

Review of Commonwealth Aged Care Advocacy Services

Options Paper Feedback Form

1 Introduction

The options paper has been developed to explore and seek stakeholder feedback on a range of service delivery options for a nationally consistent, end-to-end aged care advocacy service focussed on individual support. It is being circulated to all informants who participated in the initial round of consultations and provides an opportunity for further input to the review process.

Please note that the scope of this review is focussed on existing aged care advocacy services and models of advocacy that focus on individual support. While the options paper considers other types of advocacy for the purpose of defining individual advocacy in the aged care setting, it should be noted that systemic advocacy is out of scope for a future aged care advocacy programme.

Have your say

Discussion questions from each section of the options paper are listed below. Please respond to these questions using this feedback form. Note that not all questions may be relevant to all stakeholders.

Please email your responses to advocacy@ahaconsulting.com.au

The closing date for submissions is 4 September 2015

If you have any questions about the options paper or the feedback process, please contact **Jill Waddell** or **Tracey Higlett** at Australian Healthcare Associates:

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Stakeholder responses to this options paper will be analysed and incorporated into a final report to be provided to DSS.

AHA thanks all stakeholders for their contribution to this review.

2 Future Options

2.1 Definitions of advocacy

Discussion question:

- 2.1.1 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?

It is essential for definitions of individual advocacy, undertaken on behalf of the consumer, to include the notion of free, prior and informed consent. While focusing on individual need, the definition should follow a more holistic approach, and include systemic advocacy, which, in turns, benefits individuals.

While advocacy is a short-term approach, it needs to have a goal of building capacity of individuals. Capacity building is extremely important for people from culturally linguistic and diverse (CALD) backgrounds who may not have knowledge of government systems and services. Self-advocacy is considered to be the most effective form of advocacy, and educating individuals about their rights and entitlements is vital.

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?

A framework must recognise various barriers to self-advocacy and address them accordingly. Achieving successful outcomes through self-advocacy is dependent upon the capacity of an individual to practice it through effectively representing themselves. However language barriers, cultural attitudes, limited experience of using complex service models in Australia, and negative experience prior to resettlement such as trauma may limit the capacity of people from CALD backgrounds to become effective self-advocates.

In certain countries making complaints against services rendered by various agencies or authorities, especially government agencies, is not a cultural norm. Thus, any measures adopted to educate the public should involve a thorough discussion of the right to complain about services and what complaint mechanisms are available to them. An effective advocacy framework plays a key role in empowering individuals to be proactive self-advocates, assisting individuals to navigate through the services available to them and educating them of rights, entitlements and complaint mechanisms. To assist with individuals who may have limited English language proficiency, information should also be provided about how to access translating and interpreting services, including the Translating and Interpreting Service (TIS National) administered by the Department of Immigration and Border Protection. This information should be easy to find and understand. It is necessary for the Framework to elaborate more on what measures can be utilised to build capacity and self-advocacy.

It is imperative for an advocacy framework to focus more on capacity building, self-advocacy and other advocacy tools which are key mechanisms of self-advocacy. Older people from CALD backgrounds, their

family members and carers must have a clear understanding of what amounts to an invasion of privacy, abuse, and neglect, rights and entitlements, which can be achieved through targeted education and awareness programs.

The 2011 Australian Census showed that over 1.34 million Australians aged over 50 were born overseas in a non-English speaking country. This represents almost 20% of all Australians in that age group, and although not all will need advocacy and assistance as they grow older, they represent a large group.

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?

It is essential that any government-funded aged care advocacy body be separate and independent, to avoid any issues pertaining to bias and/or conflict of interest.

With the implementation of the Consumer Directed Care approach in aged care, advocacy services must aim to support older CALD people to ensure they are empowered to make decisions about the care they receive and how their package funding is spent. This will become an even greater imperative when the system changes in February 2017 and the consumer will receive the funds directly to spend on care, and will be able to select different providers for different elements of their package.

