



**Carers Australia's Submission to the AHA Review of
Commonwealth Aged Care Advocacy Services Options Paper**

September 2015

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.

With respect to this submission Carers Australia acknowledges the input provided by Carers New South Wales and Carers Victoria which provide support for family and friend carers within their states. Both organisations are also part of the National Network of Carers Associations, which works collaboratively to lead change and action for carers.

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Summary Comments

Carers Australia welcomes the opportunity to provide input to the Review of Commonwealth Aged Care Advocacy Services.

The deregulation of aged care services arising from recent and proposed aged care reforms and the greater responsibility placed on consumers to ensure that they receive quality aged care through the move toward Consumer Directed Care (CDC) will bring benefits; but also many challenges to the aged and their carers. The aged care market is complex and specialised. It is a market in which many consumers are at a disadvantage in comparison to the providers of services by virtue of their vulnerability and a very high level of information asymmetry. It has become more important than ever that consumers in this market and those who represent them have ready access to expert advocacy services to assist them to negotiate their way through problems arising in relation to services provision.

With respect to the Options Paper, Carers Australia's main concern is the adequate recognition of the legitimate interest family and friend carers have in relation to both the quantity and quality of formal care provided and their role both as informal advocates and as a conduit for engaging formal advocacy services. To the extent that the aged care sector also provides supports to family and friend carers of the aged, they should also have access to such services in their own right.

Against this background, responses to specific questions for discussion identified in the Options Paper are covered below. Some responses are repetitive since the inclusiveness of family and friend carers is relevant to nearly all discussion questions.

Future Options – 2.1 – Definitions of advocacy

Discussion question:

1.1.1 Do these definitions accurately describe advocacy in the context of a national end-to-end aged care advocacy service focussed on individual and independent support?

We believe the definition of aged care advocacy services should be amended to recognise role of family and friend carers in accessing formal advocacy services on behalf of the person they care for.

The explicit acknowledgement of carers alongside references to consumers would bring the definitions into line with the Objectives and Scope of the advocacy programme in the Options Paper which acknowledges:

“Individual aged care advocacy supports consumers or potential consumers of aged care services (and their relatives and carers) receiving Commonwealth subsidised aged care services by:

- Supporting consumers to speak out on their own behalf (self-advocacy)
- Speaking for the consumer to aged care service providers and other agencies
- Referring the consumer to other agencies where needed.

Individual advocacy is generally provided as one-to-one, short-term support to address a specific issue(s) identified by a consumer and/or their carer.”

Recommendation:

Amend the definition of individual advocacy services as follows:

“Aged care advocacy services can be defined as independent and confidential services delivered for the benefit of people receiving Commonwealth subsidised aged care services to support them and their carers and other representatives to understand and uphold their rights and participate in decisions affecting their care.”

2.2 Development of a national framework

Discussion questions:

2.2.1 Would you agree that a National Framework would effectively support the delivery of an end-to-end aged care advocacy programme?

2.2.2 What other considerations should be given to developing a framework?

2.2.1

A National Framework for the new aged care advocacy programme could effectively support the delivery of the programme. However, Carers Australia would like to be offered the opportunity to comment on the details of the final framework once it has been drafted.

2.2.2

The Carers Associations across Australia engage with many carers who are unpaid advocates, although often these carers undertake advocacy on behalf of those they care for without any particular training or formal recognition. Carers conduct unpaid advocacy because they have to in order to improve the support and inclusion of the person they care about and provide care for.

Acknowledging the role of carers and including them in service provision are key principles enshrined in the Statement for Australia's Carers in the Commonwealth *Carer Recognition Act 2010*. Among other provisions, the Statement includes the principles that:

- The relationship between carers and the persons for whom they care should be recognised and respected.
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

RECOMMENDATION:

Carers of people receiving benefits from Commonwealth subsidised aged care are given appropriate consideration in the guiding principles for the provision of advocacy and the objectives and aims of the programme.

