Health Carers Australia (MHCA) understands that the Productivity Commission has been tasked with exploring the social and economic benefits of improving mental health.

For the Commission's benefit, MHCA is a national peak body focussed solely on the needs of mental health carers. We are made up of seven state and territory organisations, including one national - refer to the last page for a list of our members. Our aim is to work constructively with governments to improve policies and programs that directly and indirectly impact mental health carers. More information about our organisation is accessible at: mentalhealthcarersaustralia.org.au

MHCA has fully endorsed the Caring Fairly submission, which provides a thorough analysis of the issues faced by mental health carers. We also understand that the Commission has completed a literature review. We do not intend to duplicate or re-present this work. Rather we will focus on a limited number of specific issues raised by our membership as urgent priority areas that should be considered as part of this inquiry.

The word carer can be perceived as an amorphous term. Carers are everyday Australians providing significant emotional, practical and financial support to their family member or friend living with a mental illness. There are significant, well documented impacts on carers associated with the caring role, including but not limited to: emotional distress, depression, financial insecurity, employment insecurity and loss of connections with their own family, friends and community.

Mental health carers are extraordinarily diverse, ranging from ageing parent carers, parents supporting an adolescent with emerging mental illness, to young people caring for a parent with mental ill health. They have their own stories to tell and have differing needs. These carers have the same right to live a good life as do all Australians. Government policies should aim to enhance carer outcomes across all life domains.

As the Commission has noted in its issues paper the economic cost of contribution of Australia's unpaid carers has been estimated¹. Mental Health Australia is of the view that this is a conservative estimate and the cost of caring is likely to be much higher. Our recommendations as set out below reflect the concerns of carers as heard by our wide-reaching membership base. We are also of the view that given the significant fiscal implications arising from a reduction in available informal care due to burn-out, supporting carers to continue caring is in the interest of both carers, their families, and the Commonwealth Government.

¹ Diminic S, Hielscher E, Lee Y, Harris M, Schess J, Kealton J, & Whiteford H, (2016) *The economic value of informal mental health caring in Australia: technical report*

Summary of recommendations

PRIORITY ONE - Mandate carer inclusive practice across all mental health service settings

Recommendation 1: As part of their commissioning processes, all jurisdictions require certification against the revised National Standards for Mental Health Services, which includes carer inclusive practice standards aligned to the six Partnership Standards outlined in the *Practical Guide for Working with Carers of People with a Mental Illness*

Recommendation 2: the NDIS Practice Standards are reviewed and fully harmonised with the updated NSMHS in recognition that people with psychosocial disability, their carers and families have multiple interactions with the NDIS and mainstream mental health systems due to the nature of episodic illness

Recommendation 3: that the Commission considers the evidence base and incorporation of a relational, inclusive based approach to mental health service delivery, with a greater weighted investment to community-based service settings

Recommendation 4: strengthen the Carer Recognition Act (2010) to include binding and enforceable requirements on all levels of government, the non-government and private sectors to consider the needs of carers in all planning and service delivery processes.

PRIORITY TWO - Review the carer payment system and the 25-hour rule

Recommendation 5: review the carer payments system, including the 25-hour rule to incentivise carers to re-enter the workforce, increase their hours or participate in educational and training opportunities

PRIORITY THREE - Scope a national carer peer workforce

Recommendation 6: scope and conduct a pilot to test the implementation of a national carer peer workforce to assist carers to navigate complex mental health service systems, including the NDIS

Recommendation 7: develop a national capability framework to guide the recruitment and professional development of a mental health carer peer workforce

PRIORITY FOUR - Give carers a voice at the policy table

Recommendation 8: that the Commission should recommend an appropriate level of funding to support systemic, legal and individual advocacy for carers and consumers

Recommendation 9: that the Commission recommends the establishment of a national co-design framework to support the development and delivery of mental health policies and programs

PRIORITY FIVE - Quantify and fund the unmet need for respite

Recommendation 10: that research is commissioned to better understand the unmet need for respite and its cost-benefits for mental health consumers, their families and carers, and government



Priority 1: Mandate carer inclusive practice across all mental health settings

1.1 Background

There is growing awareness and support for the adoption of carer inclusive practice at all levels of mental health service provision. In 2014 *National Review of Mental Health Programmes and Services*² recommended the development and implementation of a practical guide for the inclusion of families and support people in the planning and delivery of services.

