Mental
Health
Carers
Tasmania

Submission to
Productivity Commission inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth.

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Preface

Mental Health Carers Tasmania (MHCTas) is a statewide leader in the provision of mental health carer support and systemic advocacy. We aim to improve the quality of life for the one in five Tasmanian families, friends, carers and people living with mental health issues and mental illness. We define carers as people who provide unpaid physical, practical or emotional support to a family member, friends, neighbours or colleagues with mental ill health. On behalf of mental health carers in Tasmania, MHCTas welcomes the opportunity to provide a submission to the Productivity Commission. We note that our responses are informed by consultation with our members and relate specifically to the provision of mental health carer support specific measures.

The practical, physical, economic and emotional demands of supporting a loved one with a mental illness can be enormous. The caring role can have a significantly negative effect on the health and wellbeing of carers who provide considerable unpaid support to people with mental health issues, saving the community a great deal of money while receiving very little support themselves.

The Productivity Commission Issues Paper includes the following diagram which lists the four streams of assessment that the Commission will be undertaking in this investigation. MHCTas will be reporting against those four streams in relation to mental health carers.

Figure 3 **Assessment components**

Consequences of mental ill-health

- What it is costing individuals, their carers and Australia more broadly to forgo the participation and full contribution of those with mental ill-health

Effectiveness & cost of current programs and supports

- Effectiveness in improving mental health, preventing suicides, improving social and economic participation and contribution to wider community
- Value-for-money of current programs and supports

Gaps in current programs and supports available

- Gaps in continuity of care for particular demographic groups (such as those with less severe or episodic mental ill-health

Likely effectiveness of alternative programs and supports

- Improvements in outcomes possible and additional long-term benefits for particular consumer and carer groups and for Australia more broadly

1. Consequences for mental health carers

In a report commissioned by Mind Australia Diminic *et al* found that there are an estimated 240,000 mental health carers in Australia and that it would cost $13.2 billion to replace the informal mental health care provided by carers with formal support services.[1] The greater proportion of these carers are women and the impact on their financial future, alone, is enormous.

The Mind report noted that "The intention is never for government to completely replace the care provided by mental health carers. Rather, a replacement cost analysis is a method used to quantify the economic value of informal care, and in turn highlight the importance of carers." Page 3

It seems more than clear to Mental Health Carers Tasmania that the support provided by informal carers benefits the community as a whole and certainly saves the government quite a large sum of money.

Among the not insignificant consequences of caring for a loved one with mental ill-health are:

- Loss of income through loss of employment and subsequently loss of adequate retirement benefits.

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[1] Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess1, Jan Kealton, Harvey Whiteford 2017), *The economic value of informal mental health caring in Australia: summary report*, Commissioned by Mind Australia, https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf

- Loss of work skills due to many years out of the workforce and subsequently loss of confidence and capacity.
- Loss of connections and relationships and subsequently social isolation contributing to an Increased risk of physical and mental health issues.

The practical, physical, economic and emotional demands of supporting a loved one with a mental illness can be enormous. But to date, most of our national discussions about mental health carers have focused on their right to be involved only in service delivery and on the wellbeing of those they are providing care for.

While this involvement is something carers have been asking for, it is important that a national agenda also recognises the rights of those that care for someone with a mental illness not to have their own mental health and wellbeing compromised because of the vital caring role they play. People who love, live with and care for someone with a mental illness, including those with depression, need timely and equitable access to interventions to enhance their own wellbeing and prevent the onset of mental ill-health.

The seminal *The economic value of informal mental health caring in Australia: summary report* produced by the University of Queensland, School of Public Health and commissioned by Mind Australia reminds us that, "Qualitative data from the UQ Carer Survey 2016 expanded upon a number of issues, including poor carer mental and physical wellbeing, feelings of hopelessness and exhaustion and carers changing many aspects of their lives to accommodate the care recipient, including their careers, finances and housing. The take-home messages from these responses were that … there is nowhere near enough support for mental health carers" and that carers are "…tired of filling in the gap of the shortfall in services". Another recurring theme from carers was that inadequacies in the mental health treatment and support system for their care recipients increased the burden of informal care. Any strategies to increase support for carers should also consider the benefits that may accrue for carers in improving services available to people with mental illness. Prioritising provision of carer support services would do much to ensure that mental health carers can continue to perform their role without significant financial disadvantage and psychosocial distress. It would also do much to address some of their identified unmet needs."[2]

2. Effectiveness & cost of current programs and supports for Mental Health Carers

It is clear to MHCTas in discussions with carers in our state that not all mental health carers are accessing support services. Furthermore, many do not identify as "carers", believing that they are simply doing what is required of family members. It is also important to note that CaLD carers in particular, do not identify as carers and very rarely seek support due to extended family structures and increased stigma. Those who do try to access programs targeted to carers often feel that their needs as mental health carers are not being addressed or are neglected and so they give up on seeking support altogether.

