

Department of Social Services
Review of Commonwealth
Aged Care Advocacy Services
Final Report
December 2015

Table of Contents

1. Executive summary	1
1.1. Overview	2
1.2. Summary of key findings.....	3
1.3. Options and considerations	4
2. Introduction	8
2.1. Aged care advocacy in Australia	9
2.2. Purpose of the Review	10
2.3. Overview of Review process.....	10
3. Background and policy context	14
3.1. Introduction	15
3.2. Commonwealth-funded aged care advocacy	15
3.3. Aged care sector changes	19
3.4. Future directions for advocacy in aged care.....	20
3.5. Learnings from the literature.....	20
4. Current aged care advocacy service provision	23
4.1. Introduction	24
4.2. Snapshot of aged care advocacy.....	24
4.3. NACAP-funded advocacy	27
4.4. CHSP-funded advocacy	46
4.5. Other aged care advocacy service models	47
4.6. Summary.....	48
5. Towards a national framework for aged care advocacy: Stakeholder perspectives	49
5.1. Introduction	50
5.2. Definitions.....	51
5.3. Service delivery principles and priorities.....	53
5.4. Outcomes sought, measures and continuous quality improvement	55
5.5. Advocacy objectives and service scope	57
5.6. Service structure considerations	58
5.7. Role of the Commonwealth government	63
5.8. Service promotion	63
5.9. Funding considerations.....	64

Table of Contents

5.10. Summary.....67

6. Conclusions, Options and Considerations 68

6.1. Summary of key findings.....69

6.2. Options and Considerations70

Appendix A. Terms of Reference for Review 74

Appendix B. Key Review Questions 77

Appendix C. List of Stakeholders Consulted 80

Appendix D. Previous Reviews of the NACAP 85

Appendix E. Learnings from the literature..... 88

Appendix F. Options Paper103

Appendix G. Stakeholder Workshop: Agenda115

Appendix H. Briefing Paper117

Appendix I. Workshop Summary Report121

List of Tables

Table 4-1: Overview of independent aged care advocacy organisations (at August 2015)	Error! Bookmark not defined.
Table 4-2: National NACAP funding 2010-11 to 2014-15	Error! Bookmark not defined.
Table 4-3: Issues and approaches to addressing special needs groups	Error! Bookmark not defined.
Table B-1: Key Review Questions	78

List of Figures

Figure 2-1: Review method summary	11
Figure 3-1: Commonwealth Aged Care Advocacy programmes	Error! Bookmark not defined.
Figure 4-1: NACAP national count of contacts and educational activities	29
Figure 4-2: Proportions of advocacy cases and general information enquiries 2009–10 to 2014–15	Error! Bookmark not defined.
Figure 4-3: All NACAP contacts by jurisdiction for the 2014–15 period	Error! Bookmark not defined.
Figure 4-4: Overarching categories of advocacy issues raised in 2013–14	Error! Bookmark not defined.
Figure 4-5: Types of advocacy issues nationally in 2013–14	34
Figure 4-6: Annual proportions of advocacy cases by residential and community care	37
Figure 4-7: Geographical location of national advocacy cases, information enquiries and face-to-face education sessions in 2014–15	38
Figure 4-8: Reported NACAP special needs group of care recipient nationally in 2014–15	Error! Bookmark not defined.
Figure 4-9: Special needs groups as a proportion of advocacy cases nationally from 2009–2015	41

List of abbreviations

Abbreviation	Definition
ACAT	Aged Care Assessment Team (known as Aged Care Assessment Service in Vic)
ACAS	Aged Care Assessment Service (Victorian ACAT)
ADACAS	ACT Disability, Aged and Carer Advocacy Service
ADRT	Aged and Disability Rights Team
AHA	Australian Healthcare Associates
ARAS	Aged Rights Advocacy Service
ACCS	Aged Care Complaints Service
ATI	Advocacy Tasmania Inc
CALD	Culturally and Linguistically Diverse
CDC	Consumer-Directed Care
CHSP	Commonwealth Home Support Programme
COAG	Council of Australian Governments
CSIA	Counselling, Support, Information and Advocacy
DCLS	Darwin Community Legal Service
DSS	Department of Social Services
ERA	Elder Rights Advocacy
HACC	Home and Community Care
HCP	Home Care Package
KPI	Key Performance Indicator
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
NACAP	National Aged Care Advocacy Programme
NDAP	National Disability Advocacy Program
NDIS	National Disability Insurance Scheme
OPAN	Older Persons Advocacy Network
PICAC	Partners in Culturally Appropriate Care
QADA	Queensland Aged and Disability Advocacy Inc
TARS	The Aged Rights Service Inc

1. Executive summary

1.1. Overview

Aged care advocacy services play a vital role in helping to uphold the rights of consumers of Australian - government-subsidised aged care services and support them to receive care that meets their needs. Demand for advocacy has increased as a result of Australia's ageing demographic profile and changes to the aged care system which centre on embedding greater consumer control and choice in aged care service provision.

Commonwealth funding for aged care advocacy services is provided by the National Aged Care Advocacy Programme (NACAP) and the Commonwealth Home and Community Care (HACC) Program (which transitioned to the Commonwealth Home Support Programme (CHSP) in July 2015).¹ In light of ongoing changes to the way that consumers interact with the aged care system, the Commonwealth recognised a need to consider how advocacy can best support consumer choice, decision making and the protection of consumer rights through a nationally consistent, end-to-end aged care advocacy programme, focused on individual advocacy support.

*'Difficulty in personally exercising rights should not mean that those rights no longer apply. Rather it means that some effective method of assisting the person to exercise their rights must be found. In practical terms the notion of an advocate or advocacy services is seen as one mechanism to meet their needs.'*²

Australian Healthcare Associates (AHA) was engaged by the Department of Social Services (DSS)³ in February 2015 to undertake a review of Commonwealth aged care advocacy services (the Review), which sought to:

- Explore how individual advocacy is currently being delivered across residential, home care and CHSP (formerly HACC) services (through the NACAP and CHSP advocacy)
- Consider what is working well, what could be improved, and current challenges and gaps
- Identify differing client needs, including those from special needs groups
- Define individual and independent advocacy service
- Consider how consumer choice, decision making and the protection of consumer rights can best be supported by a Commonwealth-funded individual advocacy programme.

¹ Throughout this report, the term 'CHSP advocacy' will be used to refer to advocacy services that transitioned from HACC Service Group 2 to the CHSP.