In 2013 the Government released the national framework for recovery-oriented mental health services³. Importantly this framework described recovery-oriented practice as involving families and friends in the recovery process while accessing their own needs for counselling, therapy, education, training, guidance, support services, peer support and advocacy.

In 2016, [*A Practical Guide for working with people with a mental illness*](#)⁴ (the Guide) was released to improve carer inclusive practice across mental health services. The Guide introduced six Partnership Standards designed to improve outcomes by combining the knowledge and skills of staff with the knowledge and lived experience of family and carers in a partnership approach to service delivery across all settings. To date, services that have used the Guide have reported strong improvement in engaging with carers across all six partnership standards.

Despite these gains, carers continue to tell us that they feel locked out of the system and marginalised in decision making processes that directly and indirectly affect them. Involving carers in all aspects of service planning has multiple benefits, including reducing stress and anxiety and improving the skills and knowledge of carers in providing support to the mental health consumer in their everyday life outside the clinical/therapeutic setting.

1.2 Quality and safeguards

The National Standards for Mental Health Services (NSMHS)⁵ is an existing quality and safeguarding mechanism that includes standards related to carer engagement. Currently, the need for mental health services to comply with the NSMHS is determined by state and territory governments as part of their commissioning processes. In 2017 the Council of Australian Governments Health Council agreed to revise the NSMHS under the

² National Mental Health Commission (2014) *The National Review of Mental Health Programmes and Services Report*

³ Australian Health Ministers' Advisory Council (2013), *A national framework for recovery oriented mental health services: Guide for practitioners and providers*

⁴ Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia (2016) *A practical guide for working with carers of people with mental illness*

⁵ Australian Government Department of Health (2010), *National standards for mental health services*



*Fifth National Mental Health and Suicide Prevention Plan*⁶, which includes a process that accounts for interfaces with other relevant standards, such as the National Disability Standards.

In order that carers can expect consistency in carer inclusive practice, Mental Health Carers Australia would like to see fully harmonised national mental health service standards that incorporate carer inclusive practice in all commissioning processes across all levels of government. The NSMHS should harmonise with the National Disability Standards and the NDIS Practice Standards. All standards should incorporate the six partnership standards as outlined in the Guide.

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Recommendation 2: the NDIS Practice Standards are reviewed and fully harmonised with the updated NSMHS in recognition that people with psychosocial disability, their carers and families have multiple interactions with the NDIS and mainstream mental health systems due to the nature of episodic illness

1.3 A relational approach to service planning

There is a tendency for contemporary policy design to focus on the individual consumer without sufficient regard to the relational context of a person's life. Research has shown that there are significant benefits associated with the move to individualised funding arrangements, but the presence of supportive interpersonal relationships is critically important to ensuring that people can access these benefits⁷.

Mental health carers consistently tell us that their primary relationship with the mental health consumer is relational: husband, wife, friend, daughter, son, sister etc. They do not want their relationship defined by the caring role; however, commissioning and service delivery processes effectively confines them to this limiting identity.

There is a body of evidence emerging within Australia to support a relational approach to recovery as demonstrated through the 'open dialogue'⁸ approach currently being trialled in NSW, which the Commission may like to include in its research, if it hasn't done so already. Nationally and internationally there are other well documented inclusive models of care with demonstrated positive outcomes for consumers and carers.

⁶ Council of Australian Governments Health Council (2017) *The Fifth National Mental Health and Suicide Prevention Plan*

⁷ Meltzer A, Davy L. Opportunities to enhance relational well-being through the National Disability Insurance Scheme: Implications from research on relationships and a content analysis of NDIS documentation. *Aust J Publ Admin.* 2019;1–15

⁸ <https://www.psychologytoday.com/au/blog/hidden-and-see/201507/open-dialogue-new-approach-mental-healthcare>



Research also supports moving the focus of mental health services to community-based settings, which are co-located with primary health services, and are better positioned to involve local schools, community agencies, families and community volunteers in the recovery process⁹¹⁰.

