Mental Health Carers Australia is pleased to provide this submission on the impact that combining work and care responsibilities has on the wellbeing of carers of people with mental health needs and psychosocial disability, and those they care for, for consideration by the Senate Select Committee on Work and Care.

Our submission provides our perspective on:

1. **Low level of employment amongst mental health carers**
2. **Structural responses to mental health carers and work and care**
3. **Gender and mental health carers unpaid and informal care and support**
4. **Impact of the NDIS rollout on mental health carers' role**
5. **The carer lived experience workforce impacts on paid work for mental health carers**
6. **Impacts and lessons arising from the COVID-19 crisis.**
7. **Work and Care Policy settings as they relate to mental health carers**

A more thorough consideration of these matters is provided in a background research paper that we share with our Queensland member Arafmi Ltd - *Care and work: considerations for Australian mental health carers* available on arafmi.com.au .

We thank the committee for raising awareness and building collective understanding of the well-being of workers, carers and those they care for.

An introduction to Mental Health Carers Australia

Mental Health Carers Australia is the only national advocacy group solely concerned with the well-being and promotion of the needs of families and carers supporting someone with mental ill health.

We are achieving this by influencing systemic change in government policy and service provider practice, to improve the family and carer experience of the mental health system.

Mental Health Carers Australia grew out of the national movement of ARAFMI organisations across Australia, started in Sydney in 1975 by a concerned group of carers who identified the need for a service to specifically address the concerns of carers, relatives and friends.

Mental Health Carers Australia is now a national peak body focussed solely on the needs of mental health families and carers. The following organisations are current members:

- **HelpingMinds** - WA Member. HelpingMinds is the pre-eminent mental health services and carer support organisation in Western Australia.
- **Mental Health Carers ARAFMI NSW Inc** - NSW Member. ARAFMI NSW provides support, education and advocacy for the carers, family and friends of those experiencing mental illness across NSW.
- **Mental Illness Fellowship of Australia (NT)** - NT Member. Mental Illness Fellowship of Australia (NT) is a non-government organisation providing services for people living with a mental illness and their carer's and families.

- **Arafmi Queensland Inc** - QLD Member. Providing support services for families and friends of people with mental illness and/or psychiatric disability.
- **Mental Health Families and Friends Tasmania** - TAS Member. Mental Health Families and Friends Tasmania is a statewide leader in the provision of mental health carer support.
- **Tandem Inc**. - VIC Member. Tandem is the Victorian peak body representing family and friends supporting people living with mental health issues.
- **Mind Australia** - National Member. Mind Australia is a leading provider of community mental health services. They support people to live connected, productive and satisfying lives.

Our aim is to work constructively with governments and service providers to improve policies, programs and practices that directly and indirectly impact the families and carers of people living with mental health issues.

1. Low levels of paid employment amongst mental health carers

Numerous studies have demonstrated that informal carers experience considerably poorer health and wellbeing than the general population, particularly those who support someone with a mental health condition (Greenwood, Mezey, & Smith, 2018). A recent example is Australia's national Carer Wellbeing Survey 2021, which indicated that mental health carers have poorer outcomes across all measured indicators than carers in general (Centre for Change Governance & NATSEM, 2021). More specifically, 60.2% of mental health carers "felt their caring responsibilities regularly or always negatively impacted their health", 44% often or always experienced loneliness, only 51% agreed with the statement 'Being a carer contributes meaning and purpose in life', and 58.1% "often felt they had lost control of their lives" (Centre for Change Governance & NATSEM, 2021 p. 50-76). The Survey also found that **47%** of mental health carers (aged 15-75) were not employed, and of those who were, **77.5%** were either in insecure or only 'somewhat secure' employment (Centre for Change Governance & NATSEM, 2021 p. 45-47). The Productivity Commission found that 41% of those who were the primary carer for someone with a mental health condition "reported difficulty meeting everyday living costs as a result of caring (compared with 30% for other primary carers)" (2020 p. 883). Without adequate support, children and young people in a mental health carer role can face "lifelong effects on cognitive and social development, learning and education, work opportunities, finances" and overall health (State of Victoria, 2021 p. 85).

