



## Response to the Select Committee on Mental Health and Suicide Prevention

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## About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies and abilities.

## Introduction

Broadly, Carers Australia support any efforts to improve access to appropriate mental health services to people when they need them, where they need them and in a culturally safe and stigma-free environment.

Rather than duplicate what the Carers Network have provided to various submission processes throughout 2019 - 2021 to-date, this submission aims to briefly outline specific issues related to carers we want the Committee to be cognisant of, as it examines the findings of the Productivity Commission Inquiry Report into Mental Health, the Report of the National Suicide Prevention Officer, the Victorian Royal Commission, the National Mental Health Workforce Strategy and other recent strategic reviews of the current mental health system, taking into account the 2019 bushfires and COVID-19 pandemic.

The issues that are highlighted come from the wealth of experience that Carers Australia and the Carer Network have gained as the peak for carers across Australia for over 30 years and recognise the carers role in contributing to the recovery of individuals with mental illness. A significant proportion of the Carer Network's members are mental health carers, and Carers ACT is in fact the recognized territory peak for mental health.

We have strong established relationships with many mental health organisations, services and support organisations, where for many years we have been in partnership with SANE Australia to maintain a free and anonymous 'SANE Forum' specifically for carers of people living with complex mental health issues, and are currently funded to deliver a project focusing on mental health carers to support their self-care during COVID-19, which we are delivering in collaboration with Mental Health Australia.

Further, until introduction of the Carer Gateway, Carers Australia and the Carer Network provided mental health services nationally, including the National Carer Counselling Program (NCCP), Carer Information and Support Service (CISS), and Mental Health Respite – Carers Support Service funded by the Department of Social Service until May 2020. All Carer Network members continue to deliver mental health support for carers broadly, whether through the Australian Government Carer Gateway or funded via another means such as state/territory government.

Carers Australia takes this opportunity to draw to the Committee's attention our support for the Productivity Commission's recommendation specific to the needs of families and carers within the Mental Health Inquiry Final Report (Recommendation 18), noting the Commission stated:

*“Carers are an important, but too often forgotten, part of the mental health system. They play a vital role in the recovery of people with mental illness, but their own needs are not always considered by the mental health system. They are often excluded from discussions on their care recipient's needs — regardless of the consumer's preferences — and not made aware of services that can assist them. Embedding family- and carer- inclusive practices across the mental health system would enable more effective support to people accessing services and their carers.”*

We agree with the Productivity Commission's emphasis on family- and carer-inclusive practices, and that the delivery of psychosocial supports have been hampered by inefficient funding arrangements and service gaps. Further, Carers Australia:

- Support that any pathways to mental healthcare should be accessible, affordable, and empower people to make informed choices between a range of options tailored for the individual, given their condition and circumstances.
- Affirm the need to ensure access to preventative and ongoing mental health support and services must be extended to all carers, not just carers of people with a mental illness, and be accessible through the Carer Gateway.
- Applaud the call to amend the eligibility criteria for the Carer Payment and Carer Allowance to reduce barriers to access for mental health carers, and the need to review the Adult Medical Report Form and Adult Disability Assessment Tool to ensure they accommodate for the care needs of people with mental illness, and
- Highlight that removing barriers and supporting carers to participate in flexible and appropriate paid work is pivotal to enabling their social, community and economic participation, and greater outcomes for community and government as they maintain and thrive in their caring role to a person with a mental illness.

## Issues to highlight in response to the Terms of Reference

Carers Australia welcomes the opportunity to provide a response to the Select Committee on Mental Health and Suicide Prevention (the Committee). We are strong advocates for carer inclusion in services delivered to those they care for – whether these be clinical services or other types of support services, which is at the heart of the concept of “partners in care” as a central principle of the *Carer Recognition Act* (Cwth).

