

Carers ACT Response to

Australian Government Aged Care Financing Authority's (ACFA) Consultation Paper on carers and respite care

April 2018

About Carers ACT

Carers ACT is the ACT peak body representing the diversity of Canberrans who provide unpaid personal care, support and assistance to family members and friends living with a:

- disability
- chronic health condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness, or
- who are frail aged.

Carers are partners, spouses, parents, children, family, friends and neighbours who provide informal unpaid help with the activities of daily living. Whilst caring is rewarding, it can also bring financial hardship, social isolation, stress and other health and wellbeing issues.

There are around 48,500 unpaid informal carers in the ACT, and they are an integral part of our aged, health and disability systems.

Carers ACT has a constitutional mandate to represent the voices of carers to government, industry and the wider community. We consult regularly with a diverse range of carers and caring families to improve understanding of their needs, and better inclusion for them and the people they care for.

Carers ACT coordinates the ACT and Southern NSW Commonwealth Respite and Carelink Centres and delivers Commonwealth Home Support Program in the ACT.

We are also a member of the National Network of Carers Associations.

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Introduction

Carers ACT welcomes this opportunity to provide comments to the Australian Government Aged Care Financing Authority's (ACFA) Consultation Paper on carers and respite care, and the Australian Government's focus on adequate support for carers and the people they care for.

Carers ACT partnered with Carers Australia on its *Improving access to aged residential respite care* research project.¹ We endorse Carers Australia's response to this consultation, which draws upon the survey findings.

Our response to the ACFA consultation reflects our 25 years of experience delivering the ACT and Southern NSW Commonwealth Respite and Carelink Centres, and the delivery of CHSP (Commonwealth Home Support Program) in the ACT to carers of people who are frail aged. It also reflects our experiences of delivering cottage, day and flexible respite services to people who are frail aged in the ACT and Illawarra regions.

Our response discusses carers access to respite, the availability of informal carers, and policy implications for the Australian Government. It does not address adequacy or availability of aged care places and residential or in-home care packages, unless they impact on the capacity of carers to care and carers health and wellbeing.

We also consider the implications and benefits of the implementation of the Integrated Carer Support Service (ICSS) Services outlined in the *ICSS Service Blueprint*. The ICSS model includes a Carer navigation pathway, Emergency respite care and Carer direct support (that includes respite).²

Carers and respite access in a declining informal carer environment

It is well-documented that providing informal care to a person who needs support to live in the community can be rewarding. It can also mean social isolation, poorer health and wellbeing, long term financial disadvantage and can contribute to family breakdown or difficulties.

Evidence indicates that alleviating the stress and caring load for informal carers can benefit the carer and the person for whom they care. Respite is an important element in carer support services.

Our ageing population, the corresponding increase in the need for aged care services, and the preference for aged care in the home increases attention on the importance of adequate carer support, including access to respite, to help carers maintain their caring role:

... As an increasing proportion of care occurs in the home, the availability of respite care will need to increase to ensure that carers have the necessary support ... By increasing access to high level home care packages for people who might otherwise enter residential care, the need for residential respite care will further increase ... The Government needs to ensure

¹ Carers Australia (2018) *Improving access to aged residential respite care, February 2018*, Canberra. Accessible at www.carersaustralia.com.au/storage/residential-respite-care-report.pdf

² Australian Government Department of Social Services (2018) *Appendix A: ICSS Service Blueprint, 21 March 2018*, Canberra. Accessible at <https://engage.dss.gov.au/integrated-carer-support-service-regional-delivery-model/icss-regional-delivery-model-discussion-paper/>

that there are adequate and appropriate respite services to support informal carers in their role. (Tune Report, 2017)³

The CHSP reflects priorities and principles identified within the National Carer Recognition Framework and *The Carer Recognition Act (Commonwealth) 2010*. CHSP service provision is expected to embody the principles incorporated in the *Statement for Australia's Carers* under the Carer Recognition Act 2010, including the following: 1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality ... 3. Carers should be acknowledged as individuals with their own needs within and beyond the caring role. 4. The relationship between carers and the persons for whom they care should be recognised and respected. 5. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers ...

