



Carers Australia
Submission to the Aged Care Legislated Review

2 December 2016

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of 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

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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The 2015 Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) estimated that there were 2.7 million carers in Australia of whom about 800,000 were primary carers (those who provide the most substantial amount of support), There were 420,700 primary carers (or about 50% of all primary carers) caring for people aged over 65.¹

Although Carers Australia has a keen interest in all aspects of aged care reform, the focus of this submission is the impacts of the reforms on carers' access to services which support them in their caring role and which help to sustain the provision of unpaid care. Without family and friend carers of the aged, the capacity of older people to age at home would be severely compromised and the aged care system would be unaffordable. (Deloitte Access Economics estimated that, in 2015, the cost of replacing unpaid care with paid care was \$60.3 billion²).

This submission has been developed with the assistance of Carers Victoria and Carers NSW.

The comments below address Items 1, 6 and 9 in relation to the Scope of the Review.

ITEM 9: THE EFFECTIVENESS OF ARRANGEMENTS FOR FACILITATING ACCESS TO AGED CARE SERVICES

Problems in relation to carer referral to services through My Aged Care Gateway (MAC) and Regional Assessment Services (RAS)

The implementation of the My Aged Care Gateway, (MAC), Regional Assessment Services (RAS) and Commonwealth Home Support Programme (CHSP) has had a significant negative effect on carer access to respite services for the person they care for and to carer support services for themselves.

While not all carers, or even the majority of carers need respite services³, those who do often have a high need. These are generally carers who are required to provide a high level of care, including especially those who care for someone with challenging behaviours.

Respite care is essential for carers confronting an emergency which takes them out of the care situation and to the sustainability of providing care in many situations. The sustainability of unpaid care in turn is essential to keeping the costs to government of aged care down.

¹ Australian Bureau of Statistics, 2015 Survey of Disability and Aged Care, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

² Deloitte Access Economics, The Economic Value of Informal Care in 2015, <http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf>

³ The Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers report that 55% of primary carers said they did not need respite. Unfortunately the statistics cannot be broken down by carers of people over the age of 65. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

- **The carer experience of MAC and RAS**

As identified in the Australian Market Research (AMR) My Aged Care Stage Two Wave 1 research⁴, carers' assessment and referral needs are not being met through the new access arrangements. Carers' satisfaction with the MAC/RAS system is markedly lower than that of clients. Qualitative interviews confirmed carers are often navigating the system on behalf of family members with care needs and feel they are not always recognised clearly enough as the primary carer. The AMR research indicated that 43% of carers had been included in the RAS assessment process compared to 60% who were included in ACAT assessment. They were also concerned with the competence of RAS assessors in recommending the most appropriate care. Anecdotal reports continue of carers not being able to deal effectively with MAC on behalf of the person they care for due to poor processes for gaining client consent and establishing carers' representative or nominated person status. This has resulted in clients receiving 'cold' calls from MAC even when specifically requested to call the carer rather than call the client directly. As these processes have been prioritised for improvement, it is expected that this issue will occur much less frequently in the future.

- **The 'client' of respite is now the person with care needs**

Feedback from recent co-design workshops held with carer representatives and representatives of carer support services indicated that the failure of the MAC and RAS system to deal effectively with carers has been compounded by the merger of the former National Respite for Carers Programme (NRCP) into the CHSP Care Relationships and Carer Support sub-programme. Previously the carer was considered the 'client' of flexible respite, centre-based respite and cottage respite, and providers reported back on the carers receiving these services. Now only people with care needs can be registered as clients with MAC. Referrals from the MAC Contact Centre to RAS and referrals from RAS to CHSP respite only provide information on the person with care needs as the client. Providers of respite are only required to upload client information on the Data Exchange (DEX) system. No carer information is required or captured. This has resulted in a significant loss of data about carer needs and service usage by carers. Respite service providers also report very low numbers of referrals for flexible respite, centre-based respite and cottage respite from RAS, affecting their occupancy and meeting of performance targets. This low rate of referral also acts to perpetuate crisis-driven access to respite care by carers rather than planned access to regular respite care to maintain the care relationship.

- **Carers unable to register as clients**

Carers cannot be registered as clients with MAC unless they are over 65 years of age (over 50 for Indigenous carers) and have care and support needs in their own right. This means they are not being referred to carer support services for themselves when they interact with the MAC/RAS system on behalf of the people they care for. At most, carers are given another 1800 number to contact for further information. If the phone number they are given is

⁴ AMR and Healthdirect Australia My Aged Care Stage Two Wave 1 Research Summary of Findings https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/10_2016/amr_my_aged_care_evaluation_summary_of_findings.pdf

for the new Carer Gateway, this information-provision only service will give them another number to call for access to carer support services. This is particularly distressing for carers with urgent respite needs who call the MAC Contact Centre only to be told to make another call and then another.