### 1. Carers need support for their own mental health

**Mental health services often focus on the needs of the person living with a mental illness without considering that the person providing care may also require mental health support, and in fact may also be a consumer of mental health services themselves.**

As is the case for all carers, caring can at the best of times be a rewarding yet demanding and socially isolating experience, where carers have among the lowest levels of wellbeing of any group of Australians<sup>ii</sup>, even before the impact of COVID-19. The pandemic added another level of complexity for carers, where they have had, and in some cases continue to have, periods of reduced social support and formal and informal respite options. Add to this reduced employment and income, especially young carers and women in lower paid, casualised sectors, increased risk of violence and abuse within the home due to associated household changes and financial impacts and/or the challenging behaviours among the people they care for, increased basic living expenses, and difficulty accessing essential items through isolation processes. Carers are at breaking point.

Carers of people with a mental illness often do not have the same visibility as carers of people in other circumstances, and this can be an additional obstacle to accessing recognition and support. Carers of people with mental illness spend extensive time with the person they care for, providing practical support such as assistance with finances and transport, assistance with daily living such as personal hygiene and meal preparation, emotional support and behaviour management. Of the 994,600 people with psychosocial disability (living in households) in 2018, 94.9% need assistance or experienced difficulty with at least one activity of daily life, most commonly cognitive and emotional tasks (85.5% of all those with psychosocial disability)<sup>iii</sup>.

Processes that identify the mental health, self-care and broader health care needs of all carers are needed to maintain the caring role. All services should consider carer needs and their role in contributing to the recovery of individuals with mental illness, where the wellbeing of people with mental illness and their families and carers are interdependent.

## 2. Fragmentation of support to carers

**Reform across settings and sectors, including mental health, aged care, disability care and social services, while well intentioned has potential to further fragment the provision of psychological supports available to carers in all care relationships.**

We draw attention to Carer Gateway services which have been available online from April 2020, were *“Carer Gateway is for anyone who is a carer. You may be a carer if you are looking after someone with disability, mental illness, dementia, a long-term health condition, an illness that will cause their death, or an alcohol or drug problem, or someone who is frail because they are old”*<sup>iv</sup>. There would be significant duplication in policy development, infrastructure and administration if carer specific supports, related to mental health carers or the broader mental health of all carers, were separated from the Carer Gateway without investigation of the unintended consequence of further fracturing carer supports.

We urge the government to consider the following issues when examining potential changes in responsibility to funding or provision of services, noting we support actions that aim to facilitate a clearer division of roles for each level of government and across settings and sectors:

- Stigma with separating the needs of mental health carers from that of other carers
- Exacerbating the gap in identifying the mental health needs of all carers
- Further siloing support options for carers, noting interface issues already occurring and being scrutinised within reform processes related to My Aged Care and the NDIS, as well as introduction of the Disability Gateway in January 2021
- Possible deskilling of Carer Gateway Providers in supporting mental health carers, as they will be isolated from the detailed knowledge around mental health supports, eligibility criteria, policy and relevant regulations that mental health carers specifically need to navigate their caring role
- How non-Carer Gateway Providers will be made aware of mental health services, including those funded by Commonwealth, state or territory governments or Primary Health Networks (PHNs) commissioned carer services, and
- Logistics related to information provision between service providers and the Carer Gateway in order to adequately assess and monitor the ongoing needs of carers across settings and services.

Carers Australia also believe that actions to explore interface issues and gaps in services outside the NDIS, as well as actions to streamline access to psychosocial supports both within and external to the NDIS, should have more emphasis. The majority of carers affirm that the supports received have made a positive contribution to the wellbeing and prospects of participants and, by extension, this may have a flow on effect to those who care for them. However, many carers have found access to the NDIS difficult to navigate, slow and exhausting. Carers are also not able to access NDIS supports, and there is currently no requirement for carer needs assessment during application, planning or review. The result is that carer support in participant’s plans are often poorly matched to the needs of carers.

We note the notion assess carers needs if developing a new assessment tool for implementation across the mental health system, where it is essential to ensure a robust and person-centered approach to assessment and referrals, and how this will interface with the Carer Gateway and other 'navigation portals'. This also accounts for issues with carer needs assessment within My Aged Care and the NDIS currently being explored within other reform process, and how these will intersect with the needs assessment process and Carer Action Plan development and review within the Carer Gateway.

