



## **Submission to the Productivity Commission's Draft Report on Mental Health**

January 2020

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## Introduction

As the peak body for carers in Tasmania, we welcome the opportunity to provide feedback on the Productivity Commission's (the Commission) Draft Report on Mental Health.

Carers Tasmania acknowledges that the Commission's Draft Report centres on the mental health and wellbeing of Australia's population, the prevention and early detection of mental illness, and treatment and support for those who have a diagnosed condition.

Carers Tasmania represents Tasmania's approximate 85,000 people providing unpaid care and support to a family member or friend who are living with a disability, mental illness, chronic condition, life limiting illness, addiction or who are frail and aged. This figure represents 16.6 per cent of Tasmania's population. Of the 85,000, we estimate there are 7,600 carers under 25 in Tasmania.<sup>1</sup>

22.9% of care recipients registered with Carers Tasmania's have listed mental health as their primary diagnosis.<sup>2</sup>

Tasmania was the last state to adopt a Carers policy, and Carers Tasmania's role as a peak body is relatively new. We have however, been supporting carers for 27 years. As such, our carer awareness and considerations of carers from a policy perspective is constantly evolving. We are aligned with Carers Australia and respective State and Territory bodies representing carers.

The Tasmania Carers Action Plan 2017 – 2020 has three objectives:

1. Increase the level of recognition of carers;
2. Improve the level of support and services to carers; and
3. Involve carers in the development and evaluation of policies, programs and services that affect them and their caring role.

## Scope of Submission

Although the scope of the enclosed submission focuses on Part III - Reorienting surrounding services to people: Carers and Families Reform Objective: Increased support for the wellbeing and role of carers and families of people mental illness, Carers Tasmania has drawn on other areas of the Draft Report.

Carers Tasmania has endorsed the Caring Fairly coalition's submission to the Commission, as it also opposes recommendation 23.2 but also addresses the wider context of the report, and therefore minimised duplication of same in the enclosed submission.

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<sup>1</sup> ABS (2015) Disability, Ageing and Carers, Australia: Summary of Findings Data Cube 44300do30

<sup>2</sup> Carers Tasmania – 2019 – Annual Report

## Response to key aspects of the Commission's Draft Report

### Draft Recommendation 10.1

Assistance phone lines offering support for people with mental ill health and their carers should facilitate better exchanges of information between service providers.

There is no question of the importance for people be able to reach their targeted support or entry point without the substantial challenges currently presented when navigating multiple options prior to accessing the 'right door'.

It is noted that the Commission has acknowledged the National Mental Health Commission's findings (NMHC 2014e) in the current system of multiple call lines, limited availability of warm transfers, and that users can be caught in a loop of being transferred back and forth between services.<sup>3</sup>

It is unclear from the Commission's report on what this would look like and how it would operate. Whilst we support improved support for care pathways for consumers and their carers, there is some concern regarding accuracy of information and consistency in the provision of updated available service provisions, and where responsibility and accountability for this would sit.

As previously stated, those with comorbidity need to be considered in this space and we question how the system would operate and be integrated for those with multiple conditions and needs.

In seeking feedback from our carers on this proposal, there were mixed responses which included:

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*"I do not support this. Help is needed in the now at crisis point, not hours or days hence. Anger, frustration, stress levels will increase due to length of time waiting to get through. Left on hold, hanging up in despair, increasing anxiety levels making it worse"*

*"It is a ridiculous, unrealistic expectation of a single phone contact addressing needs in times of support/intervention. Not a recorded message, not manned 9-5pm, a redirected message will not do. Mental Health crises occur anytime and are not restricted to 9-5. Must be manned over a 24-hour period to be beneficial"*

*"Ease of access in all areas and make sure the system will allow human contact. Most systems are already robotic and that means I will not use them but go it alone"*

*"A single phone number would make it easier and you should not have to press numbers to get to the person you want to talk to like other places as we are under enough stress"*

*"Are they suggesting a one number for the whole of Australia- if so it would be a frustrating experience like MyAge CARE, and don't we have enough frustration?"*

*"We are stressed enough trying to be a good carer and to have the added stress of trying to negotiate these multiple-choice options"*

*Family carers 2019*

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<sup>3</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 340

### Draft Recommendation 13.1

Carers Tasmania agrees with the recommendation. As stated, there is clear disparity in the assessment and eligibility criteria for mental health carers, which requires amendment in the immediate future and we would welcome the expansion of the list of persons who can complete the health professional questionnaire to include psychologists and social workers.