Approximately 971,000 Australians provide care to someone with a mental illness, and for 273,000 of them this support constitutes a primary carer role. The latter figure is however an underestimate as it excludes those who are not co-resident (Productivity Commission, 2020 p. 872-873). Research indicates that primary mental health carers spend on average 40 hours per week providing support (however are effectively 'on call' at all times) (Diminic, Hielscher, & Harris, 2019 p. 138), and 41% have provided support for over 10 years (Productivity Commission, 2020 p. 873). Over half of (all types of) carers provide support to two or more people (Diminic et al., 2019 p. 9). The Productivity Commission found that "time spent caring significantly reduces the time available for the carer to

participate and thrive in the community, **through employment**, education and social interactions" (2020 p. 876).

2. Structural responses to mental health carers and work and care

There is a body of evidence that indicates that informal caregiving is associated with lower labour force participation. This is particularly pronounced for carers providing intensive care (more than 20 hours per week) (Colombo et al. 2011). In 2018, only 59 per cent of primary carers aged 15–65 were in the labour force (figure 2, panel a), compared with 82 per cent of non-carers of that age (ABS 2018). Informal carers were also relatively more likely to be in part time employment than non-carers. Primary carers who provided more than 60 hours of care per week were much less likely to be in the labour force than other primary carers (figure 2, panel b). Carers are also more likely to live in lower income households — 50 per cent of primary carers live in the lowest two income quintiles compared 26 per cent of non-carers. That said, it is uncertain if this is because people in low-income households are more likely to take up a caring role (that is, because caring does not change their income as much, or because paying for formal care is not affordable for them) or because carers are more likely to leave their jobs or are more likely to work fewer hours or in lower paid jobs

The scale of need for the support mental health carers provide is in part driven by the sheer prevalence of mental ill health. Currently, almost one fifth of Australians experience a mental illness in any given year, and half will experience a mental illness during their lifetime (Productivity Commission, 2020). This prevalence has been rapidly increasing; an analysis of six consecutive national surveys demonstrated that "Australian rates of K10 very-high distress rose significantly" between 2001 and 2017/18 (Enticott et al., 2022), a trend since intensified by "COVID, extreme weather events and financial stress from increased living costs" (Bower et al., 2022).

The extent of support that informal mental health carers provide is a direct consequence of formal mental health care throughout Australia having long been severely inadequate and inequitable. Opportunities for early intervention are most often missed due to long waitlists, and a large proportion of need remains unmet due to lack of capacity (Bower et al., 2022). Although Medicare spending on mental health has increased, most is directed towards those who can afford to pay the rebate gap generally involved in seeing a private practitioner (Duckett & Meadows, 2022). The public mental health care provision that is available is highly reactive and crisis-driven, and in general only those who are particularly acute will reach a threshold for access. The Royal Commission into Victoria's Mental Health System found that family members are often left to meet this shortfall themselves and attempts to ensure their loved one receives adequate formal provision are often highly stressful. Those who gave evidence to the Commission "often described their own experiences of caring and their interactions with the mental health system in terms of trauma" (State of Victoria, 2021 p. 81).

Australia would benefit from laws, policies, and workplace practices that will keep unpaid carers in the workplace wherever possible. Many Australian workplaces lack formal policies and practices to support carers. Supporting carers to access or retain work could yield significant economic gains for businesses, as well as improving individual economic and social outcomes.23 There is a range of views on the complexity and scale of the workplace changes needed to respond to Australia's changing

demographics. There are assumed costs to businesses and to the wider economy. International studies increasingly demonstrate that employers who have policies in place to support carers see improved service delivery, cost savings and increased productivity. Mental health carers face particularly acute challenges in the workplace. Employed mental health carers often take extended leave (13.8% have taken at least 3 months, and 28.9% have taken some time off). The right to request flexible working arrangements is codified in law but can be refused by employers on the basis of 'reasonable business grounds'. This principle was recently affirmed by the Fair Work Commission. Flexible working arrangements are critical to supporting carers in the workplace, but are not enough on their own. Employers and businesses gain significant quantifiable benefits when they design and implement carer friendly workplaces. These benefits include retaining skills and experience, higher returns on training investment, and improved productivity and performance

3. Gender and mental health carers unpaid care and support

Unpaid care and support are highly gendered, and for mental health carers the bulk of such support occurs in the critical employment years - Onset of first episode mental health 17 – 30, - the majority of mental health carers in the age range 40 – 64.