## 2. Carer recognition and national leadership

**While the *Carer Recognition Act 2010* (Cwth) formally acknowledges the valuable social and economic contribution of carers in Australia, the last National Carers Strategy lapsed in 2014. The Commonwealth government must show national leadership on carer issues and ensure that carers are considered, which should outline how to address carers' rights and needs, together with and separately from the people they care for.**

Carers Australia support the development of a new National Mental Health Strategy that integrates services and supports delivered in health and non-health sectors, and actions that strengthen the establishment of a clear and ongoing role for consumers and carers in all aspects of mental health system planning, design, monitoring and evaluation. However this must not be at the detriment of developing a National Carers Strategy that considers all carers.

A National Carer Strategy encompassing strategic direction and responsibilities across different levels of governments and portfolios should be a priority. Outcome measures are needed to monitor the impact of fragmented jurisdiction-based carer strategies, and would assist in identifying what data is needed to monitor the social and economic impact of national carer policies and programs. We also support the call for a National Stigma Reduction Strategy, noting that activities to increase social inclusion and reduce stigma must consider the carers needs as an individual separate from the person with a mental illness they care for.

Further, we highlight the need for improved responsibility and accountability for mental health related carer support within the Department of Health and relevant authorities, to address a diffusion of responsibility and perception that carer supports are a Department of Social Services only-role, or primarily focused on carers of people with a disability.

We request the Committee's response includes the requirement for clear mapping of all mental health and other relevant reform process recommendations/actions and how they interrelate, along with what the intended outcomes will be for consumers, carers, service providers and governments. This includes the National Mental Health and Suicide Prevention Agreement being developed by the Health National Cabinet Reform Committee (HNCRC), and the work of the National Federation Reform Council to collaborate a set of principles that will underpin whole-of-government efforts to transform and improve Australia's mental health system.

## 3. Respite services are a critical gap

**Investment in and increasing access to appropriate community-based respite care for mental health carers is a critical gap within mental health service in Australia, and until properly addressed, mental health carers entitlements and services will continue to be treated as a sub-component of the support to those they care for.**

Respite services are critical to many carers' own health and wellbeing and can, in many cases, mean the difference between a carer being able to provide care and support or having no alternative but to seek other accommodation options, ceasing employment or risk further strain on the carer and wider family, noting:

- Recent cessation of funding for programs including the Mental Health Respite – Carers Support Service
- Difficulty accessing respite, particularly community-based cottage respite through the Carer Gateway, and
- Very limited access to carer respite via the NDIS for people with a mental illness, as currently supports are not funded based solely on carer need.

Due to the fluctuating nature of mental illness, mental health carers manage a high level of unpredictability in their caring role in addition to a high level of emotional support, planning and behaviour management. Additional respite support for carers who play a vital role in the continuum of care for people with severe and persistent mental illness is critical.

This must also address clear pathways for accessing alternative services for themselves and the person they care for with a mental illness, including after-hours services, mobile crisis services, and post-crisis counselling/debriefing for the carer.

#### 4. Young carers are a highly vulnerable population

**All young carers are at increased risk of mental health issues, regardless of if the person they are caring for has a mental illness or another care requirement such as a physical disability or life-limiting illness.**

There are approximately 235,000 ‘young carers’ aged 11-25 years in Australia<sup>v</sup> noting that about 12% of mental health carers are aged between 15 and 25 years.<sup>vi</sup> Many young carers report<sup>vii</sup> a lack of sleep, ongoing stress and mental health issues which affects their motivation or ability to get up in the morning or go to school, and that their care responsibilities restrict their ability to achieve their potential, socialise with friends, participate in extra-curricular activities, and to build a sense of belonging.

Carers Australia believe schools are a key area where caring is often not recognised and/or not responded to appropriately. All actions to assess and support children and young people in education across systems must consider the specific requirements to enable social and emotional wellbeing in the context of the young carer as an individual, and within their caring role.