² C Ronalds, *Residents' rights in nursing homes and hostels: final report*, Canberra, Australian Government Public Service, 1989, pp 5-6.

³ The Ageing and Aged Care portfolio responsible for the Review transferred from DSS to the Department of Health in November 2015.

1. Executive summary

The Review was conducted using a mixed-methods approach, and included extensive stakeholder consultation comprising in-depth interviews, written responses to an Options Paper and a workshop to discuss options for a future advocacy model. AHA is grateful to all stakeholders who participated in the Review.

1.2. Summary of key findings

1.2.1. Current advocacy service provision

The Review identified the following points in relation to how advocacy services are currently being delivered:

- Variations exist in interpretations of the nature of advocacy work among aged care service providers, peak bodies, and even some services that report undertaking advocacy.
- NACAP activity data indicates that NACAP services are delivering a high volume of service with relatively low levels of funding. Variation in many aspects of service design and delivery between jurisdictions were noted. Due to the absence of outcomes data within the NACAP reporting system, it is not possible to draw conclusions on whether any services are delivering advocacy more efficiently than others. The Review was unable to undertake the same analysis for CHSP advocacy services due to the limited data available.
- NACAP providers endeavour to avoid waiting lists for advocacy and usually achieve this. To accommodate fluctuations in demand for advocacy, providers report that they adjust the number of education sessions or networking activities they undertake.
- The types of issues commonly addressed by NACAP providers include consumer rights, and level and quality of care. In CHSP advocacy, the scope is frequently broadened to include issues and factors outside of aged care (e.g. housing, transport, etc.).
- An increasing proportion of NACAP service is being delivered in community care settings, which is consistent with the Government's policy direction toward expansion of Consumer-Directed Care (CDC). NACAP services reported that advocacy cases relating to CDC are often complex and time-consuming.
- NACAP providers identified the following emerging challenges to delivering services:
 - Increasing demand for services
 - Increasing complexity of cases
 - Resource constraints (especially in providing access to rural and remote clients)
 - Growing concerns about elder abuse.
- Education and information sessions on consumer rights (targeting service providers and/or consumers) are a consistent and highly regarded feature of advocacy service provision. These sessions are noted to often result in consumers seeking advocacy assistance.

1. Executive summary

1.2.2. Stakeholder perspectives and priorities

The following themes emerged through consultations with advocacy providers, aged care service providers, peak bodies, government representatives and consumers:

- There is strong support for an integrated, end-to-end programme of aged care advocacy that supports consumers in their transitions through, and between, aged care services.
- Individual advocacy must be linked with, and inform, systemic advocacy processes in order to contribute to improvements in the aged care system.
- Existing independent advocacy services were recognised as providing a quality service to aged care consumers (within resource constraints).
- Some challenges in ensuring that all consumers can access advocacy were also identified, including challenges ensuring access to and appropriateness of services for people from special needs groups and other vulnerable populations, and geographical challenges related to Australia's size and population distribution.
- A key strength of the work undertaken by independent advocacy organisations is the development of local linkages with (and referral of consumers to) relevant peak bodies and other service providers. These networks play a particularly important role in supporting special needs populations.
- Opportunities exist to build consistency in the aged care advocacy service delivery model through the development of a national framework. Building consistency in aged care advocacy could drive service quality, national coverage and efficiency. However, national consistency should not be sought at the expense of local flexibility.

These findings are discussed in more detail in the main report.

1.3. Options and considerations:

Based on the findings of the Review process, the following options are presented for consideration by the Department in designing a nationally consistent, end-to-end aged care advocacy service model.

1. A National Framework for aged care advocacy

A National Framework for aged care advocacy could be developed to promote national consistency. The Framework could include:

- Definitions as described in *Section 5.2.1*
- Principles and priorities as described in *Section 0*
- Clear processes for data collection and reporting with tools to support providers to identify and report on outcomes
- A quality assurance process with a focus on continuous quality improvement. The process would need to consider options for mutual recognition of standards from other relevant program areas (e.g. Home Care Common Standards, National Standards for Disability Services) to minimise red tape and burden for service providers
- An approach for connecting with local stakeholders and service providers to optimise appropriate referral pathways, particularly for special needs populations

1. Executive summary

- Clearly articulated processes for interaction with other services, including the Aged Care Complaints Scheme (ACCS) and the National Disability Advocacy Program (NDAP)
- A set of competencies for aged care advocates to support recruitment, professional development and training (competencies developed by Advocacy Tasmania, and those included in the 2008 NACAP program materials, could be reviewed as a starting point).

2. A mechanism for coordinated action

Development of a formal alliance of advocacy providers could be considered, based on the model used by the existing Older Person's Advocacy Network (OPAN). The secretariat role for the alliance could rotate between group members in order to maintain independence from government.

Such an alliance could enhance national consistency by:

- Providing a forum for sharing information, resources, practices and learnings
- Enabling coordinated feedback to government around systemic issues and trends in relation to both advocacy and aged care service delivery
- Creating opportunities for professional development and training
- Strengthening relationships and networks with other stakeholders (including the ACCS, national peak bodies and aged care service providers).

3. Aged care advocacy model

The model of advocacy employed by the aged care advocacy programme should centre on issue-based, individual advocacy.

The model could include consideration of:

- The role of proactive/preventative advocacy and the benefits of low-level resolution of issues
- Ways to ensure that appropriate service options are available to meet the needs of individuals from special needs groups
- The importance of face-to-face interactions for many in the aged population, and particularly those from special needs groups
- The role that information provision and education plays in facilitating consumer choice and supporting self-advocacy as consumers transition through the aged care system
- Group advocacy in some circumstances where a number of people have shared issues (e.g. for some people from Culturally And Linguistically Diverse (CALD) backgrounds)
- The benefits of educating service providers about the rights of consumers (organisational advocacy)
- Expanded models of more intensive advocacy in specific cases (the Supported Decision Making model used by Advocacy Tasmania could be further explored with a view to expanding this initiative)
- The scope of issues addressed, for example, the feasibility of extending beyond those relating to aged care service provision to encompass other concerns that may affect the ability of CHSP or Home Care Package (HCP) consumers to continue living in their own homes (should they wish to

1. Executive summary

do so); where appropriate, advocacy services should refer consumers to other organisations with the requisite expertise (e.g. for financial or legal issues).

