

For Carers Australia response to the Department of Health and Aged Care:

A New Program for In-Home Aged Care Discussion Paper

25 November 2022

Introduction

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. According to the most up-to-date Government data via the ABS Survey of Disability, Ageing and Carers (2018)¹, almost two-thirds (64.9%) of carers providing care to a parent were aged between 45 and 64 years, with 36% providing this care for a parent for between 10-24 years. Among those who were primary carers to someone aged 65 years or over, 35% said that no other friends or family were available to provide this care. In addition, many carers of a person over 65 years are also aged over 65 years themselves – with 35.3% of carers over the age of 65.

In-home aged care services and supports for the people they care for are of vital concern to carers². This is not only because carers want the best for those they care for (and themselves if they are also accessing aged care services), but because substitute care and support is needed for many carers in order to combine education, training and work with their caring role, as well as look after their health and wellbeing.

A 2020 national survey conducted by Carers NSW found that 39.1% of respondents were caring for someone with a Home Care Package and 26.7% were accessing entry level services through the Commonwealth Home Support Program (CHSP). While not all respondents were employed or seeking to be employed, a large proportion (40.8%) indicated that the aged care services provided to the person they care for had enabled them to keep their job or go back to work.³

Further, the importance of timely and appropriate in-home support is now even more critical given the impact of COVID-19 on carers. According to the 2022 Carer Wellbeing Survey, in 2021, 72% of carers had an increase in intensity in their caring responsibilities due to COVID-19, with almost half (49.6%) reporting that this is long-term⁴. The majority of carers reported delays or cancellations in treatment or therapy for care recipients, and difficulty accessing broader services and health professionals.

Overall, in relation to in-home supports as they impact on carers, this Discussion Paper has little specific focus on carers outside the respite context, as has been the case in a number of the government's aged care reform consultations and highlighted by both older people and their carers participating in these consultations. There has been a long history of carers falling to the bottom of the list of priorities in aged care reform, going as far back as the "Living Longer, Living Better" reforms, and despite findings of the Aged Care Royal Commission which states in the Final Report:

¹ Australian Bureau of Statistics' (ABS) '2018 Survey of Disability, Ageing and Carers' (SDAC), [[accessed online](#)]

² Carers Australia uses the term 'carer' as defined by the [Commonwealth Carer Recognition Act 2010](#) (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

³ Carers NSW (2020). 2020 National Carer Survey: Summary report. [[Accessed online](#)]

⁴ The 2022 Carer Wellbeing Survey - a collaboration between Carers Australia and University of Canberra, and funded by the Australian Department of Social Services. The full report for 2022 is [available online](#)

“The value of informal carers to the sustainability of the aged care system is difficult to overstate, but their work is largely invisible. From the number of informal carers, the economic value they contribute, and the important care and support they provide, there is no doubt the aged care system depends on the contribution of informal carers.

Providing informal care for an ageing family member or friend can bring personal rewards and satisfaction. But we learned that a caring role can also have detrimental effects on the health, wellbeing and financial security of the carer. Over time, this can affect the quality of care an older person receives and the sustainability of the caring relationship.

The Australian Government should ensure that informal carers are properly supported. The current aged care system fails to do so and provides reactive, inadequate support. Supports are often not provided until the strain on a caring relationship has already reached crisis point. We propose instead a preventative approach to support informal carers.

*A preventative approach would equip carers with skills at an early stage in their caring role, and access to timely, well-coordinated supports and respite throughout. Early access to services is critical to supporting the wellbeing of the informal carer as well as the sustainability of the caring relationship”.*⁵

Carers Australia realises this Discussion Paper is only one component of regulatory, funding and program design activities underway, and it will be necessary for us to consider further iterations of in-home support and concurrent work to evaluate the extent to which the program, as a whole, recognises and provides support to older people and their carers. Our response is focused on some of the more clearly defined issues and program delivery propositions raised in the Discussion Paper that primarily support and assist carers. We note that many of the focal points of the consultation are best directed to aged care service providers, including respite and other CHSP services that support carers.