We strongly advocate for the replacement of the '25-hour rule'. It is immaterial whether a carer in this respect is a mental health carer or otherwise. As such, while we support Draft Recommendation 13.1 – *Reduce Barriers to Accessing income support for Mental Health Carers*, it is reasonable to expect a complete review for all carers.

We note that Commission concedes that while changes to Carer Payment, Carer Allowance and Carer Supplement may be warranted, such reforms would affect all carers and as such, are considered “*beyond the scope of this inquiry.*”<sup>4</sup>

Legislation and associated policies pursuant to carers create clear objectives and outcomes. Government and non-government agencies strive to implement change, continuous improvement, and recognition of carers, however, there currently remains inequality. Regardless of the supports in place encouraging active participation of carers in economic, social and community life, carers will continue to struggle, given the restrictions placed upon them in regard to equitable income support.

It is recognised that primary carers are more likely to live in low-income households and have lower rates of full-time employment. This is particularly true in Tasmania, given that we have small and dispersed population centres; lower socio-economic levels; reduced access to health care; lack of social services infrastructure in rural/regional areas and an aging population (Tasmania has the oldest median age of all the jurisdictions (41.9 in 2015)).<sup>5</sup>

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*“The costs to my brother who voluntarily took on the full-time carer’s role for our mother, were immense.*

*He eventually gave up his employment position as his employer would not accommodate the restriction of hours and income support barriers placed upon him. He became more and more isolated, his living standards were below the poverty line, he became depressed, withdrawn, and became alcohol dependant.*

*All the while, he didn’t want to accept that it was all too much for him, and resisted family attempts to step in and provide respite and make alternative arrangements, as he did not want to be seen as a failure, or see our mother go into formalised care. This situation lasted five years until he attempted suicide.*

*As a carer, he became part of the mental health system”*

*Family member of a Carer- 2019*

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<sup>4</sup> Productivity Commission – Volume 1 – Mental Health Draft -Page 477

<sup>5</sup> ABS (2015) Population by Age, Sex, Regions of Australia 3235.0

## Draft Recommendation 13.2

Carers Tasmania acknowledges that the Federal Government is keen to improve the employment prospects of carers, and in doing so would potentially create benefits to both the economy and carers. Supporting carers to continue to engage or re-engage with the paid workforce, or to study and undertake voluntary work, has the potential to enhance carers' quality of life.

Many carers want to work but at the same time it must be recognised that no single caring situation is the same, and flexibility for 'return to work' initiatives will be required. In order to be active members of the paid workforce, carers need support to re-engage and remain engaged with the workforce, as well as support for the person they care for. If unemployed carers are to return to work, they will need access to quality services to 'take on' the caring roles that they currently play.

Carers Tasmania agrees with the above recommendation but asks that the below information be considered.

As the Commission's report states: "The value to the community of the informal care provided by mental health carers is immense. They provided over 200 million hours of care in 2015, which would have cost taxpayers \$13.2 billion to replace with formal support services that were fully funded by government (Diminic et al. 2017)."<sup>6</sup>

It must be recognised that although many carers either stop work or reduce employment hours due to their caring role, the savings overall to government are clear regardless of the interpretation of '*reduced tax revenue*.'<sup>7</sup>

Nationally, family carers provide 1.9 billion hours of unpaid care each year and each day, family carers contribute \$165 million equivalent value to the economy.<sup>8</sup>

Carer's access to work and study is important enough that it is the seventh principle of the *Tasmanian Carer Policy 2016: Carers are to be supported to enjoy optimum health, social and economic wellbeing, and access to educational and employment opportunities*.<sup>9</sup>

We acknowledge the Commission's reference to the Diminic, Hielscher and Harris (2018) posit, that over half of all working aged primary mental health carers have a possible need for more employment-related support to maintain, improve or enter employment.<sup>10</sup>

It is our contention that given comorbidity issues, recommendations in this area need to be broadened to be inclusive of all carers. The Commission notes that people with mental illness have a relatively high rate of physical illnesses (SCRGSP 2019i), and for people with mental illness, 59% report having a co-existing physical illness.<sup>11</sup>

Whilst we acknowledge particular differences in mental health carers' needs (stigma, discrimination, isolation, unpredictable episodic nature of those they care for), we argue that separating mental health employment needs from other carer's needs could instigate silos and further duplicate what is currently being undertaken in this area to support carers in the area of education and employment.