4. Service structure

The following factors could be considered in developing a future service structure (noting that the optimal number and spread of aged care advocacy organisations has not been determined):

- Aged care advocacy should ideally be provided independently from aged care services, due to the possibility of perceived/real conflicts of interest
- Independence from government and faith-based organisations should also be considered, in order to maximise acceptability
- Opportunities to increase national consistency in aged care advocacy could drive service quality, national coverage and efficiency, but should not come at the expense of local flexibility.
- A new aged care advocacy programme should, wherever possible, seek to build on existing expertise and networks with other organisations and services (including those involved with people from special needs groups)
- Options for maximising the geographical reach of advocacy services include:
 - Establishing multiple branch offices within advocacy organisations or co-locating advocacy outlets with other complementary organisations (including those appropriate to people from special needs groups)
 - Continuing support (and sufficient resourcing) for outreach visits by advocacy services to rural/remote areas.

Options provided in *Section 5.6.2* could be considered to ensure access to, and appropriateness of, advocacy services to people from special needs groups.

5. Service promotion

The advocacy programme could be branded as a national programme in order to increase visibility and minimise consumer confusion. Consistency of messaging in all communication materials developed under the national brand should be encouraged.

Given that lack of awareness of advocacy services, and misconceptions about the nature of individual advocacy can be key barriers to uptake, promotional materials should include a focus on educating the public about the role of advocacy in upholding consumer rights and the potential benefits of engaging with advocacy services.

The range of opportunities for promotion described in *Section 5.8* could be considered, including approaches to maximise access for people from special needs groups.

6. Funding considerations

Funding decisions for a future advocacy programme could take into account the following (noting that the funding model will largely be dependent on the agreed service structure — and, to some extent, vice versa):

- The predicted increase in the proportion, and absolute numbers, of people aged over 65 years of age is likely to drive higher demand for advocacy services. At a minimum, funding could

1. Executive summary

increase in line with these projections and inflation to maintain current service levels. In tandem, advocacy services may need to adapt their service models to meet growing demand

- Funding could include support for ongoing provision of educational activities (with service providers and consumers) as well as networking and proactive engagement with other organisations, as these are considered key to effective advocacy service provision
- The funding model should reflect the increased advocacy support that will be required to support consumers to exercise their rights to informed choice, given the expansion of community-based aged care and the roll-out of CDC
- The funding model should account for the proportion of special needs (including rural/remote) populations, because providing services to these groups is resource-intensive
- Given that a core aim of aged care advocacy is to support those who are ‘hard to reach’, particularly vulnerable, or with complex needs (and for whom advocacy support may be more resource-intensive), any efforts to drive efficiency should be balanced with the need to ensure quality, accessibility and responsiveness for all eligible consumers
- Regardless of the funding model, greater certainty around ongoing funding would assist organisations in forward planning and staff retention

2. Introduction

2.1. Aged care advocacy in Australia

The ageing Australian population and the associated increase in the prevalence of age-related mental and other chronic illnesses are set to put rapidly-increasing pressure on Australia's aged care system. In 2013–14, recurrent Australian Government expenditure on aged care programmes and services was approximately \$14.8 billion.⁴ It is estimated that by 2050 more than 3.5 million Australians will access aged care each year, with around 80 per cent of services delivered in the community setting.⁵

Against the backdrop of this demographic shift, the aged care system in Australia is undergoing significant change to ensure that the system:

- Is sustainable and affordable
- Offers choice and puts control back into the hands of consumers
- Encourages businesses to invest and grow
- Provides diverse and rewarding career options.⁶

From a consumer perspective, the changes centre on embedding greater choice, control and flexibility. This is being effected through:

- Recognising consumers as active partners throughout their aged care experience
- Empowering consumers to exercise individual responsibility in making decisions about their care
- Embedding a Consumer-Directed Care (CDC) approach to service delivery
- Incorporating a restorative approach, which focuses on wellness and reablement, as the key philosophy in the design of the Commonwealth Home Support Programme (CHSP).

The development of an independent aged care advocacy programme was recommended in Ronalds' 1989 report, which noted a range of barriers that residents of aged care services may experience in raising issues or concerns about their care.⁷ Since this time, independent aged care advocacy services have served a vital function in supporting the delivery of quality aged care services and assisting consumers to uphold their rights. Over time, the focus of aged care advocacy has broadened to include growing numbers of consumers receiving aged care services in their own homes.

In response to the aged care developments outlined above, the Government has signalled that the aged care advocacy system will require changes to optimally support consumer empowerment into the future. Government priorities for an end-to-end, individual aged care advocacy programme include:

- The provision of independent and individual advocacy support for consumers of residential, home care and CHSP aged care services
- Supporting consumers to exercise Consumer-Directed Care as well as be able to benefit from the CHSP restorative, wellness and reablement approach

⁴ Australian Institute of Health and Welfare, *Residential and Home Care 2013-14*, accessed 20 October 2015, <http://www.aihw.gov.au/aged-care/residential-and-home-care-2013-14/aged-care-spending/>

⁵ Australian Government Productivity Commission, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra, 2011.

⁶ Australian Government Department of Social Services, *Draft Commonwealth Home Support Programme Good Practice Guide for Restorative Care Approaches (incorporating Wellness and Reablement)*, DSS, 6 February 2015.

⁷ C Ronalds, *Residents' rights in nursing homes and hostels: final report*, Canberra, Australian Government Public Service, 1989.

2. Introduction

- Ensuring access for all consumers nationally
- Addressing current consumers' needs to assist them in making appropriate transitions through the system, while also ensuring that they continue to be supported, empowered and have their rights protected during ongoing change and within an evolving aged care system.

2.2. Purpose of the Review

AHA was engaged by DSS in February 2015 to undertake this Review in order to inform the development of a nationally consistent end-to-end aged care advocacy service model focused on individual advocacy support. The Review sought to:

- Explore how individual advocacy is currently being delivered across residential, home care and the CHSP (formerly HACC Service Group 2)
- Consider what is working well, what could be improved, and current challenges and gaps
- Identify differing client needs, including those from special needs groups
- Define individual and independent advocacy service
- Consider how consumer choice, decision-making and the protection of consumer rights can best be supported by a Commonwealth-funded individual advocacy programme.

The Terms of Reference for the Review are provided in *Appendix A*, and the key review questions are provided in *Appendix B*.