... Carers make a significant contribution to the lives of the older people they care for and an important economic contribution to the community. (Australian Department of Health, 2017)⁴

Deloitte Access Economics in its report on informal caring⁵ highlights the increasing need for informal carers and their decreasing availability (known as the carer gap or the carer ratio) and the significant policy implications:

The widening carer gap has significant policy implications for Australia's future with the need to investigate possible solutions to help boost the propensity to supply care and to soften the demand for informal care where possible. There is a strong case to consider the following suggestions as part of a concerted policy effort to reduce the carer deficit:

- greater flexibility in working arrangements to accommodate workers' caring responsibilities and employment preferences
- improvements in access to, and awareness of, carer support services such as respite care to encourage service utilisation and alleviate the impact of caring ...

Deloitte Access Economics also discusses the decline in the natural inclination or tendency [propensity] to provide care across of all ages since 2003, except for female carers over the age of 55. Likely influences for this include:

- Increased female participation in the workforce
- Rapidly rising rates workforce participation among older workers
- Increased availability of government-supported care in the home environment
- Growing duration and complexity of caregiving because of extended life expectancy that may place greater pressure on future informal carers

³ Australian Government Department of Health (2017) *The Legislated Review of Aged Care 2017* (the Tune Report), Canberra. Accessible at <https://agedcare.health.gov.au/legislated-review-of-aged-care-2017...>

⁴ Australian Government Department of Health (2017) *CHSP Programme Manual 2017*, Canberra. Accessible at https://agedcare.health.gov.au/.../chsp_manual_april_2017_final_0.pdf

⁵ Deloitte Access Economics (2015) *The economic value of informal caring in Australia, 2015*. Canberra. Accessible at www.carersaustralia.com.au/storage/Access Economics Report.pdf

- Changes in intergenerational attitudes and perceptions of caregiving, which may reduce willingness to care for friends and family members
- Changes in family structures with smaller families and other factors.

This increased workforce participation by older Australians may force downward pressure on the availability of future older carers, according to Deloitte Access Economics. This increase is caused by people tending to work later into their lives, and partly because of government policy, e.g an increase in eligibility age for the Age Pension. If faced with greater opportunities and economic motivations to continue or commence workforce participation, older carers may choose to work and reduce their caring hours or responsibilities. As older carers are a significant proportion of the informal caring population, a fall in the older carer population is likely to greatly reduce the supply of available informal care. (In 2015, the number of informal carers from ages 35-75+ was nearly 2.4 million carers, while the peak caring ages was 45-64 years with nearly 1.2 million carers.⁶)

The ageing of carers caring for an ageing spouse, partner, family member or friend is also problematic as they are likely to have their own care needs associated with age-related conditions and unable to maintain their caring role.

The economic sustainability of the aged care sector is intrinsically linked with the level of informal support by carers provided to aged care recipients, and their propensity to care. Across all carer cohorts over five years from 2010-15 there was an approximate 10,000 carer decline due to individuals' propensity to assume a caring role.⁷

The economic value of all informal caring in Australia in 2015 was estimated to be \$60.3 billion (equivalent to 3.8% of gross domestic product and 60% of the health and social work industry.)⁸ This estimated value is nearly three times higher than the \$17.4 billion cost of aged care services to governments in 2016-17 (for 232,252 older people in permanent care and 57,408 people in residential care during this period).⁹

Carers ACT's engagement with carers and respite access

Carers ACT's experience in supporting carers reveals that the lack of respite (across age and disability care) creates difficulties for carers and caring families. They need to have a break from their caring role, or to spend time with their spouse or children who can feel neglected because of the care needs of the cared for person. Respite, or replacement care, is needed to ensure that carers maintain their own wellbeing, to participate in the workforce and to maintain and continue their caring role into the future.

⁶ Of all carers, including for disability and aged care.

⁷ Deloitte Access Economics (2015) see footnote 5

⁸ Deloitte Access Economics (2015) See footnote 5 pages ii-iii.