Recommendation 3: that the Commission considers the evidence base and incorporation of a relational, inclusive based approach to mental health service delivery, with a greater weighted investment to community-based service settings

1.4 Carer rights legislation

The Carer Recognition Act (2010) aims to increase the awareness and recognition in the role that carers take in providing day to day support to people living with a mental illness. While this legislation has been instrumental in developing carer aware services, it does not go far enough. Australia is lagging behind comparable jurisdictions on embedding carer rights in legislation.

In the UK, the Carers (Equal Opportunities) Act 2004¹¹ came into force in 2005, which gave carers new rights to information. Under this legislation, local authorities are required to inform carers that they may be entitled to an assessment and when undertaking a carer's assessment, the local authority must consider whether the carer works, undertakes any form of education, training or leisure activity, or wishes to do any of those things.

The Care Act 2014 (England)¹² put in place significant new rights for carers including a focus on promoting wellbeing, a right to a carer's assessment on the appearance of need, a right for carers' eligible needs to be met and a duty on local councils to provide information and advice to carers in relation to their caring role and their own needs.

Given the fragmented nature of Australia's mental health and adjacent services systems such as health, housing and education, the lack of comparable legislation results in considerable inconsistency in how carer needs, goals and aspirations are assessed and incorporated into planning processes.

MHCA suggests that the Productivity Commission recommends to Government the feasibility of introducing carer rights legislation. The introduction of such legislation will send a strong message to carers that their role in providing practical and emotional support to mental health consumers is valued as a vital contributor to sustaining a strong and viable mental health service system.

⁹ Rosen A, Gurr R, Fanning P, (2010) *The future of community health services in Australia: lessons from the mental health sector*

¹⁰ National Mental Health Commission (2014), *Report of the National Review of Mental Health Programmes and Services*

¹¹ Carers (Equal Opportunities) Act 2004 (United Kingdom): <https://www.legislation.gov.uk/ukpga/2004/15/contents>

¹² The Care Act 2014 (England): <https://www.legislation.gov.uk/ukpga/2014/23/contents>



Recommendation 4: strengthen the Carer Recognition Act (2010) to include binding and enforceable requirements on all levels of government, the non-government and private sectors to consider the needs of carers in all planning and service delivery processes.



Priority 2: Carer payments and the 25-hour rule

Mental health carers face considerable barriers to participating in the workforce, education and training. The intense and episodic nature of mental illness, combined with a lack of adequate replacement care systems available for the person they care for, make it difficult for carers to balance employment, education and training with their caring roles. This is further compounded for those wanting to enter or remain in the workforce by inflexible or unsupportive workplace culture and design.

Another barrier for carers who currently rely on the Carer Payment from Centrelink for income can be its restriction on a carer's participation in work and education to 25 hours per week (including travel time). For carers who need to provide care on an unpredictable or episodic basis, this can create challenges when carers need to transition in and out of work or education as their caring role intensifies or reduces. Carers can also find this rule disincentivises them pursuing new educational or employment opportunities as they come at a significant financial risk to them and their families.

Lower levels of employment, education and training for mental health carers, compared to their non-carer counterparts, can have a range of social, economic and health impacts on mental health carers. The financial impacts of limited participation in the workforce are both immediate and cumulative, including lower income, disrupted careers and lower savings and superannuation. Other negative effects of unemployment can include reduced social networks and poorer health outcomes. Reduced participation in the workforce also has negative consequences for government, including lower tax revenue, increased spending on health and income supports.

MHCA suggests that a full review of carer payments and allowances is undertaken to understand the impact on carer participation in the workforce and educational opportunities. We also suggest that alternative mechanisms are identified, in a co-design approach with mental health carers, to increase carer participation in work and study. The revised payment system should take into account the unpredictable nature of episodic illness and should specifically address the needs of young mental health carers who face additional disadvantage when supporting a parent who is unable to work due to mental ill health.