The key principles listed in the discussion paper represent good practice, but FECCA would like to see an acknowledgement of particular considerations for older CALD people, who have unique barriers to overcome. While language is a major barrier to accessing information and services for some older CALD people, cultural beliefs and expectations may also be important barriers. While the particular situations, experiences and preferences of different CALD groups and individuals vary greatly, any advocacy framework must recognise the common challenges which FECCA's research shows exist for some older CALD groups, such as socio-economic disadvantage, language, cultural translation difficulties, lack of exposure to Australian services and systems, and lower rates of access to services.

See FECCA's *Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*, March 2015, available from www.fecca.org.au.

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?

The objectives as provided in the Discussion Paper are appropriate, however, they lack of any reference to people who may be more vulnerable and have a greater need for such advocacy services, including

older people from CALD backgrounds. FECCA believes the objectives should clearly recognise the importance of cultural sensitivities and cultural appropriateness of advocacy services, to assist minimising the barriers faced by older CALD people when accessing aged care services.

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?

The objectives as listed in the discussion paper are appropriate although they must incorporate cultural and linguistic considerations for older CALD people. For instance, the outcome ‘consumers are empowered to participate in decisions about their care, exercise choice and are supported in reaching their wellbeing and reablement goals’ would be greatly strengthened if it included words that acknowledged and supported the special needs of older CALD people.

A robust evaluation component must be included in any advocacy framework.

2.6 Eligible client populations

Discussion question:

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

Consumers may require advocacy services once in the system, and FECCA fails to understand why they have been excluded. This is particularly important with the Consumer Directed Care approach, where circumstances may change for consumers while receiving financial support.

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?

FECCA believes more detailed information is needed about the proposed options before one in particular can be selected, however we recommend evaluation of the current model as to its responsiveness. Any option must include nationally consistent advocacy services to support the needs of older CALD people, supported by language services when required.

2.8 Funding considerations

Discussion question:

2.8.1 What factors should be considered in developing a funding model for the advocacy programme?

For many CALD individuals, Australian laws, regulations and processes are different to those in their country of origin. Hence, having community organisations with people who understand the system is invaluable to individuals in accessing services.

Any funding model must ensure that the specific needs of older CALD people are catered for at no additional cost to the individuals, including the provision of language services when needed. It is imperative that advocacy bodies appreciate and understand the demographics in different States and Territories, and social and cultural sensitivities in diverse communities. Community organisations should be sufficiently funded to ensure that hard-to-reach vulnerable communities are properly assisted and heard in decision making processes.

Ensuring access and appropriateness for people from special needs groups

Discussion questions:

2.8.2 Are there other options to facilitate more effective access by special needs groups that should be considered?

2.8.3 Within special needs groups there are people who are more vulnerable than others. It could be argued that the particularly vulnerable are less likely to seek assistance and more likely to require it. What additional strategies could be put in place to identify those who are truly vulnerable?

It is key for advocacy services to collaborate and engage with specialist organisations working with and representing vulnerable people, with a view to enhancing understanding of factors amongst particular groups and individuals which may increase their risk. FECCA notes that building the capacity of groups that support older CALD people, such as multicultural and ethno specific community organisations will help to identify those who are vulnerable and support them through the aged care system.

Informal advocacy should be considered within the framework, as informal advocacy is particularly important in CALD communities. Measures could be adopted to educate CALD community leaders, family members and carers of older CALD people about relevant services, rights and entitlements. While we do not subscribe to a reliance on informal advocacy, it should still be recognised and supported.

Data collection and reporting should measure the performance and responsiveness of advocacy services for special needs groups, including older people from CALD backgrounds.

2.9 Interface with other services

Discussion questions:

- 2.9.1 Are there any key strengths of the NDAP that could be considered in a future aged care advocacy model or conversely from aged care advocacy within the NDAP?
- 2.9.2 Are there synergies and improved interactions between the existing programmes that should be considered?

FECCA provided a submission on the National Disability Advocacy Framework (available at www.fecca.org.au). It is essential that the design of these frameworks includes consultation with and participation by relevant stakeholders and peak bodies, to ensure culturally inclusive disability and aged care advocacy considerations.