⁹ Productivity Commission (2018) *Report on Government Services 2-19: Part F Community Services*, Canberra. Accessible at <https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services>

Carers ACT and respite support for carers and aged care recipients.

We support carers of people who are ageing by arranging three types of short-term in or out of home care for their cared for person: in-home help provided by support workers, cottage respite in a home-like setting and residential respite in an aged care home. Carers ACT strongly believes that respite is much more than just replacement care. We give carers an opportunity to reduce their stress and carer load through: in or out of home care, community access or recreational activities, assistance with purchasing products or equipment that makes caring tasks easier and educational support. While carers are requested to contribute to the cost of services provided, we don't refuse services if carers cannot afford this cost. In 2016-17 Carers ACT provided supports to carers of more than 2000 people aged over 65 years.

In planning adequate and appropriate respite, the Australian Government needs to consider – what is its purpose, how can we ensure that sufficient services are built into a consumer's Home Care Package or through CHSP support to provide regular respite for carers and how much respite is enough. As many carers who provide informal care to aged care recipients also provide informal care to another family member, Carers ACT believes their caring role should be more consistently and rigorously considered in the aged care assessment process.¹⁰ (See Carers ACT Case study – Cottage respite below.)

Regular respite is essential to maintain a caring role. It is not a luxury for carers, nor does it disregard the needs of the aged care recipient. Caring is a relationship between the carer and the person they care for. The success and longevity of the relationship depends upon the wellbeing of both people. Without respite carers experience burnout, resentment and despair and this impacts on the quality of the caring relationship and the care provided.

The disconnect between aged care service provision and aged care packages also increases the caring load as carers need to navigate a pathway to manage the package of the aged care recipient. There is also the additional caring responsibility while the aged care recipient is assessed and the time before they receive their Home Care Package. The increased delay in accessing higher care needs packages, even if the aged care recipient is assigned a lower level package as an interim measure, can significantly increase the caring responsibilities and the associated stress.^{11,12}

Carer stress can also relate to the unmet demand for services, including paid care workers, and the need for them to try to fill the unmet service need. The Aged Care Workforce Strategy is currently

¹⁰ For example, the *National Disability Insurance Scheme ACT 2013 (Clth)* allows for what is reasonable to expect families, carers and informal networks and the community to provide in assessing the funding or support provision in an NDIS plan – see s.34. Accessible at http://www.comlaw.gov.au/Details/C2013A00020/Html/Text#_Toc352761880

¹¹ In the ACT, as at 31 December 2017 there were 669 aged consumers in the National Prioritisation Queue who were not in, or assigned, an interim level package. Level 2 queue was 253, Level 3 queue was 254 and the Level 4 queue was 261 consumers. The number of HCP packages released in the December 2017 quarter was 789, with Level 2 – 453 and Level 4 – 124 packages. (Source: Gen Aged Care Data: Home Care Report 2017-2018 2nd quarter. Accessible at https://gen-agedcaredata.gov.au/www_aihwwgen/media/Home_care_report/HCP-Data-Report-2017-18-2nd-Qtr.pdf).

¹² Carers ACT's experience with caring families indicates that when an aged care recipient is offered a Level 2 package while waiting for a Level 4 package that carers take on the additional care required. If an aged care recipient is assessed they may also have a reduced care needs assessment if they have an informal carer, who is undertaking much of the care need. And, many aged care recipients won't take up a Home Care Package, especially lower levels, because of the associated cost.

conducting consultations to look at “Building sector-wide capabilities to innovate and extend new ways of working tailored to the needs of the older people who use aged care services, their families, carers and communities” among other things.¹³

Research indicates that carers of a person living with dementia have one of the highest care loads, carer stress and burnout.¹⁴ Carer stress can also increase the risk of a carer perpetrating abuse of the cared for person.

Often the Home Care Package respite allocation isn't adequate to provide respite for the carer as well as the aged care recipient. For example, the aged care recipient will use the respite allocation for their own respite needs (e.g to have a restorative break) and the carer must forego their own respite needs. This does not consider the rights of carers to have their own needs acknowledged, or recognise and respect the caring relationship. The move to consumer-directed aged care packages may exacerbate and demonstrate the insufficient allocation of respite care and the need for carers to forego their own support needs.