Many women shift from working in part-time and flexible work arrangements to provide family support are then taking on further care and support roles in relation to their adult children and often their parents also.

Mental health carers struggle to return or remain in the workforce due to the unpredictability of mental health challenges, the lack of consistent carer friendly workplace policies across the public and private workforce. (see Caring Fairly Campaign 2019).

The issues of skill loss and the loss of knowledge capital that is the consequence of women leaving the workforce from the ages of 40 – 65, should not be underestimated. Taking on an intense care and support role sees MH carers leaving the workforce at the point at which they have reached maturity of skills and are often highly trained. This capacity is often not factored into considerations regarding how and by whom the bulk of unpaid carer and support is undertaken.

Where families' carers and supporters choose/or need to take on the caring role in a full-time capacity there are few consistent financial and social supports in place to recognise and to offset the individual economic costs of such choices or responsibilities.

- Including the cost of providing financial support to the person being supported
- The loss of superannuation contributions
- The loss of the capacity to fund their own health and wellbeing needs
- The risk of housing instability

There are also consequences from an employment perspective if they do manage to remain in the paid workforce these include

- Employment in roles beneath their skills and capacity
- Precarious employment in casual roles
- Loss of access to work-based skills and training opportunities

4. The impact and lessons arising from the COVID-19 crisis for Australia's system of work and care

Covid 19 intensified the level of care and support provided by mental health carers due to the loss of both external and outreach supports. Th emotional impacts of the pandemic of people with mental health issues.

Recent research undertaken through the National Mental Health Commission generated a report on ***Australian family experiences supporting people with mental health challenges during COVID-19***

This research found that during COVID-19 services reduced hours, closed or changed modes of practice that only suited some people. The experiences contributed to carers being overwhelmed, feeling distress and fear, and increased burden

Caring increased during the pandemic to an average of 40 hours a week (up from 26 hours) spent providing support amid increased complexity.

The findings of the current report reiterate and extend findings and recommendations in the Productivity Commission report. Given this compatible information, there is a case to be made that the Australian Government immediately deliver on the 5 short-term recommendations and strengthen efforts to deliver on the 5 longer-term recommendations with an expedited timeline.

One of these recommendations speak directly to the work and care challenge:

> The Australian Government to fund available and responsive mental health carer respite to ensure carer workload does not overwhelm family members so they are able to remain in paid work

Mental Health Carers Australia and its member organisations conducted a national survey of carers of NDIS participants with psychosocial disabilities on the impacts of Covid-19 in April 2020.[1]

> … early on in the outbreak we started hearing that as services were reduced, altered or withdrawn that this was having severe and consequential impacts on NDIS participants with psychosocial disability, their families and carers. There were a number of themes emerging from this anecdotal evidence base that we decided to validate further by conducting a survey.[2]

The survey was distributed through our member and stakeholder networks. We received 103 responses from carers of NDIS participants from across Australia.

Key impacts of Covid-19

Our analysis of the responses identified three key impacts.

1. **Provision of NDIS supports dropped significantly** for participants, families and carers. 60% said lockdown impacted the NDIS supports received to a great or a very great extent.

[1] Menta Hea th Carers Austra a 2020, *Survey on the impacts of Covid-19 on families and carers of NDIS participants with psychosocial disability*, Menta Hea th Carers Austra a.
[2] Menta Hea th Carers Austra a 2020, *Survey on the impacts of Covid-19 on families and carers of NDIS participants with psychosocial disability*, Menta Hea th Carers Austra a, p2.

2. **Families and carers stepped into the breach** left by providers - and it was impacting their personal and family's mental health. 75% were concerned about their family's mental health, and 65% about their own mental health. 50% reported their caring role increased significantly or more than they could cope.

3. **Carers were an at-risk cohort** more vulnerable to COVID and more likely to be struggling financially on pension-level incomes. 60% had experienced an increase in day to day expenses.

We have selected one carer's story illustrating the experience of many of the respondents.