Although benefits for carers have been described by the Australian Government as a significant burden on the welfare system, "detailed data from the UQ Carer Survey 2016 participants showed that "43.4% of

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[2] Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Schess1, Jan Kealton, Harvey Whiteford 2017), *The economic value of informal mental health caring in Australia: summary report*, Commissioned by Mind Australia, p. 15, https://www.mindaustralia.org.au/sites/default/files/publications/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf

mental health carers did not receive any form of Centrelink support."[3] The above-mentioned *The economic value of informal mental health caring in Australia: summary report* demonstrates that an estimated 240,000 Australians care for an adult with mental illness.[4] These mental health carers provide large amounts of unpaid support, often on a fluctuating basis. The report found that "overall, the total annual replacement cost for all informal mental health carers in 2015 was $14.3 billion. After adjusting for $1.1 billion offset in Centrelink payments, this figure was $13.2 billion. This is how much it would cost governments to replace all of the caring tasks currently provided by mental health carers with formal mental health support services, such as PHaMs or disability support workers."[5]

MHCTas emphasises that supports aimed at Mental Health Carers in the form of both programs and benefits cannot make a difference if the majority of informal carers are not aware of them. This is particularly the case for carers from particular cohorts including CaLD, people in remote and rural areas and young carers. There seems to be no consistency in providing information and little funding to Mental Health Carer organisations like Mental Health Carers Tasmania to support the dissemination of information across the community

MHCTas also notes that the number of carer support programs has declined since the advent of the NDIS. With regards to the NDIS, MHCTas has found that:

- Although there is an intention to provide supports through NDIS Tier 2, it is not yet entirely clear what these are and how they are benefitting carers. The NDIS has stated that it aims "to support carers – whether or not they are family members - so that they can continue to provide care. While it does not pay carers directly for their work, it may be able to pay for training that will help carers maintain or improve their care. The NDIS might also fund other supports that make life easier for carers, such as respite." These are yet to be demonstrated as ongoing and established initiatives.
- There seems to be a lack of clear understanding about the needs of carers supporting an individual with severe mental ill health. Although the NDIS acknowledges the important role a person's support network plays in their recovery, this does not yet translate into consistent practice. The NDIS refers to "a range of supports which provide care for a person with disability, which may provide a respite-effect for families and carers by providing a break from the caring role including overnight assistance with self-care and assistance in a host family or alternative family situation." Welcome though these initiatives may be, they do not go to the heart of the issue and display little understanding of the needs of mental health carers. For a start, most care provided by carers is not "self-care" and many consumers would not agree to assistance in a "host family".
- In a submission to the Joint Standing Committee on The National Disability Insurance Scheme Mental Health Carers Australia made the following points (with which MHCTas heartily concurs) "We recognise that NDIS potentially offers eligible people with psychosocial disability and their carers/family great benefits. An assessment of some of our member organisations clients over the past three years indicates that only about 14 per cent of the services provided were to people caring for a family member with a diagnosis that would make them eligible for the NDIS. In a survey conducted by Carers NSW in 2012 they found that 60 per cent of mental health carers reported needing support in comparison with about 30 per cent of other carers who responded. Mental health

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[3] Diminic *et al*, p. 14.

[4] Diminic *et al*, p. 4.

[5] Diminic *et al*, p. 12.

> carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant state government funding into the NDIS will leave many families caring for someone with a severe mental illness without access to any supports."[6]

3. Gaps in current programs and supports for Mental Health Carers

MHCTas notes that there are a number of programs for carers generally and some specifically for mental health carers offered in jurisdictions across the country. However, these programs are not universal and do not cover entire communities, seeming to operate like pilots, as indeed some of them are.

Children in a caring role are particularly vulnerable to being overlooked, especially as they too, do not immediately identify as carers but believe that they are simply doing what is required of them as family members. Their needs are considerable with the caring role having a significant impact on their school and social lives. The shift which comes with the roll-out of the NDIS means that a young person caring for their parent with a mental illness may no longer be eligible to participate in the school holiday program that existed prior to the introduction of the NDIS. This particular program introduced young carers to each other, offering peer support, as well as providing them with communication, coping skills, and resilience tools. This is clearly a situation that could prove to have extremely negative consequences, not least of which is the development of mental health issues in the child carer.

The Carer Recognition Act 2010, includes as Schedule 1 *The Statement for Australia's Carers* which makes, amongst other statements, the following:

- All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- The valuable social and economic contribution that carers make to society should be recognised and supported.
- Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.

Consistent with the *Statement for Australia's Carers*, the supports required by carers, which are by no means universally provided, include:

- Support services should be extended to facilitate a carer's need or desire to discontinue their caring role due, for example, due to concerns about their own health, wellbeing and safety.