The difficulty in accessing appropriate respite that meets the needs of carers and their caring families can also add to a carer's stress and their dissatisfaction with their caring situation. Barriers, or difficulties include:

- The tendency of residential respite providers to offer minimum stay periods, usually two weeks¹⁵
- Inadequate residential respite care beds, particularly for low care needs (due to low subsidies), high needs and dementia care
- Inability to book respite well in advance and for the times required (e.g so carers can plan holidays)
- Lack of residential respite over the weekend
- Lack of transport to residential respite and day care respite – unless a Home Care Package provider can arrange the transport, many aged care recipients and their carers struggle to find transport options
- Delays in ACAT assessments required to access respite care
- Lack of secure settings and, or enough trained staff to support dementia and other aged care recipients with high care needs¹⁶
- Insufficient respite included in a Home Care Package to meet respite needs.

Carers' preferences for respite are:

¹³ See Aged Care Workforce Strategy Taskforce at <https://agedcare.health.gov.au/reform/aged-care-workforce-strategy-taskforce>

¹⁴ Carer research indicates that 16% carers of people living with dementia have contemplated suicide more than once in a year. (Source: Siobhan T. O'Dwyer, Wendy Moyle, Melanie Zimmer-Gembeck, Diego De Leo, Suicidal ideation in family carers of people with dementia, *Aging & Mental Health*, 2016, 20, 2, 222).

¹⁵ Residential respite data 2016-17 – 59,228 people received respite care, with an average of 1.4 respite care stays with each stay being an average of about 26 days. Residential respite care is most commonly accessed in weekly units. A fortnight is by far the most common residential respite care length of stay. One, three and four weeks are the next most common lengths of stay. (Source: The Tune Report, see footnote 3.).

¹⁶ Carers Australia (2018) *Improving access to aged residential respite care February 2018*. Canberra. Accessible www.carersaustralia.com.au/storage/residential-respite-care-report.pdf

- It is flexible; it includes planned longer stay respite and shorter stay respite to provide shorter, more frequent breaks to better manage their caring, employment and family responsibilities
- Cottage style respite for overnight or weekend respite options
- More in-home and day respite
- Secure respite for the aged care recipient living with dementia, or high care needs.

In 2016-17 Carers ACT supported 132 families to have a vital break from caring through our Deakin Cottage. Our 'home away from home' Deakin Cottage provides a welcoming environment in which carers can leave their dementia or ageing parent or partner for short stays, enabling them to take a break from caring. The Cottage has four comfortable bedrooms and can cater for four overnight and 12 daytime guests. This 'boutique' size means we can give each client a personalised experience, and activities tailored to their own interests.

Carers ACT Case study – Cottage respite.

When Alice developed dementia several years ago her daughter Maree became her full-time carer — a role that turned Maree's life upside down. "Looking after mum's been a big strain on my family. We were all unprepared and thinking 'what's happened to our perfect world?' One of my teenage sons developed a chronic illness around the time I started caring for Mum, so my stress levels went through the roof. Then I found out about Deakin Cottage and it's been a lifesaver. Mum is really active and needs to be stimulated. I just don't have the time and energy. But the staff there do. They make it a really happy place. When Mum gets there she just lights up. She loves going there and it provides her with the vital social interaction she so enjoyed before her dementia. It's a part of our family routine now and the staff are wonderful — I can talk about anything with them. Leaving Mum at the Cottage on a regular basis meant I could re-connect with my children and give them the attention they deserved and were missing. I could do family things again, like going to watch my sons play soccer. Without the Cottage I couldn't do it. It's as simple as that."