- **Carer support services cannot be listed for referral from MAC**

Only CHSP funded services can be listed for referral through the MAC/RAS system. This effectively excludes core national carer support services; the National Carer Information and Support Service, the National Carer Counselling Programme and all 54 Commonwealth Respite and Carelink Centres. None of these services can receive referrals through MAC except for any CHSP funded services they may also offer. MAC Contact Centre staff cannot 'warm transfer' carer callers to either these services or to the new Carer Gateway. RAS assessors cannot make a referral to these carer support services through the MAC system and their practice in making use of any alternative referral systems in place for these services is highly variable. ACAT assessors can directly register clients into the MAC system and, as they continue to complete approvals for residential respite care, they do make some referrals directly to carer support services for urgent respite and other carer support services.

- **Carer needs not being identified or assessed**

RAS assessors using the National Screening and Assessment Form (NSAF) can use this tool to assist them to identify some carer needs. These include:

- What type of care does the carer provide? How often?
- Have there been recent significant changes in carer or family support arrangement?
- Does the carer experience any difficulties or have any concerns with the caring arrangement?
- Are carer arrangements sustainable without additional services or supports?

However as less than half of carers report being involved in a RAS assessment, these questions may not be asked and their needs are likely to be overlooked. Only carers over 65 years of age (over 50 for Indigenous carers) and who have care and support needs in their own right may be assessed by RAS assessors and subsequently referred for CSHP services. The majority of carers are therefore not assessed as having any needs in their own right or referred for any services such as the National Carer Information and Support Service, the National Carer Counselling Program or a Commonwealth Respite and Carelink Centre which can assess their needs as carers and/or provide services to them that will complement any services the person they care for may or may not receive.

Recommendation 1:

The Department of Health cannot afford to wait for the Department of Social Services to complete its deliberations regarding nationally integrated carer support services to address the issue of greater carer recognition and inclusion identified in this submission in relation to My Aged Care and Regional Assessment Services. Carers and people receiving care are missing out on necessary services to support the maintenance of their care relationship now. Flow-on effects of the lack of recognition and inclusion of carers in MAC/RAS is significantly affecting the efficiency and effectiveness of CHSP respite services and national carer support services. As government-funded service providers, MAC and RAS should be required to provide a better service to carers in keeping with the principles of the Carer Recognition Act 2010, which states they must take carers' needs into account when developing and implementing their services.

ITEM 1 (WHETHER UNMET DEMAND FOR RESIDENTIAL AND HOME CARE PLACES HAS BEEN REDUCED) and ITEM 9 (THE EFFECTIVENESS OF ARRANGEMENTS FOR FACILITATING ACCESS TO AGED CARE SERVICES)

Access to residential respite care

- **Declining access to residential respite positions**

Carer Respite and Carelink Centres across a number of states have reported that they are finding it increasingly difficult to find respite places since the aged care reforms have come into effect. It can take a number of their staff many hours to find a free respite bed even in emergency cases. Obtaining respite positions for care recipients with higher needs is particularly problematic.

Carers Australia was first alerted to this trend in 2014, about the time when changes to fees were introduced and accompanied by means-tested care fee advice provided by the Department of Human Services (DHS) to aged care providers in relation to people seeking access to permanent residential aged care. Residential aged care providers began to put people seeking to become permanent residents into respite beds pending correct confirmation of the prospective residents' fee contribution. This situation took many months

to resolve. However the availability of respite beds to allow carers to take a break from caring does not appear to have bounced back. A number of reasons have been proffered including:

- the practice of taking on short-term clients seeking to become permanent residents who are keen to experience a “try before you buy” opportunity;
- over-burdened hospitals are increasingly and rapidly transferring patients to residential care facilities for recovery;
- the new Short-term Restorative Care Programme is likely also to have drawn down on short-term residential care places.

Other circumstances which pre-date the reforms also contribute to the reluctance of aged care providers to offer respite. This includes the fact that requirements for accepting clients into respite care involves unnecessarily onerous administrative effort and paper work on the part of providers. Also providers are generally unwilling to provide respite care for a period of less than 14 days, so if the family only wants a few days or a week there is no flexibility within the system to enable this to occur.

Finally, due to a growth in demand with the ageing of the population, it is likely that supply for residential respite just hasn't kept up with demand. The 2012 Productivity Commission report on Government Services 2010-11 (before the Living Longer Living Better reforms) identified a national ratio of 19.3 residential care respite positions per 1000 people in the relevant demographics⁵. According to the Commission's 2015 report, by 2014-15 this had dropped to 14.1 positions per 1000 people.⁶ While the number of clients nationally has increased (from 46,147 in 2010-11 to 53,021 in 2014-15), the rate of residential respite clients appears not to have risen sufficiently to keep up with the ageing of the population.