It is important to note that individual advocacy is only one element of a suite of possible and/or necessary supports to assist consumers to exercise choice and control in aged care services. This Review focused on informing an effective individual advocacy programme that will contribute to a broader approach to supporting consumer empowerment. This work is being pursued through the DSS Aged Care Sector Committee through its work on the Aged Care Roadmap.

A wide range of stakeholders has provided input to the Review, and AHA is grateful for their participation. A full list of participating organisations is provided in *Appendix C*.

2.3. Overview of Review process

The Review was undertaken between February and October 2015, and involved a mixed-methods approach to data collection and analysis, comprising:

- A literature scan
- Review of background documentation (including reports of previous reviews)
- Analysis of available advocacy service data for CHSP and NACAP providers
- A three-phase consultation process with a wide range of stakeholders to develop and discuss options for a future aged care advocacy model.

2. Introduction

The key steps are summarised in

2. Introduction

Figure 2-1: Review method summary

Method section	Description	Report
 Background review	<ul style="list-style-type: none"> • Programme documentation <ul style="list-style-type: none"> – Key directions for Commonwealth Home Support Programme discussion paper – NACAP annual data reports (2009–2014) & funding information – Evaluation of NACAP (2006) – Internal administrative review of the NACAP (2011) • Commonwealth HACC Service Group 2 report (produced by AHA in 2013) 	Chapters 3, 4
 Literature scan	<ul style="list-style-type: none"> • Identify service delivery models for advocacy in aged care and comparable sectors • Explore advocacy definitions 	Appendix E
 Activity analysis	<ul style="list-style-type: none"> • NACAP annual data reports* • CHSP advocacy activity informed by HACC CSIA/Non-output funding questionnaire responses[†] 	Chapter 4
 In-depth interviews	<ul style="list-style-type: none"> • Peak organisations/aged care providers (22) • DSS, including ACCS representatives (14) • NACAP service providers (9) • CHSP-funded advocacy providers (15) (Note: a number of NACAP services also deliver CHSP-funded advocacy) 	Chapters 4, 5
 Options development	<ul style="list-style-type: none"> • Paper outlining high-level options for a future advocacy model 	Appendix F
 Options consultation	<ul style="list-style-type: none"> • Stage 1: Invitation for written response to options paper <ul style="list-style-type: none"> – Written invitation to in-depth interview participants – Media release & options paper posting on DSS website – 49 responses received • Stage 2: Stakeholder workshop (Sydney 24/09/15) with 43 participants to discuss key themes and issues 	Chapter 5 Appendices G, H, I
 Analysis & reporting	<ul style="list-style-type: none"> • Activity data • Thematic data gathered through <ul style="list-style-type: none"> – In-depth interviews – Options paper submissions – Stakeholder workshops • Development of interim report (delivered 23/07/15) 	

2. Introduction

Figure 2-1: Review method su.

2. Introduction

Figure 2-1: Review method summary

Method section	Description	Report
 Background review	<ul style="list-style-type: none"> • Programme documentation <ul style="list-style-type: none"> – Key directions for Commonwealth Home Support Programme discussion paper – NACAP annual data reports (2009–2014) & funding information – Evaluation of NACAP (2006) – Internal administrative review of the NACAP (2011) • Commonwealth HACC Service Group 2 report (produced by AHA in 2013) 	Chapters 3, 4
 Literature scan	<ul style="list-style-type: none"> • Identify service delivery models for advocacy in aged care and comparable sectors • Explore advocacy definitions 	Appendix E
 Activity analysis	<ul style="list-style-type: none"> • NACAP annual data reports* • CHSP advocacy activity informed by HACC CSIA/Non-output funding questionnaire responses[†] 	Chapter 4
 In-depth interviews	<ul style="list-style-type: none"> • Peak organisations/aged care providers (22) • DSS, including ACCS representatives (14) • NACAP service providers (9) • CHSP-funded advocacy providers (15) (Note: a number of NACAP services also deliver CHSP-funded advocacy) 	Chapters 4, 5
 Options development	<ul style="list-style-type: none"> • Paper outlining high-level options for a future advocacy model 	Appendix F
 Options consultation	<ul style="list-style-type: none"> • Stage 1: Invitation for written response to options paper <ul style="list-style-type: none"> – Written invitation to in-depth interview participants – Media release & options paper posting on DSS website – 49 responses received • Stage 2: Stakeholder workshop (Sydney 24/09/15) with 43 participants to discuss key themes and issues 	Chapter 5 Appendices G, H, I
 Analysis & reporting	<ul style="list-style-type: none"> • Activity data • Thematic data gathered through <ul style="list-style-type: none"> – In-depth interviews – Options paper submissions – Stakeholder workshops • Development of interim report (delivered 23/07/15) 	

2. Introduction

Figure 2-1: Review method su

*NACAP activity data

NACAP services are required to submit annual activity data to DSS (now Department of Health) as a condition of funding. The following data for 2009-10 to 2014-15 has been reviewed and summarised in this report:

- Total contacts (comprised of advocacy cases and general information enquiries), including services provided to people from special needs groups, and geographical location of services provided
- Information/education sessions (for residential care facilities, aged care services providers, and directed to consumers/staff, etc)
- Types of issues raised through advocacy
- Referrals to the ACCS.

National NACAP funding amounts were also supplied.

†CHSP advocacy data (informed by HACC CSIA questionnaire)

In January 2015, DSS circulated a questionnaire to 356 HACC-funded organisations in order to obtain a clearer picture of activity funded under Counselling, Support, Information and Advocacy (CSIA) and 'non-output funding' (which may include funding for individual and systemic advocacy), ahead of the transition to the CHSP.

DSS collated responses to the CSIA questionnaire and forwarded them to AHA in order to characterise the advocacy activities undertaken with HACC/CHSP funding. It was not possible to develop quantitative summaries of the data provided through the CSIA survey due to inconsistencies in the data provided by respondents and the absence of clear definitions of advocacy within the questionnaire. Moreover, the response rate varied between jurisdictions. As a result, it has not been possible to develop a complete picture of HACC/CHSP-funded activity using this data source. However, in collaboration with DSS, and based on descriptions of the advocacy work undertaken, AHA identified a number of service providers to participate in consultations for the Review. Many of these service providers also participated in subsequent stages of the Review.