Recommendation 5: review the carer payments system, including the 25-hour rule to incentivise carers to re-enter the workforce, increase their hours or participate in educational and training opportunities



Priority 3: A national paid carer peer workforce

When consulting with our membership base as part of preparing this submission, a recurring idea of a paid national carer peer workforce to support to carers in crisis or who are navigating complex mental health service systems, including the NDIS, was raised.

There is a growing body of evidence that supports the employment of peer workers across the mental health services sector and a number of service providers are actively engaging consumer and carer peer workers on a voluntary basis.

Carers have reported to us that they find the mental health service system complex to navigate and distressing when they are dealing with multiple professionals across the public and private health systems, private practitioners, and community based mental health service providers.

The introduction of the NDIS has added an additional layer of complexity for carers of people with psychosocial disability. Despite the NDIS being specifically targeted towards participants, carers report that they have taken on additional unpaid work associated with the administrative activities associated with managing a NDIS plan, when the participant is unable or unwilling to do so. A study in the UK found that person centred funding increased the numbers of hours spent caring as the caring role shifted from direct care to managing supports¹³.

Outside of the NDIS, carers are burnt-out from engaging with various mental health service systems and the additional administrative demands that impacts on their time. This is often in addition to accompanying consumers to various appointments and providing practical and emotional support as part of their usual caring role. As mental illness is often cyclical in nature, multiple interactions with private practitioners, the public and private health system, is the norm.

MHCA understands that the National Disability Insurance agency is currently scoping a carer competency framework including the possible appointment of paid peer workers within the NDIA and their Local Area Coordinator partners.

Given the nature of episodic mental illness and the reality that carers are required to navigate a variety of public and private mental health services at any point in time, MHCA suggests that the Commonwealth Government considers commissioning a national, paid carer peer workforce to assist mental health carers to navigate the *entire* mental health service system, including and not limited to: the Integrated Carer Support Service,

¹³ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). *Transitioning Australian Respite* (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.



Primary Health Networks, the NDIS, and private and community-based mental health services.

In order to achieve this, it is suggested that the Commission gives consideration to including a recommendation that Government scopes the cost-benefits of commissioning a national carer peer workforce. It is our recommendation that a paid carer peer workforce:

- is independent from government
- is funded at a national level and is independent of service provision
- provides information and support to families and carers from the point of initial diagnosis through to acute care admissions
- provides time-limited intensive support at initial diagnosis or change in circumstances, but is accessible to families and carers at any time when they need support or advice
- provides individual advocacy when families and carers experience difficulty in navigating the mental health service system
- identifies the specific needs of families and carers, and provides assistance to apply for carer specific support services
- can interact with families and carers via face to face, phone or web-based communication systems

In order to understand the potential benefits of a carer peer workforce, MHCA suggests that a pilot is conducted and evaluated to measure quality of life changes for carers across the following domains:

- engagement in employment, education and training opportunities
- emotional well-being
- physical well-being
- interpersonal relationships
- participation and connection to community
- navigating the mental health service system
- carer rights and recognition

The evaluation should also measure outcomes for consumers, which are then included in the overall cost-benefit analysis. The results of the evaluation could inform a nation-wide implementation strategy, including the development of a competency and capability framework to guide the commissioning and professional development of carer peer workers.

Recommendation 6: scope and conduct a pilot to test the implementation of a national mental health carer peer workforce to assist carers to navigate mental health service systems, including the NDIS



Recommendation 7: develop a national capability framework to guide the recruitment and professional development of a mental health carer peer workforce that is also funded across all mental health settings



Priority 4: Carer representation and advocacy

Government is increasingly recognising that the design and implementation of good policies is highly dependent upon listening and working with constituents with lived experience of the policies that impact them. Mental health services at the national level are going through a period of profound change. The shift to individualised funding packages with the NDIS, and the new approach to carer support services through the Integrated Carer Support Service, will fundamentally transform how mental health support services are delivered to both consumers and carers.