The long and the short of it is that accessing respite care in aged care facilities has become problematic and the causes may be complex. However, the evidence base for evaluating the size of the problem, the causes of it and the means to address it is difficult to obtain.

⁵ Productivity Commission, Report on Government Services 2015 (<http://www.pc.gov.au/research/ongoing/report-on-government-services/2012/2012/47-government-services-2012-chapter13.pdf>, Table 13A.4)

⁶ Productivity Commission, Report on Government Services 2012((<http://www.pc.gov.au/research/ongoing/report-on-government-services/2016/community-services/aged-care-services>, Table 13A .3).

Recommendation 2: That the Review investigate trends in the provision of short-term care in residential facilities for the purposes of respite with a view to considering what further reform is required to ensure that carers are able to take both planned and emergency breaks from caring through the provision of such respite opportunities. We further recommend that longitudinal trends in the demand for respite become integrated into national data collections pertaining to the adequacy of the provision of current and future respite service requirements.

Recommendation 3: That the administrative requirements for accepting a respite care client in an aged care facility be reviewed with a view to removing unnecessary red tape.

ITEM 6: THE EFFECTIVENESS OF ARRANGEMENTS FOR PROTECTING EQUITY OF ACCESS TO AGED CARE SERVICES FOR DIFFERENT POPULATION GROUPS

The AMR My Aged Care Stage Two Wave 1 research⁷ revealed that Culturally and Linguistically Diverse (CALD) respondents rated information supplied to the My Aged Care Contact Centre and the sensitivity of their aged care assessment to their particular demographic less positively than non-CALD respondents. Those from CALD groups were often less positive about the relevance of the services they received to their Support Plan.

Since July 2015 the majority of aged care funded services now have access to the Translating and Interpreting Service (TIS National) free of charge. This list includes Aged Care Assessment Teams (ACAT), the My Aged Care Call Centre, Commonwealth Home Support Programme (CHSP) and Home Care Package (HCP) providers. In contrast, Regional Assessment Service (RAS) providers are still required to budget for interpreters as part of the unit price in their funding agreement.

RAS providers must absorb the cost of using an interpreter which, on top of the additional time required when using an interpreter, increases the unit cost of servicing CALD clients. Unit pricing that does not acknowledge the complexity of individual consumer needs may act as a disincentive to provide adequate time and resources to overcome inequities. This could place pressure on carers to inappropriately cover additional services like interpreting from their own resources; noting that family members may not be satisfactory alternatives to professional interpreters as there is no guarantee of accuracy and impartiality.

⁷ AMR and Healthdirect Australia My Aged Care Stage Two Wave 1 Research Summary of Findings https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/10_2016/amr_my_aged_care_evaluation_summary_of_findings.pdf

Similarly, very remote and high needs consumers may also be at risk of further access inequity due to real or perceived additional costs.

Individual advocacy and case management are critical in ensuring that disadvantaged groups including (but not exclusive to) CALD people receive equitable access to services. Such funding was available under HACC Counselling/Support, information and Advocacy prior to this service being rolled into the CHSP. NACAP could also provide these services however it is unclear how this funding will continue beyond mid-2017. In the meantime, there is increasing pressure on RAS and ACAT teams to provide short term case management, however the unit price driven funding model of the RAS means that this capacity is limited by cost, does not allow for time to build rapport with consumers and is only available once a consumer has been assessed as eligible for services.

The My Aged Care website and consumer portal via MyGov can be valuable tools for carers to make informed decisions, research support options before a RAS assessment and manage supports. However, these online access points are only useful to consumers and carers who are computer literate. Research indicates that in older populations women are less likely to use the internet compared to men, whilst those of an English-speaking background, higher socioeconomic status and home-owners have a greater likelihood to be using the internet.

The Network has received positive reports from carers able to use the portal and it should be expected that future generations will engage better with the online format. However without access to a print directory or face to face assistance many of the most vulnerable consumers will be unable to become informed consumers.

Recommendation 4: Regional Assessment Services (RAS) providers should be reimbursed for the cost of using an interpreters.

Recommendation 5: Review the effectiveness and appropriateness of utilising RAS for short term case management.

Recommendation 6: Individual advocacy to assist disadvantaged groups to access services – including to prepare them for RAS engagement - should be available in the community and provided by organisations that know and can cater for the community demographic (for example, regional and remote populations and the CALD population).

Recommendation 7: Continue to improve accessibility to the MY Aged Care website and carer access through MyGov while maintaining alternatives for the less computer literate.