#### 5. Carer-inclusive workplaces

**Explicit carer-inclusive workplace practices must be a component of mentally healthy workplaces - the reality is that if a significant number of carers are not able to combine work and care, they will have to abandon one of these roles. If it is employment there will be a very substantial rise in the cost of social welfare. If it is care, there will be a decrease in the propensity to care and a significant rise in the cost of paid supports.**

Carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities<sup>viii</sup>. While the hours spent caring can affect carers’ ability to participate in the labour force, a lack of employer flexibility and little understanding of the caring role are also barriers to employment. This is particularly the case for mental health carers who regularly encounter stigma or lack of awareness regarding mental illness. Many carers give up their employment, especially when they are first confronted with a caring role or if it intensifies. What carers and their employers need to consider are adjustments to their working conditions which may include working from home, job sharing, requesting lower-level work to accommodate caring, flexible working hours and /or days. While in some cases the nature of employment is such that it cannot accommodate flexibility, if

COVID-19 has demonstrated anything it is that there are many more options open to employers and employees than observing traditional working hours in the workplace, and it is clear that more flexible working arrangements are likely to be the wave of the future.

In addition to being receptive to flexible arrangements to accommodate carers, it is also important that employers make it known to all their staff, including managers and co-workers, that they are a 'carer friendly' workplace which has advantages to everyone:

- Work can constitute respite from caring, less social isolation and the maintenance of a more robust sense of self
- Retaining connection to the workforce is particularly important as after years of dedicated caring, many carers find it very difficult to find employment with 'gaps' in their resume and a lack of current referees
- For employers the retention of experienced staff and the value of a loyal workers who appreciate the support they receive is beneficial, as are the recruitment and retraining cost savings, and
- The benefits of workforce diversity has become a prominent theme in management and business literature.

## 6. Digital literacy and infrastructure needs

**Solutions to improve access to mental health supports must also improve digital inclusion or risk increasing the 'digital divide' which will impact on carers ability to not only undertake their caring responsibilities, but also manage their own health and wellbeing.**

With an increased reliance on technology it is important to note that while many carers do use digital technology a significant number are digitally disadvantaged<sup>x</sup>, where an Australia-wide survey found that only about 70% of carers were confident about accessing information on-line.<sup>x</sup> Expenditure on internet usage has increased faster than increases in household income, and for those with low household incomes affordability not only remains a critical issue, but the gap has widened over the period 2014-2019<sup>xi</sup>. Consideration must include the costs associated with acquiring and setting up various IT equipment, maintaining an adequate internet connection and a private space within a home.

Carers Australia highlight that it is also critical to continue offline service delivery options for those who cannot, or do not want to for various reasons, engage in an online environment. There are variety of reasons non-face to face standards are not suitable for many people, for example, cultural norms, level of comfort, disabilities that may affect communication and accessibility needs, for example, availability of translators, and hearing or vision impairment.

<sup>i</sup> Productivity Commission – Mental Health Inquiry Final Report - p.148 Vol 2

<sup>ii</sup> Deloitte Access Economics (2020). 'The value of informal care in 2020' Commissioned by Carers Australia [accessed online]

<sup>iii</sup> ABS, 2018 Survey of Disability, Ageing and Carers (SDAC). 'Psychosocial disability' released 25/09/20 [accessed online].

<sup>iv</sup> Australian Government, Carer Gateway 'About us' webpage [accessed 16/02/2021]

<sup>v</sup> ABS, 2018 Survey of Disability, Ageing and Carers (SDAC).

<sup>vi</sup> Productivity Commission – Mental Health Final Report (p.257, Volume 2)

<sup>vii</sup> Moore T et al (2019). 'No space in my brain to learn - Young carers and their engagement with education: an analysis of applications to the Carers Australia bursary program 2017-2018'. University of South Australia for Carers Australia [online]

<sup>viii</sup> Deloitte Access Economics (2020). 'The value of informal care in 2020' Commissioned by Carers Australia [online]

<sup>ix</sup> ABS 'Use of information technology by people with disability, older people and primary carers', 2020 [accessed online]

<sup>x</sup> Carers NSW in association with the Carers Australia network, 2020 National Carers Survey [accessed online]

<sup>xi</sup> Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2019, RMIT University and Swinburne University of Technology, Melbourne, for Telstra [accessed online]