To further highlight the need for clearly co-designed carer supports within future in-home aged care services, we note that if carers are unable to continue their caring role, at the same or increased intensity, the aged care system which is already stretched and struggling with workforce, in a tight fiscal environment, will have to provide more. Most hours of ‘informal’ care are provided by primary carers, who are estimated to spend an average of 35.2 hours per week providing this care, and up to 60 hours per week⁶. When you consider primary and non-primary carers combined, they provided nearly 2.2 billion hours of care in 2020, at a replacement cost for formal paid care of \$77 billion.⁷

Response to Discussion Paper

Additional grant funding

The Discussion Paper canvasses a number of circumstances where service providers will require grant funding in addition to activity based funding (ABF). We are pleased that this includes social support groups and cottage and centre-based respite.

Respite provided in the community is highly valued by carers of older people, including carers of people with dementia and carers of people in non-mainstream demographics seeking culturally and linguistically attuned community respite services for those they care for.

⁵ Australian Government, Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect – p.103 Vol 1 [[accessed online](#)]

⁶ Deloitte Access Economics, ‘The Value of Informal Care in 2020’, Commissioned by Carers Australia [[accessed online](#)].

⁷ Ibid,

As the Aged Care Royal Commission identified, there is a lack of respite services generally, and a lack of access to services of the right type and duration.⁸ While residential aged care facilities have their place, disadvantages include that most residential care providers only offer respite in larger blocks of time than meet the desires and needs of both carers⁹ and those they care for, and that admission to a residential facility can be a very confronting experience for the older person. Shorter and more frequent stays in cottage-style accommodation which provides a home-like environment and fewer unfamiliar faces is a much more normalised experience. Along with dedicated day care programs, many cottage-based providers also offer day care which can allow carers to combine work and care, something which residential respite does not. Nor do these forms of respite serve as a “try before you buy” basis as can be the case for residential respite, to test out facilities before they commit to becoming permanent residents, rather than providing opportunities for carers to have a break or undertake other duties. Of the 67,775 people who received residential respite care in 2020-21, 39,404 (approximately 58.1 per cent) went on to be admitted for permanent care.¹⁰

Unfortunately, respite available in the community is in short supply both demographically and geographically and accessing cottage-style respite or day care programs can be a postcode lottery. There is very little public data about the demand and supply of respite outside the residential context. Carers Australia has been advocating for a national demand and supply survey focussing on carer supports, including respite, in order to identify unmet demand and establish a baseline against which funding requirements and the impact of the new models of support can be evaluated. Note the 2022 Carer Wellbeing Survey revealed that 49% of carers reported poor access to in-home care support such as personal care, and only 27.7% had used respite care services. Of those that did have access, a high percentage reported poor access to all types of respite provided in community settings¹¹:

- 80.6% for in-home overnight respite
- 73.9% for overnight respite out of home
- 65.7% for day respite out of home
- 61.8% for in-home day respite.

We draw attention to the challenges small organisations delivering specialist respite care face, including:

- The high cost of delivering person-centred specialist respite services, and high administrative costs associated with delivering the services and meeting funder requirements, which cannot be reduced through economies of scale and the subsequent need for high reserves to manage the cash flow issues related to payment in arrears
- An inability to provide a holistic response drawing from a range of funding sources to ensure comprehensive, client centred and responsive care
- Additional costs associated with brokering the engagement of support workers to cover the broad needs associated with flexible respite options
- An often-complex client base of carers and people receiving care, including special needs groups such as those from culturally and linguistically diverse backgrounds and First Nations Peoples, and
- High demand for higher cost rural and remote service delivery, which also must be culturally responsive.

⁸ Royal Commission into Aged Care Quality and Safety (2021) Summary of the Final Report, p.111

⁹ According to the 2020-21 Report on the Operation of the Age Care Act, respite recipients on average received 1.2 episodes of residential respite care during 2020–21, and their average length of stay per episode was 28.6 days, p.36. [[accessed online](#)].

¹⁰ Ibid, p.17

¹¹ Note this data is across all types of care situations, not only aged care.

Against this background, we welcome that long-term grant funding will be extended to providers of community respite in addition to ABF (paid in arrears). However, the devil will be in the detail – i.e., the amount of the grant and the detail of circumstances under which it will be made available. It is not clear to us whether organisations that qualify for additional grant funding will also be eligible for the proposed annual innovation grants program. We certainly think it should be. It is also unclear from the Discussion Paper as to whether the grant will include capital funding for the acquisition or modification of new respite premises, as recommended by the Aged Care Royal Commission.¹² Such funding is essential if the number of community respite facilities are to be expanded.

Care Partners

The introduction of ‘care partners’ is a welcome development, however Carers Australia strongly believes there is already enough unhelpful linguistic confusion between family and friend carers and paid care workers without adding another layer of complexity.