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[6] Mental Health Carers Australia (2017), *National Mental Health Carer Voice: A submission to the Joint Standing Committee on The National Disability Insurance Scheme The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, http://www.mentalhealthcarersaustralia.org.au/wp-content/uploads/2017/11/Mental-Health-Carers-Australia-NDIS-submission-to-Productivity-Commission.pdf

- Better provision for carers with the shift of funding of carer supports to NDIS. Carers must be assessed based on their own needs as well as the needs of the person they care for.
- Families and carers of people experiencing severe mental ill health or psychosocial disability need to continue to access the services they need to maintain their caring role, especially with the funding for the Mental Health Respite: Carer Support Scheme being transitioned to the NDIS. Lack of appropriate services may occur where:
    - The person with a mental illness is not eligible for the NDIS.
    - The person with a mental illness chooses not to engage with the NDIS. Many people with mental health issues do not seek services so it is likely, in the absence of assertive outreach, that some people with severe mental ill health will not engage with NDIS.
    - The person is eligible for the NDIS, but the caring role is not fully acknowledged.
    - The support required by the carer is not accommodated by the activities funded through the NDIS.[7]

Furthermore, the extent to which State mental health services will engage with and fund carer services, during and following the transition to the NDIS, remains unclear. The Commonwealth Department of Social Services (DSS) is currently developing a model to deliver integrated support services to carers across the nation which will, in theory, cater for the needs of carers not met through the NDIS. Whilst MHCTas supports this initiative to improve access to carer services, there remain significant concerns including:

- Proposed regional service areas may potentially disadvantage rural and remote areas where public transport can be poor.
- DSS indicates that it will “link to but not fund” many elements of the local service delivery system. Who then, will be responsible for funding?

4. Likely effectiveness of alternative programs and supports for Mental Health Carers

The Inquiry’s Issue Paper asks, “To what extent has the workforce participation of carers increased due to the Australian Government’s Carers and Work Program?” This is something MHCTas cannot make any meaningful response to because it is not being provided in Tasmania. Certainly, something of that nature would be a useful step forward in this state where helping Mental Health Carers into employment is a patchwork affair at best.

In 2017, MHCTas submitted a grant request to the *Try, Test and Learn Fund* which was announced in the 2016-17 Federal Budget to finance small-scale trials of new or innovative approaches to support people at risk of long-term welfare dependence. Tranche 2 had four priority groups one of which was carers aged 16-64 and receiving Carer Payment. This grant opportunity invited applications for small-scale trials to

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[7] Mental Health Carers Australia (2017), *Submission to the Joint Standing Committee on The National Disability Insurance Scheme The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, http://www.mentalhealthcarersaustralia.org.au/wp-content/uploads/2017/11/Mental-Health-Carers-Australia-NDIS-submission-to-Productivity-Commission.pdf

provide services or supports to improve workforce participation or capacity to work for people at risk of long-term welfare dependency. Our application highlighted the need to engage mental health carers in their return to employment by providing realistic information and practical skills which can be utilised to secure and maintain employment. This submission also prioritised the need for support to develop an improved sense of self-worth and self-confidence, the opportunity to interact with others in a group setting and the re-establishment of a routine similar to that of the work force. A significant proportion of primary mental health carers both here and across the country are mature aged women who already have issues returning to work, exacerbated by caregiving responsibilities.[8] This kind of program would be a great starting point for people re-entering the workforce after many years of caring.

MHCTas recognises that NDIS potentially offers eligible people with psychosocial disability and their carers/family great benefits. There are indications that many carers of people who will be ineligible for NDIS packages will continue to provide the caring needs that the people they care for will still require. In a survey conducted by Carers NSW in 2012 it was found that 60 per cent of mental health carers reported needing support in comparison with about 30 per cent of other carers who responded. Mental health carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant state government funding into the NDIS will leave many families caring for someone with a severe mental illness without access to any supports. Given the NDIS will be the primary avenue for people with severe mental illness and psychosocial disability it must have the flexibility to cater for the unique needs and circumstances of consumers and their families/carers.

Catherine's story

I am a carer of a son diagnosed with schizophrenia 14 years ago. He is an adult now, living with me and his father. Our son is not eligible for an NDIS package because he is able to take public transport and can make appointments on his own. However, he needs a great deal of emotional support, does not like to be on his own and finds it difficult to navigate his way around forms and procedures. He needs our support and we are dedicated to giving it to him. But what about our need for some alone time together?

The practical, physical, economic and emotional demands of supporting a loved one with a mental illness is draining. But to date, most of the discussion about mental health carers seems to have been focused on our right to be involved as partners in the care team. Which is a good thing but where are the direct supports to carers? We are developing mental and physical health issues ourselves. We are isolated, neglected and often stigmatised by our own families. We deserve the same opportunities as everybody else. We give so much and are given so little from the system.

Mental Health Carers Tasmania strongly endorses both submissions entered by Caring Fairly and Mental Health Carers Australia. Mental Health Carers Tasmania is an active member of the Caring Fairly Campaign and Mental Health Carers Australia.

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[8] Dina Bowman, Michael McGann &Helen Kimberley (2017), 'Rusty, invisible and threatening': ageing, capital and employability, *Work, Employment and Society*, Vol 31, Issue 3, https://journals.sagepub.com/doi/abs/10.1177/0950017016645732