It is generally recognised that the longer a person is out of the workforce, the more difficult it is to re-enter. Regardless of the caring role undertaken, the difficulties in re-entering

<sup>6</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 464

<sup>7</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 466

<sup>8</sup> Carers Tasmania – Key Facts about unpaid family carers – National Carers Week 2019

<sup>9</sup> Department of Premier and Cabinet Communities Sport and Recreation, 2016: *Tasmanian Carer Policy 2016*

<sup>10</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 489

<sup>11</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 151

employment are significant. Carers Tasmania is working with other national networks to assist all carers in access to education, retraining and re-entry into the paid workforce. Two of these initiatives are:

- [Work and Care Initiative \(Carers Australia\)](#)
- [Carers + Employers program](#)

The Work and Care Initiative spearheaded by Carer Australia aims to improve the capacity of carers to combine employment with their caring responsibilities and assist long-term carers on income support to transition into employment when their caring role is reduced or ceases.

The [NSW Carer Survey 2018](#) includes information on mental health carers' and other carers' employment experiences. Highlights in the findings included:

- The most common career impacts of caring on respondents' paid work were reduced working hours and exiting employment;
- The majority of carers (72%) indicated they were not interested in being a paid care worker;
- Working carers were most likely to report that their caring often interfered with their jobs; and
- Almost half of all working carers had used carer's leave and flexible start/finish times in their current jobs.

The Carers NSW 2020 Carer Survey is currently under development and will have a national scope for the first time, with the support of all state and territory Carers Associations and will include a substantial employment section. The Commission should consider utilising the results of subsequent findings following full evaluation.



### Draft Recommendation 13.3

We strongly advocate for family-focused and carer-inclusive practice. Too often we hear from carers that the service system is a constant maze and that service providers often work against them. It is not uncommon for carers themselves to become consumers of mental health services, given that the inclusion of carers in a person's journey to recovery is sporadic and inconsistent. Carers often find themselves trying to fit in to the service provider's needs and requirements. Carers need to be recognised as being integral to a consumer's care plan and recovery. Their voices deserve inclusion and recognition.

It is vital that professional mental health services become aligned to a framework of standard procedures in this area, and the short- and medium-term recommendations, should they be accepted, will assist in determining a positive shift in future policy and service reforms.

Mental Health Families and Friends Tasmania, in their submission at the Commission's public hearing (Launceston, 9 December 2019), advocated for the development of a national consumer and mental health family and carer framework to be applied across the service industry. This would include mandating a practical guide for working with carers of people with a mental illness. Carers Tasmania supports this.<sup>12</sup>

The Commission's overview states that one of the key factors driving poor outcomes in Australia's mental health system includes a focus on clinical services which often overlooks other determinants of, and contributors to, mental health, including the important role played by carers, family and kinship groups, and providers of social support services.<sup>13</sup>

Dr Aaron Groves, Chief Civil Psychiatrist, Chief Forensic Psychiatrist and Taskforce Chair in the 2019 *Better Integration of Mental Health Services in Southern Tasmania Report*, stated the following "...reforms will require re-consideration of every aspect of service delivery, and will require all staff and every component of the system to be involved and an acknowledgement that the system will be focussed on needs of consumers, their families and carers rather than on the needs of the service provider."<sup>14</sup>

Change to the system need to commence at the 'coal face' - for the consumer, carers and first responders in the mental health system. It is hoped that the Commission, in its final report, may adopt a similar stance.

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*"I need to be recognised as my son's mother, not just his carer or his primary carer. I need to be listened to and respected about how he is to be cared for when he is ill requiring hospitalisation. Most of the time, the carer is ignored even though the provider of 24-hour care. I know he is an adult, but he is one requiring special needs. He is compliant and will not speak up for himself therefore, very vulnerable."*

*Mental Health Carer 2019*

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*"My role, the carer. Constant would be the right word to use. Set routine, daily grind, except for the sleep overs and the 6 hours per week of supported care my son receives. Constant worry of what will happen to him when I fall off the perch, and who will care as I do? Housing for him, I hope he will not be homeless."*

*Mental Health Carer 2019*

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<sup>12</sup> Productivity Commission – Public hearing into Mental Health – Transcript – Page 78

<sup>13</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 6

<sup>14</sup> Mental Health Integration Taskforce Report and Recommendations – Mental Health, Alcohol and Drug Directorate Department of Health (2019);;



## Reform Area 5

As mentioned at 13.1 in the Commission's Draft – Volume 1 report, the Integrated Carer Support Service (ICSS) will provide carer support services across the country.<sup>15</sup>

The Commission reports:

*“One benefit of the ICSS being a comprehensive program for all carers, rather than many targeted programs, is that service providers will be able to be more responsive to carers’ individual needs and prioritise carers most in need”.*<sup>16</sup>

The Australian Government has committed to the provision of continuity of support to clients of the Mental Health Respite: Carer Support (MHR:CS).