2.3 Service delivery principles and priorities for an end-to-end aged care advocacy service model

Discussion questions:

- 2.3.1 Do these principles represent good practice for the programme?
- 2.3.2 Are there other principles or key priorities that are critical to the success of an end-to-end aged care advocacy service delivery model?

The principles harbour the potential to represent good practice but would be improved with more explicit acknowledgement of the roles and rights of carers in relation advocacy. Against this background it is important to take into account the following:

- Many older people, irrespective of their background, will have a carer who has a legitimate interest and role in facilitating, assisting or participating in advocacy.
- This interest is obvious in the context where formal care is provided in the home.
- However, the caring role does not necessarily cease when the older person enters residential aged care. Carers continue to be concerned about their family members and the care they receive. Especially when these carers have been caring for the resident prior to entry, they will have developed expertise in relation in the individual's personal preferences and care needs and may seek, on behalf of the resident, to convey concerns about care arrangements – not always with success.
- Many carers spend considerable time in the residential facility providing supplementary care and have first-hand experience of the quality of formal care provided.
- In other words, upon entry into residential care, the caring role often transforms from providing care to that of an unpaid advocate for the care of the older person.

The principles and priorities listed in the Options Paper must take these realities into account. Some particular examples include the following:

- **Consumer directed care and empowering those with cognitive decline** - For those who cannot communicate their own wishes adequately anymore – or who may feel uncomfortable complaining on their own behalf due to their necessary reliance on service providers and staff - the role of family and friend carers in advocating for their interests needs to be acknowledged.
- **Pro-actively engaging consumers** - Often carers form the link between the consumer and the advocacy service; identifying and contacting the advocacy service on behalf of the consumer. For example, family members of aged care consumers currently initiate many complaints to advocacy services run under NACAP, in some instances making up more than 70% of annual contacts (Carers Victoria 2011: *Discussion paper on Individual Advocacy and*

Caring Families, p17). Pro-active engagement must also be directed to carers and not only consumers.

- **Strengthening their capacities** - Needs to go hand in hand with strengthening the capacity of consumer’s immediate friends and family to advocate on their behalf when required.

We also note that the near-total absence of carers from the NACAP Policy Guide 2013-2015 is disconcerting. The only instance where the Guide mentions carers is in the context of culturally and linguistically diverse (CALD) clients:

“Services must meet the needs of older people from CALD backgrounds, their families and carers.”

Carers of all backgrounds should be seen as “partners in care” in the sense of the *Carer Recognition Act* mentioned above. They should also be regarded as “partners in advocacy”.

RECOMMENDATION:

The principles and priorities must reflect that family and friend carers seek expert advocacy assistance and advocacy capacity building on behalf of those they care for.

2.4 Objectives and Service Scope

Discussion questions:

- 2.4.1 Are these objectives appropriate for an end-to-end aged care advocacy model?
- 2.4.2 Are there other objectives that should be included?

NACAP is functioning well for those clients who access it, but could be better promoted. In order to achieve its objectives NACAP needs a high profile and a good reputation among older people and their carers.

In the past, aged care providers have refused representations by family members of clients because they did not possess a Power of Attorney. The lack of a Power of Attorney should not be used as a barrier to prevent carers from speaking up on behalf of their family members. Recent changes to the User Rights Principles and the Quality of Care Principles made under section 96-1 of the *Aged Care Act 1997* have curtailed the advocacy rights of carers in relation to service providers, because these changes have reduced the legal obligations of aged care providers towards representatives of their consumers. As a result, it becomes more important to support carers to work with funded advocacy services.

RECOMMENDATION:

The objectives should include the promotion of NACAP to all carers and family members of aged care service users, including carers of people living in residential aged care facilities.

2.5 Outcomes sought

Discussion questions:

- 2.5.1 Are there other outcomes that an end-to-end aged care advocacy service should aim to achieve?
- 2.5.2 Can these outcomes be effectively measured?