The term is more commonly understood to relate to family and friend carers, both colloquially and in other aged care documentation. In addition, the injunction that family and friend carers should be recognised as ‘partners in care’ is enshrined in the [Commonwealth Carer Recognition Act \(2010\)](#). The Aged Care Quality and Safety Commission uses Partners in Care to refer to families and close friends in the residential context¹³, and “Partners in Care” or “Care Partners” is already a propriety name for a number of organisations (including some who do not provide this kind of support).

We recommend an alternative name as this can lead to ambiguity and further confusion, however for the purposes of this submission we will use the term ‘carer partners’.

The care partner concept¹⁴ as it relates to having a trusted, qualified person to identify the need for higher level supports, as the physical, cognitive or mental health of older Australians decline, and they need access to more complex services on a short-term or long-term basis is one we strongly support. Especially since this may relieve much of the onus on their family and friend carers to take full or significant responsibility for this role.

While we understand that the desires of the older person are paramount in the care partner context, it also must be carer inclusive, not only because family and friend carers are uniquely placed to identify a deterioration in the older person’s condition, but also because previous consultations identify that this kind of support “should support and sustain the informal support network”.¹⁵ In evaluating the support needs of older people, the care partner should also consult with carers in relation to their ability and desire to keep providing substantial care and what supports are available, especially where the amount and type of care identified as being needed increases.

As stated in the “Co-designing the care management role for the Support at Home Program” paper, planned and timely access to respite should be integral to care plans and the type of assistance these paid care partners provide.¹⁶

We can see merit in these professional care partners being independent of providers, noting that previous consultations on care management stress that this should be about relationships and not be

¹² Royal Commission into Aged Care Quality and Safety (2021), Summary of the Final Report, p.111

¹³ Aged Care Quality and Safety Commission, ‘Partnerships in care – Provider fact sheet’ [\[accessed online\]](#)

¹⁴ Our understanding of the Care Partner concept is largely based on the very informative Department of Health and Aged Care ‘Co-designing the care management role for the Support at Home Program’ released in September [\[accessed online\]](#)

¹⁵ *Ibid.*, p.6

¹⁶ *Ibid.*

transactional. If the care partner is employed by a provider, and their ongoing employment is in the hands of that provider, it may be difficult to avoid some degree of transactional involvement or influence, especially to the extent that they monitor the quality of care being provided. We can also envisage the possibility of complications or disputes arising where multiple providers are involved in responding to a revised care plan which changes the mix of services, but the care partner is employed by only one of those providers. There will also need to be an independent source of care partners when clients are self-managing their packages, including directly employing care workers and health professionals such as dietitians, nurses, OTC and physiotherapists and other allied health professionals.

We agree with the proposition that care partners should be focused primarily on the provision of care needs and supports for clients (including goods, equipment and assistive technology, short-term restorative care, and the respite needs of family and friend carers) rather than domestic services. However, they should be able to report back to providers when they observe that clients have a need for a higher level of domestic assistance.

Quarterly funding without carryover

We are supportive of initiatives designed to reduce the accumulation of unspent funds, while there is also a substantial queue of people waiting to access in-home care.

We do note, however, that circumstances may arise where there is a need not predicted in the care plan which may require the consumer to exceed their quarterly allotment. The Discussion Paper suggests that such circumstances can be met by provider access to a funding pool set at about 25% of the total cost of their clients' budgets each quarter, without the need for formal re-assessment of the clients' needs. It would be up to providers to allocate these funds to clients needing top ups. We are assuming and seek clarification that these funds would also be available to providers who offer single or limited service supports. For example, it should apply to cottage and centre-based respite providers to allow carers to access additional or unanticipated breaks from caring. We would also expect that this funding would cover additional substitute care in the home under circumstances where a carer has an unanticipated need and this support is required for the client.

It is of concern that some people self-managing their supports, particularly if they are doing this largely through sole contractor arrangements, will also need to exceed their quarterly budgets from time to time. It is not clear to us whether they also have access to a pool of funding to cover overspends to cope with additional needs within the quarter.

Summary

We look forward to learning the outcomes of this consultation and further development of how they would operate in practice and intersect with other aspects of reforms across the new in-home support program.

We assume, and would support, further public consultations as these high level concepts take shape and provide opportunity for clear engagement of carers.

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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
- Who 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.