2. Introduction



3. Background and policy context

3.1. Introduction

This chapter provides an overview of Commonwealth aged care advocacy, along with a brief discussion of the policy context for the Review. It focuses on elements of the recent aged care policy changes that are of primary concern to aged care advocacy services.

3.2. Commonwealth-funded aged care advocacy

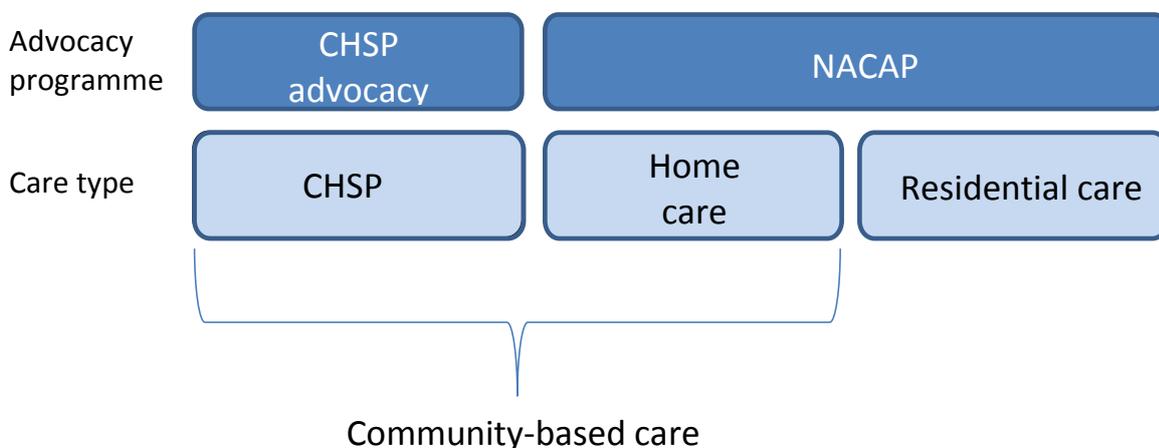
In recent years, advocacy services for consumers of Commonwealth-subsidised aged care services have been primarily provided through two programmes:

- National Aged Care Advocacy Programme (NACAP)
- CHSP (formerly the Commonwealth HACC Programme).

These programmes are described below. The NACAP provides advocacy for consumers of Home Care Packages (HCP) and Residential Care, whereas CHSP Advocacy serves clients receiving CHSP Services (as shown in **Error! Reference source not found.**).

These programmes are described below. The NACAP provides advocacy for consumers of Home Care Packages (HCP) and Residential Care, whereas CHSP Advocacy serves clients receiving CHSP Services (as shown in **Error! Reference source not found.**).

Figure 3-1: Commonwealth Aged Care Advocacy programmes



National Aged Care Advocacy Programme (NACAP)

3. Background and policy context

The NACAP was established in 1990⁸ and is funded under the *Aged Care Act 1997* and *Aged Care Principles 1997* to provide free, independent and confidential advocacy services to assist those receiving or seeking to receive Australian Government-subsidised aged care services (HCP and Residential Care). The NACAP is designed to support aged care consumers to exercise their rights through the provision of information, education and advocacy services. Nine state/territory-based organisations are funded under the NACAP. The programme objectives are to:

- Assist people receiving aged care services or their representatives to resolve problems or complaints in relation to aged care services, through the provision of advocacy
- Support people receiving aged care services to be involved in decisions that affect their life
- Provide people receiving aged care services with information and advice about their rights and responsibilities
- Promote the rights of people receiving aged care services to aged care service providers.⁹

In recent years, NACAP funding has increased in order to boost the capacity of services to address identified unmet needs, particularly those of Australians living in rural and remote areas and other 'special needs' groups.¹⁰ Details of the current operation of the NACAP (based on analysis of available activity data and stakeholder consultations) is provided in *Chapter 0*.

Special needs groups as defined in the Aged Care Act:

- People from Aboriginal and Torres Strait Islander communities
- People from Culturally and Linguistically Diverse (CALD) backgrounds
- People who live in rural and remote areas
- People who are financially or socially disadvantaged
- Veterans
- People who are homeless or at risk of becoming homeless
- Care-leavers (including Forgotten Australians, Former Child Migrants and Stolen Generations)
- Parents separated from their children by forced adoption or removal
- Lesbian, gay, bisexual, transgender and intersex people (LGBTI)
- People of a kind (if any) specified in the Allocation Principles.

The NACAP has been the focus of two evaluations. A 2006 evaluation made a number of recommendations in relation to management, monitoring and reporting. An internal review in 2011 focused largely on DSS grant management processes. Summaries of these evaluations can be found in *Appendix D*.

⁸ National Aged Care Advocacy Programme (NACAP) members, *By the consumers' side: National Aged Care Advocacy Program submission to the Productivity Commission Inquiry into Caring for Older Australians*, 2010.

⁹ Australian Government Department of Social Services, *National Aged Care Advocacy Programme (NACAP) Policy Guide 2013-2015*, DSS, 2013.

¹⁰ DSS, *NACAP Policy Guide 2013 – 2015*.

3. Background and policy context

3.2.1. CHSP-funded advocacy services

While NACAP-funded organisations provide assistance to those receiving residential care and HCPs, support for aged care advocacy is also provided separately through the CHSP (formerly HACC Programme), which provides for consumers requiring lower levels of support at home.

Within the HACC funding structure (prior to the transition to the CHSP), HACC Service Group Two explicitly included 'Counselling, Support, Information and Advocacy' (known as the 'CSIA' service type) for clients and carers. This service type was intended to help clients understand and manage issues associated with their transitions into and through the aged care system.

However, the activities that were categorised under the CSIA service type were not clearly defined within service guidelines, and the distinction between 'support', 'information' and 'advocacy' was somewhat unclear. A review of HACC Service Group Two undertaken by AHA in 2013 revealed that each state and territory had developed its own interpretations of the CSIA service type. Moreover, not all jurisdictions fund CSIA, and within those that do, the amount and nature of advocacy services provided was variable. This situation has continued with the roll-out of the CHSP, given that existing funding has been extended to 1 July 2016.

In many jurisdictions, funding for CHSP advocacy is provided to organisations addressing the needs of people with specific conditions (e.g. dementia) or special needs groups (e.g. people at risk of homelessness or CALD groups). However, it is not easy to establish whether the advocacy provided through these services is (a) focused on issues relating to aged care service provision; or (b) independent of other services delivered. It should also be noted that in a number of jurisdictions, NACAP-funded service providers also receive CHSP funding in order to provide advocacy services to CHSP clients.