> "The COVID-19 lockdown has placed much more stress on my son and myself. My son has been much more anxious and losing hope for his future. He has also felt very lonely.
>
> My caring role has been stretched to its limit on many occasions and I have had very little time to relax and recuperate. I know that this is not sustainable for me but there is no-one else to fill my role.
>
> My son became suicidal and has just returned home from hospital, so now he is readjusting to new medications and feeling exhausted. The hospital stay was difficult for him, as visitors could only meet patients outside for half an hour. We were not allowed inside the hospital at all."[3]

Key lessons from Covid-19 for future times of national crisis

This research identified seven key lessons, with focused on the role of NDIS in Australia's system of work and care.

1. Proactive outreach. NDIS participants and their families and carers (if nominated) should be contacted during periods of crisis to discuss any adjustments to services needed. This would be undertaken by someone who has an existing relationship with the participant and their carer, such as a local area coordinator or support coordinator.

The focus would include: if a review of the NDIS plan is required; identification of at-risk carers requiring additional supports; and alternative ways of receiving services when face to face service delivery is not possible, including access to digital technologies.

2. Additional financial support. Consideration should be given as to how participants, their families and carers can access timely and adequate financial assistance.

3. Additional mental health supports. The Federal Government should fund additional mental health and carer supports in response to the impacts of the crisis, including specific supports designed to meet the needs of carers in a crisis.

4. Plan flexibility. We need greater flexibility in NDIS plans to deal with unexpected events - in particular the ability to swap funding between core and capacity building supports would give people greater control over their plans in periods of crisis.

[3] Menta Hea th Carers Austra a 2020, *Survey on the impacts of Covid-19 on families and carers of NDIS participants with psychosocial disability*, Menta Hea th Carers Austra a, p8.

5. Collaboration with major retailers. Contingency planning and collaboration are needed to ensure that in future crises the needs of vulnerable people for access to groceries, supermarkets and other goods are catered for, earlier.

6. Business continuity. There should be a greater requirement for NDIS and other providers to have robust business continuity plans in place that address operational and service delivery changes required to support participants during periods of crisis.

7. Personal protective equipment (PPE). There should be earlier and clearer guidance from the federal and state governments regarding requirements for and access to PPE.

Recent research in the United Kingdom identifies similar lessons there:

> In this global pandemic and without an approved vaccine in the short-term, resources and health care professional time will inevitably be focused on prioritised or vulnerable groups. However, it is less clear who could and should assume responsibility or has capacity for thinking about and responding to the specific needs of mental health carers, many of whom will be vulnerable to poor health outcomes.[4]

Recommendation: We urge members of the Senate Select Committee on Work and Care to support this proactive work on these reforms of the NDIS and other support mechanisms - so Australian carers are better equipped and supported, in a timelier manner, next time we face a significant crisis. And so they have capacity to provide support and remain in work if that is their preference or their need

5. The impact of the NDIS rollout on care and work for mental health carers

The pressure on carers created by the inadequacy of Australia's clinical mental health care systems has been exacerbated in recent years by the impact of the NDIS upon non-clinical psychosocial support (Hancock et al., 2018 p. 6). Block-funded community mental health services have been largely decommissioned in order to fund NDIS provision, and as only those deemed to have a lifelong psychosocial disability are eligible for the NDIS, most of those who experience a severe mental illness do not qualify (Hancock et al., 2018 p. 13). The transition from block funding to individual support packages has also entailed "a loss of funding for carer support groups, carer-directed support and carer-specific services" (State of Victoria, 2018 p. 21).

Mental health Carers Australia is currently part of a significant campaign alongside a wide range of partners to advocate for proper funding and supports in the missing middle.

The missing middle is the term used to describe the approximately 154,000 Australians with severe and complex mental illness who do not receive support from the National Disability Insurance Scheme (NDIS) or from other Commonwealth and State/Territory psychosocial programs. These members of our community are missing out on the community-based psychosocial supports they and their families and carers so desperately need to improve their quality of life and be equally valued and respected.