Carers caring for somebody from a special needs group

Carers ACT supports carers who identify as an Aboriginal or Torres Strait Islander and those who are from a non-English speaking country (CALD) through specific carer support groups and activities. These two carer cohorts are included as special needs groups under the *Aged Care Act 1997 (Clth)*, and both have lower access to residential respite and transition care compared with representation of other aged care recipients, although they access low and high needs care packages. The Productivity Commission suggested the availability of care and support from family, friends or neighbours can also affect the use of services across different population groups that reduces the need for government funded aged care services.¹⁷

Our engagement with Aboriginal and Torres Strait Islander carers and CALD carers reflects the Productivity Commission's assumption, as well as research by Carers ACT and other organisations.

¹⁷ Productivity Commission (2018) see footnote 9 page 14.12.

However, this cultural tradition or resistance to formal aged care services does not account for the impact on their primary informal carers and families who are providing these services, particularly as the aged care recipients are less likely to access residential respite or transitional care. Also, many older Aboriginal and Torres Strait Islander people and older people with a CALD background are themselves a carer for a family member or a member of their community and can face cultural and other barriers in accessing carer support services. These older carers often experience social isolation and their own health issues, including depression, anxiety and stress because of their caring role.

Carers ACT research found that both these special needs groups have similar barriers to, or, support requirements. These include:

- Barriers – the need for transport to attend day care respite or community access individual and group, lack of culturally appropriate aged care services, or respite, lack of awareness of service availability, and language barriers.
- Service preferences – day care programs for aged care recipient, culturally appropriate in-home respite, community access respite that provides social contact with people to talk to in their own language or from their cultural background, respite where the carer and the aged care recipient can have a break together.

A Carers ACT survey of CALD carers found that while carers identified their need for services, their access to these services was different. For example:

Needs of carers:	Transport 40%, support for social contact 48%, in-home respite 18% and culturally appropriate residential respite 14 per cent. Seventy per cent of carers said having a support worker from their own background was very important.
Access by carers:	Transport 24%, day centre programs or social contact activities 4%, respite accommodation 3 per cent.

Another barrier to aged care access for both population groups – including carers and aged care recipients – is their low access to the Internet and lack of IT skills. In 2015, Carers SA carer research found that 77% of carers of aged people had not used the My Aged Care gateway – 16 language groups had participated in the carer survey and 68% of carers surveyed were aged 56 years or older.¹⁸

It is estimated that between 25% to 35% of carers in Australia are from CALD backgrounds. Of people aged 65 years or older who identified as having an informal carer 306,300 people were born outside of Australia, 62,500 did not speak English well and 22,900 did not speak English at all (10.4% combined).¹⁹

The Australian Government has recently reviewed its *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*, which identifies that the proportion of older people from CALD backgrounds is increasing at a faster rate than other older

¹⁸ Carers SA (2015) *Carers Survey 2015: Our Carers, Our World*, Adelaide. Accessible at www.carers-sa.asn.au

¹⁹ Carers Australia (2013) *Culturally and linguistically diverse carers in Australia: background report*, Canberra. Accessible at <http://www.carersaustralia.com.au/storage/Carers%20Australia%20CALD%20carers%20background%20report.pdf>. Carers ACT contributed to this background report.

people. It also identifies the importance of recognising the valuable role of carers in providing care and support for older people from CALD backgrounds, who can experience greater difficulty in accessing and navigating the aged care system.²⁰

Carers ACT believes it is important for the Australian Government to ensure its aged care services, particularly respite, adequately reflect the needs of Aboriginal and Torres Strait Islander and CALD carers and the aged care recipients they care for – higher allocation or choice of in-home respite and flexible respite, and assessment of carers needs to ensure their own respite needs are met.

Implications of the Integrated Carer Support Service (ICSS)

The Australian Government has consulted widely with carers, carer peak organisations, service providers and other stakeholders to develop a new model of carer support service. It released its *ICSS: Regional Delivery Partners: A draft regional delivery model discussion paper* and supporting documents, including *Appendix A – ICSS Service Blueprint* on 9 April 2018. The *Blueprint* includes nine services, including a Carer Navigation Pathway, Emergency Respite Care and Carer directed support. It is envisaged that ICSS access will be through the existing Carer Gateway, a 1800 Carer Gateway number that will be directed to the proposed Regional Delivery Partners (RDP), and in person through a RDP or other service. The proposed ICSS has a ‘no wrong door’ approach.