As a result of these issues, it has not been possible to develop a distinct and comprehensive picture of CHSP advocacy. Most of the information about CHSP-funded advocacy contained within this report is based on stakeholder consultations, including those with a number of CHSP advocacy representatives identified through the HACC CSIA questionnaire (see *Section 2.3*).

3.2.2. Other advocacy services

A range of other advocacy services are provided at state/territory or local levels with variable funding sources and service delivery mechanisms. Such services are out of scope for this Review, as are legal aid and mediation services for seniors.

3.3. Aged care sector changes

This Review occurred at a time of widespread change to the aged care sector. The policy developments discussed below are key drivers for the development of an end-to-end aged care advocacy model.

3.3.1. Commonwealth Home Support Programme (CHSP)

From 1 July 2015, the CHSP consolidated the Commonwealth HACC Program, the National Respite for Carers Program (NRCP), the Day Therapy Centres (DTC) Program and the Assistance with Care and Housing for the Aged (ACHA) Program, to provide a comprehensive basic home support programme. This has further improved the interface between basic home support and other programmes in the aged care system. With the introduction of the CHSP, a number of changes were made to the way HACC services are funded and delivered. Of most relevance to this Review are:

- Changes to the delivery of services under HACC Service Group Two, including CSIA services, which included plans to transfer advocacy services to a single aged care advocacy programme following this Review,
- The cessation of funding for the 'Case Management' service type.

3.3.2. Home Care Packages: Introduction of Consumer-Directed Care (CDC)

Since 1 July 2015, all Home Care Packages have been provided on a CDC basis. CDC is designed to enable aged care consumers and their carers to exercise more influence over the design and delivery of the services. The approach seeks to empower consumers to make decisions about the services they receive and provide “a flexible and seamless system for more choice, control and easier access to a full range of services, where aged care recipients want it and when they need it”.¹¹

3.3.3. Focus on wellness and reablement

A key element of the aged care changes is a focus on wellness, reablement and restorative care. This focus – which is particularly pertinent to the CHSP – represents a shift from traditional models of care (in which it is assumed that an individual’s capacity will decline over time, leading to greater dependency) to one that actively promotes independence and emphasises ‘doing with’ rather than ‘doing for’. Ways in which advocacy services can align with this modern focus are considered in this report.

3.3.4. Other policy developments

At a broader level, the Australian Government is implementing a range of aged care changes to address current limitations in the system and keep up with the demands of a rapidly ageing population. These include:

- Significant expansions of home care to assist people to remain living at home and to introduce more choice and flexibility for people receiving HCPs through the CDC approach
- Changes to improve the fairness and sustainability of the aged care financing arrangements, with strong safeguards implemented to ensure access to care for those who cannot afford to contribute to the cost of their accommodation and care

¹¹ DSS, *NACAP Policy Guide 2013 – 2015*.

3. Background and policy context

- The commencement of the Australian Aged Care Quality Agency to monitor quality consistently across the sector
- Other initiatives to strengthen quality improvement processes within aged care services.^{12 13}

Further initiatives were introduced as part of the 2015 budget, including:

- Increased funding for HCPs, with individuals to control their own HCP funds and have greater control and choice over who provides their care (from February 2017)
- A single integrated care at home programme (combining the the HCP program and the CHSP) will be established (from July 2018)
- Responsibility for the ACCS shifting from DSS to the Aged Care Commissioner (from 1 January 2016)
- More funding for short-term restorative care
- Changes to the Quality Framework for aged care.¹⁴

3.4. Future directions for advocacy in aged care

With the increasing demand for aged care services and the shift towards CDC, advocacy support for those entering into or transitioning through the aged care system is vital. In 2011, the Australian Productivity Commission undertook an inquiry into Aged Care, *Caring for Older Australians*, and recommended the Australian Government fund an expanded system of individual aged care advocacy by (in the first instance) increasing funding and access to advocacy under the NACAP (Recommendation 9.4).¹⁵ This notion gained momentum through the CHSP development process, with calls for an end-to-end advocacy programme that explicitly and universally supports clients receiving Commonwealth-funded aged care services.

While individual advocacy forms a crucial part of the aged care system, it is only one element of a suite of possible and/or necessary supports to assist consumers with exercising choice and control in their service provision. The Aged Care Sector Committee, through its work on the Aged Care Roadmap, will consider what shape this additional consumer support might take.

3.5. Learnings from the literature

A literature scan was undertaken to inform the Review. A brief overview is provided here. A full account of literature scan findings is provided in *Appendix E*.

¹² Australian Government Department of Social Services, 'Ageing and Aged Care: What has been achieved so far', 12 October 2015, accessed 27 October 2015 < <https://www.dss.gov.au/ageing-and-aged-care-aged-care-reform/what-has-been-achieved-so-far>>.

¹³ Australian Government Department of Social Services, *Commonwealth Home Support Programme Manual (Draft for consultation as at 2 March 2015)*, DSS, Canberra, 2015.

¹⁴ The Hon Scott Morrison MP, 'Supporting Greater Choice for Older Australians (Media Release)', 12 May 2015, accessed 27 October 2015, <<http://www.formerministers.dss.gov.au/15486/supporting-greater-choice-for-older-australians/>> .

¹⁵ Australian Government Productivity Commission, 2011.

3. Background and policy context

The literature scan identified a number of key approaches to grouping and defining advocacy services. These included:

- Consideration of who the advocacy is for (e.g. an individual or a group)
- The capacity of the advocacy recipient (i.e. instructed or non-instructed advocacy)
- Who provides the advocacy (e.g. a trained citizen, a lawyer, the individual themselves)?
- The approach used to provide the advocacy (e.g. assistance, support/empowerment advocacy or representation);
- How the advocacy is funded (e.g. volunteer, paid).

Individual, systemic and group advocacy are key mechanisms for upholding the rights of consumers discussed most often in the literature, and other forms of advocacy described include family, self and informal advocacy.

Individual advocacy, as its name suggests, is provided to or on behalf of individuals, by individuals, in a one-on-one manner to support and promote the recipient's rights and interests. It can include a variety of approaches including:

- Assistance (e.g. accompanying people to meetings, helping them clarify and express goals and views)
- Support (e.g. helping a person to speak up or self-advocate)
- Representation (e.g. speaking for or acting on behalf of a person).