MHCA members, individually and as a coalition, are being called on to participate in a range of complex, rapidly moving policy formulation processes. MHCA's ability to be a strong voice for mental health carers limited by its lack of resources. Furthermore, the absence of a coordinated approach to the provision of systemic, legal and individual advocacy at a national level only adds to the marginalisation of carers in decision making processes.

It is proposed that individual advocacy could be met through a carer peer workforce as previously described. Legal and systemic advocacy should be led at a national level by an organisation that is independent from Government. As mental health policy and program design increasingly shifts to a national level as demonstrated by the introduction of the NDIS, it is imperative that carers have a national voice in the exchange of ideas on how to improve carer outcomes.

Carers with lived experience should also be included in the development of policies and programs that affect them using emerging co-design principles and techniques. There is growing evidence for positive outcomes relating to individual agency and autonomy, connectedness and skills development. Co-design should be considered a value proposition for government with benefits including reduction in the usage of crisis care services and positive employment outcomes¹⁴

Recommendation 8: that the Commission should recommend an appropriate level of funding to support systemic, legal and individual advocacy for carers and consumers

Recommendation 9: that the Commission recommends the establishment of a national co-design framework to support the development and delivery of mental health policies and programs

¹⁴ Slay J, Stephens, L, (2013) *Co-production in mental health: A literature review*



Priority 5: Quantify and fund the unmet need for respite

Prior to the introduction of the NDIS, mental health carers were able to access respite through a national funding program, called Mental Health Respite: Carer Support. Along with a range of other services, this program provided carers with temporary relief from their caring responsibilities through planned short-term respite.

As part of bilateral agreements related to NDIS transition, the Mental Health Respite: Carer Support program is now closing, with its funding rolling into the NDIS. Modelling undertaken by Mental Health Australia in 2017 identified that in 2013-14 the Mental Health Respite: Carer Support program assisted over 40,000 carers¹⁵. When the NDIS is fully rolled out, it is anticipated that it will fund supports for 64,000 people with a psychosocial disability. However, only around 1.3% of all NDIS participants are currently receiving short-term accommodation support (respite)¹⁶. If this rate continues, at full roll out this will equate to an estimated 830 people with a psychosocial disability receiving short-term accommodation support (respite) through the NDIS.

Even if additional NDIS funded supports that could be considered carer respite, such as overnight in-home care, are added to this estimate, it is still highly likely that the respite available under the NDIS will fall significantly short of need.

To further compound this issue, the NDIS has significant shortfalls in its recognition of mental health carers and the important role they play in supporting those eligible for the scheme. Eligible NDIS participants are given individualised funding plans. While the NDIS has admirable aims for delivering individualised support to the participant, it is not always compatible with meeting the support needs of their carer.

In the case of respite, while a carer might identify their need for respite, respite might not be a priority for the participant, or the carer may not be invited to the planning meeting. This results in highly variable outcomes for carers with many not receiving the levels of respite that they previously accessed under state and territory programs, or at the level they require to maintain their own well-being in order to continue in their caring role.

On review of the existing data it is difficult to determine the quantum of reduced funding for respite due to transition to the NDIS. Furthermore, it is difficult to quantify the level of unmet need. MHCA suggests to the Commission that research is undertaken to better understand the demand and cost-benefit of respite care, including but not limited to:

¹⁵ David McGrath Consulting, 2017, The implementation and operation of the psychiatric disability elements of the National Disability Insurance Scheme: A recommended set of approaches

¹⁶ NDIA spokesman quoted in Probono news, September 2018 <https://probonoaustralia.com.au/news/2018/09/family-faces-devastating-loss-support-son-disability/>



- quantifying the level of unmet need for respite following transition to the NDIS
- the relationship between respite and the frequency of acute care admissions
- the relationship between respite and entry into full time supported accommodation
- outcomes for carers across the seven life domains described previously in this paper
- outcomes for consumers.

The results of this study should inform the development of a national approach to the provision of respite care.

Recommendation 10: that research is commissioned to better understand the unmet need for respite and its cost-benefits for mental health consumers, their families and carers, and government