Funding for psychosocial supports outside of the NDIS has decreased drastically since its introduction and what remains is fragmented, inadequate and inequitable. The system channels people into

[4] Onwumere, J. 2021, 'Informa carers n severe menta hea th cond t ons: Issues ra sed by the Un ted K ngdom SARS-CoV-2 (COVID-19) Pandem c', *International Journal of Social Psychiatry*, Vo . 67(2), p108.

emergency and hospital services, adding extra pressure to that system and in turn traumatising those involved. This results in an unreasonable reliance on mental health carers to fill the gaps created by the inadequacies of the provision of psychosocial supports for all, with the provision of informal care. This means that for mental health carers their capacity to return to paid work, make reasonable choices (or any choices) about how much and for how long they wish to provide intensive support is severely curtailed.

6. Carer lived experience workforce

Evidence shows that returning to work after a long absence can be a challenge for mental health carers as they have often not received updates to their qualifications, training, or professional and workforce experience due to long passages of time out of the workforce.

Evidence is emerging through the Centre of Mental Health Learning and the CLEW (care lived experience workforce) that roles and positions developed with a focus on lived experience expertise within a workforce that honours and values the lived experience that mental health carers have accrued through their care and support role, provides mental health carers with an important avenue back into the paid workforce. The lived experience workforce also allows them to build on their experience rather than seeing that experience as having no value in the workplace. Attention is being given to this workforce through the reforms in Victoria and at a national level across a range of mental health peaks and mental health carer organisations. Supporting and building the lived experience workforce not only benefits carers wanting a pathway back into work, or wanting to build on their lived experience as professional practice but also this workforce has a flow on effect on the quality of life, and the choices available to other mental health carers.

7. Work and Care Policy settings as they relate to mental health carers

Currently there are a number of policy settings around work and care for mental health carers. Government at all levels are keen to see fuller participation of carers (particularly women) in the paid workforce and research shows that the bulk of unpaid care and support is undertaken by women across the life journey. On the other hand? as the Terms of Reference of the recent Productivity Commission investigation into carers leave attests, Government is also seeking to direct policy settings that not only maintain the level of support provided by unpaid and informal carers but increase the level of participation in the provision of unpaid or informal support? to offset the cost to the State providing such supports. These tension between wanting carers to maintain and even increase their unpaid contribution, and issues with improved participation in the workforce (at a time of low unemployment) creates a policy space that results in contradictory approaches that do not contribute to improved access to paid work for mental health carers.

At the same time the well documented lack of systemic supports both for people living with mental health distress and mental illness and for the family members that provide primary care, results in mental health carers having a precarious relationship with paid work. This has consequences for their financial security, older age and their health and wellbeing. MHCA would argue that regardless of how much mental health carers wish to support their loved ones, their wellbeing is corroded as economic, political, and social conditions restrict their agency to determine the nature and intensity of their carer role, and their opportunities to meet their wellbeing needs.

Sen and Nussbaum's capabilities approach offers a useful framework for conceptualising wellbeing and how it can be undermined. Here, an individual's wellbeing reflects their capabilities – the set of real opportunities to choose to 'be and do that which they have reason to value' (Nussbaum, 2011). In the capabilities approach, conversion factors – such as policies and practices that reflect economic, political and social conditions – enable or restrict an individual's capability set, the actual freedoms they have to live a life in which they can thrive (Nussbaum, 2011). The capabilities approach provides a framework to articulate how although improving the availability of services such as respite, peer support groups and psychoeducation is vital, the wellbeing of mental health carers as a cohort will only substantially improve by addressing the systemic and structural drivers, and cultural mental models, that currently undermine their capabilities.

The capabilities approach invites the question 'what social, political and economic conditions would enable mental health carers to have the actual opportunities to live a life in which they can flourish?' Enabling conditions would include those in which: the prevalence of mental ill health within the wider population was reduced and therefore the global need for intensive support was less; upon beginning to become unwell, a family member could access timely, adequate intervention from the mental health system and feel it was socially acceptable to do so; a carer would be therefore less likely to reduce or cease employment or education, and flexible arrangements could be accessed if needed.

Conclusion

Mental Health Carers Australia appreciates the opportunity to present this submission. We have focused on our own particular areas of expertise - a national perspective on the wellbeing of carers of people with mental health needs and/or psychosocial disability. We would be happy to provide more detailed comment if requested.

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