Provision of education and information are integral elements of individual advocacy.

Systemic advocacy, or public policy advocacy, attempts to influence change within the 'system' (i.e. government policies, regulations, provider systems and broader public attitudes and discourse), generally in response to a group's shared issues, needs or concerns.

Group advocacy (or collective advocacy) occurs when groups of individuals with common issues or concerns come together to enable mutual benefits.

Other models of advocacy have also been described, and these may have some relevance to the current exploration of aged care advocacy service models. These include citizen advocacy, family advocacy, legal advocacy, peer advocacy, professional advocacy and self-advocacy, and are outlined in the literature scan.

There is only a small volume of literature dealing with aged care advocacy specifically, and it is noted that there "is a lack of robust evidence-based research around 'what works' in relation to [information, advice and advocacy and] the literature...is rarely empirically grounded and therefore seldom offers robust evidence about whether or not these models actually 'work'".¹⁶ However, Action for Advocacy outline ten key themes for good practice in advocacy more broadly, which resonate with national and international policies and practices. These are: putting people first, empowerment, equal opportunity,

¹⁶ C Williams, J Harris, T Hind & S Uppal, *Transforming Adult Social Care: Access to Information, Advice and Advocacy*, Improvement and Development Agency, London, 2009.

3. Background and policy context

clarity of purpose, independence, accessibility, accountability, support of advocates, confidentiality, and a complaints mechanism.¹⁷

Potential funding scenarios for aged care advocacy include government, local administration of funds (e.g. from a pooled budget), a central body with specialist initiatives, multi-source funding (sought by service providers) and 'no strings attached' funding allocation.¹⁸ However, regardless of the funding source, independence from government as well as service providers has been highlighted as a key feature of some successful advocacy programs, such as New Zealand's Health and Disability Advocacy Service.¹⁹

¹⁷ Action for Advocacy, *Quality standards for advocacy schemes*, Action for Advocacy, London, 2006.

¹⁸ A Stewart & G MacIntyre, *Advocacy: models and effectiveness*, Institute for Research and Innovation in Social Services, Glasgow, 2013.

¹⁹ J Drage, 'New Zealand's national health and disability advocacy service: a successful model of advocacy', *Health and Human Rights: An International Journal*, vol. 14, no. 1, 2012.

4. Current aged care advocacy service provision

4.1. Introduction

This chapter provides an overview of how Commonwealth-funded aged care advocacy currently operates. It is informed by:

- Review of available NACAP data and relevant NACAP and CHSP advocacy information
- Stakeholder consultations (including with advocacy service providers, peak body representatives, aged care service providers and DSS representatives).

As noted in *Section 2.3*, while activity data were available for the NACAP, none were available for the CHSP. The information on CHSP advocacy activity is primarily informed by consultations with programme representatives identified through the CSIA questionnaire process as having relevant or promising models of individual/group advocacy. As such, there is an imbalance in the depth of information provided on current NACAP and CHSP advocacy service delivery. However, the emphasis on the NACAP within this chapter is not intended to suggest that NACAP providers, or the current NACAP model, will be prioritised above CHSP or other providers/models within a future national aged care advocacy system.

4.2. Snapshot of aged care advocacy

The Australian Government currently funds aged care advocacy services through the NACAP and the CHSP. NACAP services are provided by a single independent organisation in each state/territory (with the exception of the NT, where there are two NACAP providers).

Seven of the nine NACAP providers also deliver CHSP-funded advocacy (WA is funded through the WA HACC programme). CHSP advocacy is also provided by a variety of other organisations, including many that also receive CHSP funding to provide other aged care services and therefore may not necessarily be characterised as providing *independent* advocacy (see *Section 4.4* for further discussion of CHSP advocacy services).

Error! Reference source not found. provides an overview of the main Australian Government-funded independent aged care advocacy services in each state/territory at August 2015. Note that there may be other small, independent CHSP advocacy services that are not included in this overview.

4. Current aged care advocacy service provision

Table 4-1: Overview of independent aged care advocacy organisations (at August 2015)

Jurisdiction	Service provider	NACAP	CHSP	Other advocacy services	Reach
NSW	The Aged Rights Service Inc (TARS)	Yes	Yes	Also provides legal advice (through the Older Persons' Legal Service and the Retirement Village Legal Service)	Office in Sydney
VIC	Elder Rights Advocacy (ERA)	Yes	No	-	Melbourne office with travel out to rural areas
QLd	Queensland Aged and Disability Advocacy Inc (QADA)	Yes	Yes	Guardianship advocacy service (Legal Aid) State-based disability advocacy programmes	Main office in Brisbane with 7 regional offices. All staff do outreach trips
SA	Aged Rights Advocacy Service Inc (ARAS)	Yes	Yes	Retirement Village Advocacy Aboriginal Advocacy Programme	Office in Adelaide; staff do outreach work
WA	Advocare Inc	Yes	Yes	CHSP advocacy including Aboriginal Advocacy (note currently funded by WA state government) Elder Abuse Helpline	Perth office. Regional/remote areas serviced by week-long 'road trips'
TAS	Advocacy Tasmania Inc (ATI)	Yes	Yes	Older Persons Advocacy (CHSP & NACAP) National Disability Advocacy Programme External Merits Review for NDIA Mental Health and Alcohol and other Drugs Advocacy Elder Abuse Helpline	Offices in Hobart, Launceston and Devonport

4. Current aged care advocacy service provision

Jurisdiction	Service provider	NACAP	CHSP	Other advocacy services	Reach
NT Darwin	Aged and Disability Advocacy (ADAS) <i>Part of Darwin Community Legal Service (DCLS)</i>	Yes	Yes	National Disability Advocacy Programme Also provides a range of legal services	Based in Darwin Monthly visits Katherine Provide services across the Top End of NT (to Tiwi Islands)
Alice Springs	Catholic Care NT	Yes	No	-	Based in Alice Springs with extensive outreach work (from Katherine south to SA border)
ACT	ACT Disability, Aged and Carer Advocacy Service (ADACAS)	Yes	Yes	National Disability Advocacy Programme Mental Health Consumer Advocacy Programme	Office in Canberra 2 teams servicing different parts of the territory

4.3. NACAP-funded advocacy

4.3.1. Overview

The NACAP was established in 1990 and is funded under the *Aged Care Act 1997* and *Aged Care Principles 2014* to provide free, independent and confidential advocacy services to assist those receiving or seeking to receive Australian Government-subsidised HCPs and Residential Care.²⁰ The NACAP is designed to assist consumers or people seeking to receive aged care services to effectively access and interact with the aged care system and to exercise their rights by providing information, education and advocacy services.