The services are designed to provide one-off practical support that enables carers to access support, and the provision of Carer Directed Packages that give carers a greater say and more control over the design and delivery of the support provided to them and the people they care for. The Carers Directed Package includes respite, cooking, cleaning and assistance with transport.

The Emergency Respite Access service will allow for easier to emergency access where a carer is not known to a Regional Delivery Partner, with processes for carer follow-up and assessment. The Carer Navigation Pathway is to facilitate service planning for carers and carer directed support.

Under the existing Carer Respite and Carelink Centre model, service providers are encouraged to operate a residential respite booking service for carers of people who are frail aged. This service operates to reduce the impact on carers of sourcing residential respite by collating vacancies, helping identify suitable services, processing paperwork and making bookings. This service is highly valuable to carers as it prevents them from having to find the time to ring numerous respite providers to find a vacancy. There is no indication in the proposed ICSS that this service will continue and Carers ACT is concerned about the impact of this on carers.

The Australian Government identified that \$120 million will be allocated to the ICSS, and that service delivery transition commences in September 2019.

Conclusion and recommendations

Carers ACT believes the availability of carers or their intention to assume a caring role for older parents or relatives and friends should be an imperative consideration by the Australian Government in its planning of and allocation of resources that recognises and respects the

²⁰ Australian Government Department of Health – Ageing and Aged Care, National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds, Canberra. Accessible at <https://agedcare.health.gov.au/older-people-their-families-and-carers/people-from-diverse-backgrounds/national-ageing-and-aged-care-strategy-for-people-from-culturally-and-linguistically-diverse-cald-backgrounds>

relationship between carers and the people they care for, as well as improving support for carers to maintain their caring role if they choose.

Nearly 12 years ago NATSEM identified the carer gap due to our ageing population and the availability of carers (primarily female carers) or their inclination to assume a caring role in *The cost of caring in Australia 2002 to 2005*. They stressed that this was a significant policy issue for Government. At the time of the NATSEM report nine in every 10 Australians aged less than 65 years who cared for a frail parent were women. The workforce participation rates of women aged 45 to 65 years had continued to grow strongly and are expected to continue. According to NATSEM, more women in their 40s, 50s and 60s are “likely to experience growing conflict between their desire to have a job and a pay packet and their family obligations to ageing parents. Given the smaller families of today, most people will have fewer siblings to help them with caring for aged parents.” NATSEM projected that by 2052 the carer ratio of females 50 to 64 years to persons aged 80 years and over would have fallen from just 2.5 to less than one.²¹

Recommendations

Carers ACT recommends that:

1. With the shift to consumer-directed aged care the Australian Government should ensure that the aged care assessment processes include a consistent and rigorous assessment of the caring role so carers are assessed in their own rights for a carer respite package, which is separate to the respite allocation for the aged care recipient.
2. The Australian Government should increase its investment in respite services to improve access to adequate flexible and planned respite to meet carers’ needs to balance their caring role, with their health and wellbeing, workforce participation and family and social participation needs.
3. The Australian Government should ensure its investment in respite services better aligns with the needs and preferences of carers, including cottage style respite, to encourage and facilitate a propensity to care and the sustainability of the aged care sector.
4. The Australian Government should increase its investment in culturally appropriate respite for special needs groups – particularly Aboriginal and Torres Strait Islander and CALD carers, that reflect their respite preferences and their higher caring load, including joint respite for both the carer and the aged care recipient to take a break together.
5. The Australian Government should ensure that My Aged Care recognition and support for carers reflects the carer benefits of the proposed Integrated Carer Support Service, including the Carer Directed Package service, Emergency Respite Access service and the Carer Navigation Pathway.

²¹ AMP.NATSEM (2006) Income and Wealth Report – *The cost of caring in Australia 2002 to 2005 – Who cares?*, Canberra. Accessible at www.natsem.canberra.edu.au/storage/AMP_NATSEM_13.pdf