Whilst the Commission's report outlines the benefit of the ICSS' comprehensive program for all carers, the report also includes concerns raised by various mental health participants, including:

- the belief that less funding will be quarantined for mental health carers;
- identified barriers in access to carer support services that include:
  - poorly coordinated services and fragmented funding;
  - difficulties navigating service access; and
  - insufficient funding and services available to meet community need.

Prior to the National Disability Insurance Scheme (NDIS), respite for carers of people with mental illness was available through the MHR:CS. This program has now been transitioned into the NDIS, significantly reducing access to respite care for carers of people with mental illness who are not engaged with or supported through the NDIS.

Timely access to appropriate respite for carers outside of the NDIS is essential in times of emergency (medical, family, other) or to provide the carer with the necessary time to maintain social connections, friendship and a sense of engagement with the community (mental health protective factors). Carer respite needs to be at a point of time that is appropriate for the carer and not solely based on the needs of the person who is being cared for.

With the advent of the NDIS and the ending of programs like MHR:CS, Carers Tasmania is concerned that access to carer respite will be significantly reduced and, when available, will be at the behest of the consumer and not the carer. It is yet to be seen if this will have a detrimental impact on the willingness of individuals to volunteer/nominate for carer roles.

The above concerns are valid and we remain cautious about the potential loss of vital funding specifically available to carers, particularly as governments by and large rely to some extent on family members and friends being the first port of call, and a continued source of support (free of charge), through a consumer's journey to recovery. The need to provide the required services and supports to consumers is obvious but supporting and maintaining the carer in their role is less visible, and yet imperative to the consumer's quality of life.

Of interest, is the investigation in 2016 into total expenditure on mental health carer support services and the difficulty isolating funding specifically for mental health carers (Schess et al.

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<sup>15</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 484

<sup>16</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 484

2018). Further, the study could not identify services funded by the Tasmanian Government.<sup>17</sup>

Notwithstanding the above, as the Commission noted “it is too early to know how well the ICSS and NDIS will meet the needs of mental health carers”.<sup>18</sup>

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<sup>17</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 485

<sup>18</sup> Productivity Commission – Volume 1 – Mental Health Draft – Page 484

### Recommendation 23.2

We strongly oppose the removal of mental health carers from the Integrated Carer Support Service and assert that this would be counter-productive, creating duplication of effort and erode a major reform that has bi-partisan support.

The Department of Social Services has undertaken one of the most extensive consultation processes in its history to co-design the Integrated Carer Support Service (ICSS), which will trade as the Carer Gateway.

The drivers for this change were:

- increasing demand from families for family members to care
- services tended to be reactive and not preventative
- low ease of service access
- carers providing information to multiple organisations
- inconsistent service across the nation

In co-designing and establishing the ICSS, the Department established clear principles for design:

- services most focus on improving the quality of life of carers
- creating efficient and effective preventative services
- identify and support carers early in their caring journey
- support carers most in need
- provide an easy-to-navigate system
- provide consistent experience across the country

Co-design was extensive and included carer associations and mental health organisations, including Carers Tasmania and mental health family and friends TASMANIA.

As a result, for the first time, unpaid, informal carers will access supports through a single front door, namely a single 1800 number and website. Reform of service providers also means that instead of over 140 providers nationally, from April 2020 there will be ten across the country, thus simplifying the provision of services for informal carers.

Providers within the ICSS – there is a single provider for Tasmania – have flexibility in allocating funding and providing support, whilst ensuring that supports are delivered at a local level.

We are concerned and question whether devolving funding to newly formed Regional Commissioning Authorities, who will have responsibility for the allocation of all mental healthcare, psychological and carer supports (with the exception of those people receiving NDIS funding) will result in better services for carers and address current service gaps. We would argue that it could, unintentionally, produce wider gaps in terms of support services to carers.

We also question whether State and Territory Governments should assume responsibility for mental health carer support services following their removal from the ICSS.

Isolating mental health carer support funding from the ICSS would create additional confusion, create further (duplicated) infrastructure (and thus wastage), and interrupt current efforts being made to streamline and integrate carer services into an effective service system in its own right.