Many contacts with the NACAP are initiated by family members of aged care package consumers or facility residents, especially those on Level 4 packages and residents with dementia. However, in spite of this, the current guidelines for the NACAP preclude the family carer from complaining about their own treatment by the aged care provider. They are only able to make a complaint on behalf of the family member or friend they represent. This is highlighted in the unfortunately not uncommon example of a facility where there is disagreement or conflict between staff and family over the care of the resident and the management of the facility seeks to restrict visits by relatives or in extreme cases to 'ban' a relative from visiting at all. The NACAP is only able to address this from the perspective of the resident's right to receive visitors of their choice, not from the perspective of the family member's right to the continuation of their relationship with their relative.

Aged care providers need to address these issues with improved complaints management processes and staff training in good communication and working effectively with families to avoid conflict. The NACAP should have a role (in conjunction with Carer Associations) in this education.

RECOMMENDATION:

An additional outcome of an end-to-end aged care advocacy service should be that carers are able to receive advocacy support where the provider has not adhered to the principles of the Carers Recognition Act; such as demonstrating lack of recognition and respect for the relationship between carers and the persons for whom they care or failing to acknowledge the unique knowledge and experience of carers or to treat carers as partners with other care providers.

2.6 Eligible client populations

Discussion question:

- 2.6.1 Are there any anticipated problems with how eligibility is defined above?

The inclusion of representatives of consumers in the eligible client population needs to carefully balance the interests of the representatives with those of the people they represent and other stakeholders. A good definition of "representative" would safeguard against anticipated problems. We consider that the definition offered under section 5 of the Quality of Care Principles 2014 under section 96-1 of the Aged Care Act 1997, strikes the correct balance between these various interests:

“5 Meaning of representative

(1) In these principles, representative, of a care recipient, means:

- (a) a person nominated by the care recipient as a person to be told about matters affecting the care recipient; or
- (b) a person:
 - (i) who nominates himself or herself as a person to be told about matters affecting the care recipient; and
 - (ii) who the relevant approved provider is satisfied has a connection with the care recipient and is concerned for the safety, health and well-being of the care recipient

(2) Without limiting subparagraph (1) (b) (ii), a person has a connection with a care recipient if:

- (a) the person is a partner, close relation or other relative of the care recipient; or
- (b) the person holds enduring power of attorney given by the care recipient; or
- (c) the person has been appointed by a State or Territory guardianship board (however described) to deal with the care recipient’s affairs; or
- (d) the person represents the care recipient in dealings with the approved provider.

Note: Nothing in this section is intended to affect the powers of a substitute decision-maker appointed for a person under a law of a State or Territory.”

RECOMMENDATION:

Representatives of clients should be defined according to section 5 of the Quality of Care Principles 2014 made under the *Aged Care Act 1997*.

2.7 Service structure

Discussion questions:

- 2.7.1 Bearing in mind the trade-offs and benefits of each option in relation to efficiency, national consistency, access and flexibility to respond to local needs, which option is preferred or seen as achieving the most robust model?
- 2.7.2 In the preferred option, how can the trade-offs be minimised?
- 2.7.3 Are there other options to consider?

2.7.1: Retaining the current structure of separate jurisdiction-based organisations (Option 2) would continue to be the most efficient aged care advocacy service model. Sufficient (and increased) funding will be required by the current organisations to enable appropriate service delivery, tailored not only for special needs groups but also according to local need in rural and regional areas within each jurisdiction.

2.7.2: We think that any trade-offs would be minimised in Option 2 as the existing structure and expertise is being utilised and expanded on. This minimises the additional expenditure of setting up a new, single, national, centralised aged care advocacy service as proposed in Option 1. However, we believe that it is critical for our preferred option to be properly resourced and funded to be able to reach its full potential, being an inclusive national end-to-end aged care advisory service.