Although the Commission recommends funding levels be based on an evidenced-based, transparent planning framework with monitoring and evaluation, there would need to be

strong accountability and adherence, which does not appear to have been considered. Embedding accountability would limit Ministerial discretion and ensure carers are not at risk of losing vital services should State and/or Territory Governments seek to shift carer support funding into the consumer focussed system.

## Conclusion

Although our submission is relatively narrow in its focus due to our role specialising in the carer and family support area, we do support reforms leading to better mental health care outcomes in Australia and recognise the need to reprioritise many areas of mental health, as the Commission's report quite clearly demonstrates. The current and ongoing reforms in place have not as yet been fully implemented and they need to be bedded down, monitored, and comprehensively evaluated to allow for gaps and shortfalls to be identified and improvements made as required.

## Additional comments from Tasmanian family carers

"Training and good pay packages is what the government needs to provide carers and training bodies"

"A lot of funding and care is needed"

"The government needs to put in vast funds, infrastructure and good levels of training for staff in the areas of mental health and wellbeing."

"A single phone number would make it easier and you should not have to press numbers to get to the person you want to talk to like other places as we are under enough stress".

“No single number for all Carer supports please. Link to individual needs please, we don’t have that much time at our disposal.”

“If there are multiple systems to get through, then I probably won’t use the system”

“We are stressed enough trying to be a good carer and to have the added stress of trying to negotiate these multiple-choice options. I am unsure of what the category of mental health covers, because when you are a carer the constant worry about being a carer brings on a mental health state. Having a counsellor in Carers Tas office is of great assistance to me”

“Ease of access in all areas and make sure the system will allow human contact”

“Most systems are already robotic and that means I will not use them but go it alone”.

“I would like to see a more tiered system for carers. There is a huge difference from someone caring for someone who doesn’t live with them and someone who does. Living with someone with severe and multiple mental health problems is a lot different than a carer who ‘visits. As a recipient of Carers allowance respite of 62 days a year sounds like a lot but, but believe me, when you live with someone with multiple mental health issues, it’s not enough. This is a 24 hr a day, 365 days a year responsibility”.

“I think that for me the most challenging thing in the care for my parents who both have dementia – was the extraordinary delay between the ACAT assessment and any actual help in the form of a care package. In the case of my father it was too late after 2 years of waiting he ended up in care after too many falls, and then passed away. The same for my mother 6 years later. We got no help at all even though she qualified for a care package – all the care was done by me”

“The system is quite confusing as it is without any more change”.

“Working Multiple systems to get what you need as a carer of someone with mental illness will not only take precious time, we could also be called from the telephone while we are waiting by our clients (patient)”

“I have no idea who to call. I am also absolutely lost and feel that I am on a boat without a rudder”.

“First of all, I am in full support of a single contact number, where Carers can call the agency on one contact number, thus saving being put from one office to another to sort an enquiry out.”

“I was put through to four different phone numbers when I tried to get some respite for my mother earlier this year and ended up back at the first number I called. This was very frustrating at the time. I eventually received the respite for my mother.”

“The more available contact number, the more confusing it will be for Carers”

“With the one number in place all enquiries made by Carers can be directed via the initial contact number they have rung to the appropriate office if the request is of a specialist nature, that way, the carer is not left to phone up themselves in the hop of finding someone to solve their enquiry”

“In dealing with any improvement to the system, may I suggest a form of a “Flyer” sent via email to Carers with an email address or hard copy for those who do not have email, outlining the initial contact number together with any other relevant contact numbers which may deal with situations of a specialist nature where Carers can actually talk to someone who deals in that field, for example, the process of placing a loved one into a home on a permanent basis.”

“No doubt there is a huge amount of work needed to overhaul the present system, which in my view has a number of loose ends to tie up.”

“I am very pleased that changes are being made and hopefully will streamline the present situation and all the excellent work that staff are doing at present will in time be beneficial to all concerned.”

“Thank you for the invitation to make comment. I hope it's a useful contribution.

“I am not a carer for a person whose primary disability is a mental illness. However, anxiety and depression abound in our lives :) I approach this with many years' experience as a social worker paid to be a systemic advocate for people with disabilities and later working in a large Commonwealth department.

*“While on balance I think it's a good idea, I do have a caution. If a government cannot spend less by shifting costs, it may seek to spend less by improving efficiency narrowly conceived of as cost per unit of service. This might mean spending more on consumers to avoid greater expenses on carers whose health has been damaged. However, it might also mean spending less on consumers, relying on unpaid carers to replace expensive health services and not trying too hard to pick up the pieces for carers whose health suffers.”*