4.3.2. Service delivery and reporting arrangements

Over its years of operation, the NACAP has been guided by a range of service delivery policies and other resources, including the *National Aged Care Advocacy Manual of Standards* (2007) along with a *Service Charter*, *Standard Intake Process*, and a set of *Core Competencies*.²¹

More recently, the level of national guidance to the NACAP has reduced, affording individual NACAP providers a greater degree of flexibility in addressing local needs. Currently, the strategic policy direction for the NACAP is primarily articulated in the *NACAP Policy Guide (2013–2015)*.²² This guide emphasises the delivery of services to people from special needs groups as defined in the *Aged Care Act* (see *Section 0*).

The *NACAP Policy Guide (2013–2015)* indicates that NACAP-funded services should provide high quality consumer-focused practices, and delivery must align with the Standard Funding Agreement that sets out the Key Performance Indicators (KPIs) and reporting requirements.

In addition, services produce a qualitative summary of ‘emerging trends’ in advocacy provision. This offers valuable information to monitor the impact of policy changes on advocacy service provision.

Through the *Policy Guide*, advocates are also encouraged to continue networking activities (supported via six-monthly network meetings and teleconferences) and to build relationships with the ACCS.

Although the core business of NACAP services is individual and organisational advocacy, the nine NACAP providers have established the Older Persons Advocacy Network (OPAN), through which they can undertake systemic advocacy around areas of common concern. OPAN also provides a forum for networking and discussion of common issues.

²⁰ NACAP members, *By the consumers’ side: National Aged Care Advocacy Program submission to the Productivity Commission Inquiry into Caring for Older Australians*.

²¹ Unpublished documents.

²² DSS, *NACAP Policy Guide 2013 – 2015*.

4. Current aged care advocacy service provision

4.3.3. Funding

Error! Reference source not found. shows the National NACAP funding between the 2010–11 and 2014–15 funding periods.

Table 4-2: National NACAP funding 2010-11 to 2014-15

Year	Total funding
2010–2011	\$3,122,771
2011–2012	\$3,036,118
2012–2013	\$3,096,231
2013–2014	\$3,789,787
2014–2015	\$3,789,787

As shown in **Error! Reference source not found.**, a 20 per cent increase in funding was provided to NACAP services from 2013—14. This funding was aimed at:

'boosting the capacity of NACAP providers to meet unmet demand for advocacy services, particularly in rural and regional areas of Australia ... [and] ... enable older people and their families to have a greater say in the way care is provided to them ... [and] ... support additional training sessions for aged care providers and their staff so that they can better understand and support the rights of aged care consumers from diverse backgrounds'.²³

²³ DSS, *NACAP Policy Guide 2013 – 2015*.

4. Current aged care advocacy service provision

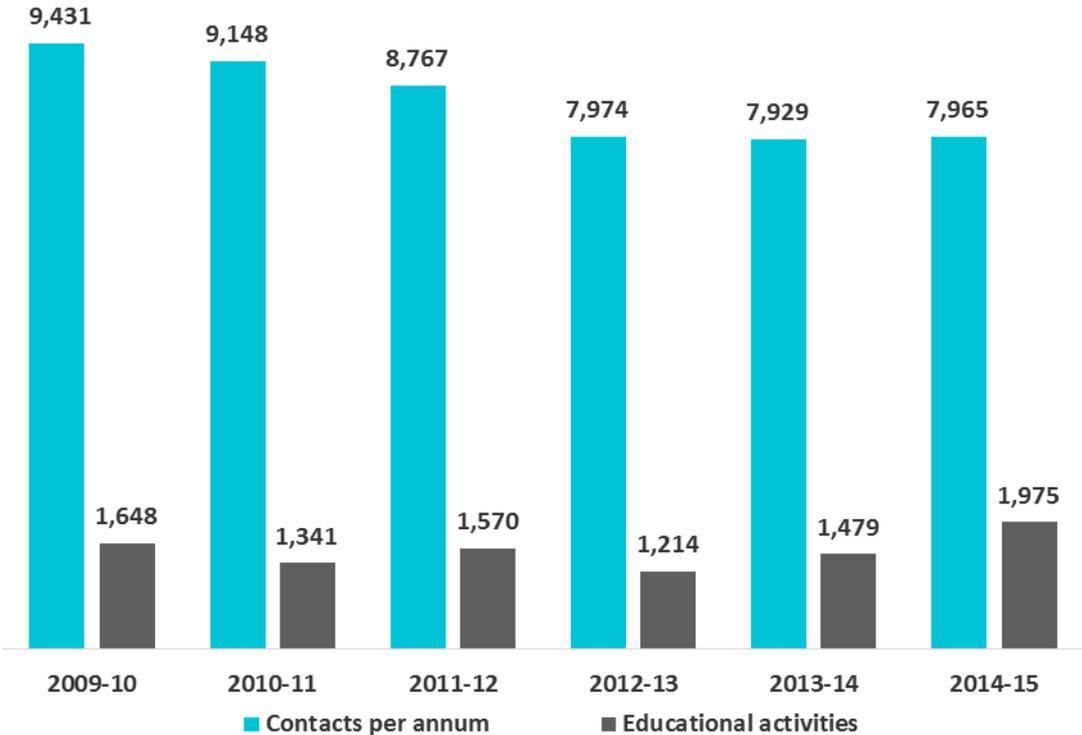
4.3.4. Overview of NACAP activity data

There are two main types of NACAP-funded activity:

- Contacts, comprising:
 - advocacy cases (note that no data were available on the amount of time/number of sessions etc. involved in advocacy cases)
 - general information enquiries
- Face-to-face education activities, comprising:
 - information sessions for aged care consumers
 - education sessions for aged care service staff.

As shown in *Figure 4-1: National count of contacts and educational activities*, at the national level, between 2009–10 to 2013–14 NACAP services experienced an overall decline in numbers of total contacts, with minor fluctuations in the number of educational activities. Between the 2013–14 and 2014–15 periods, increases in the number of contacts and educational activities were observed.

Figure 4-1: National count of contacts and educational activities

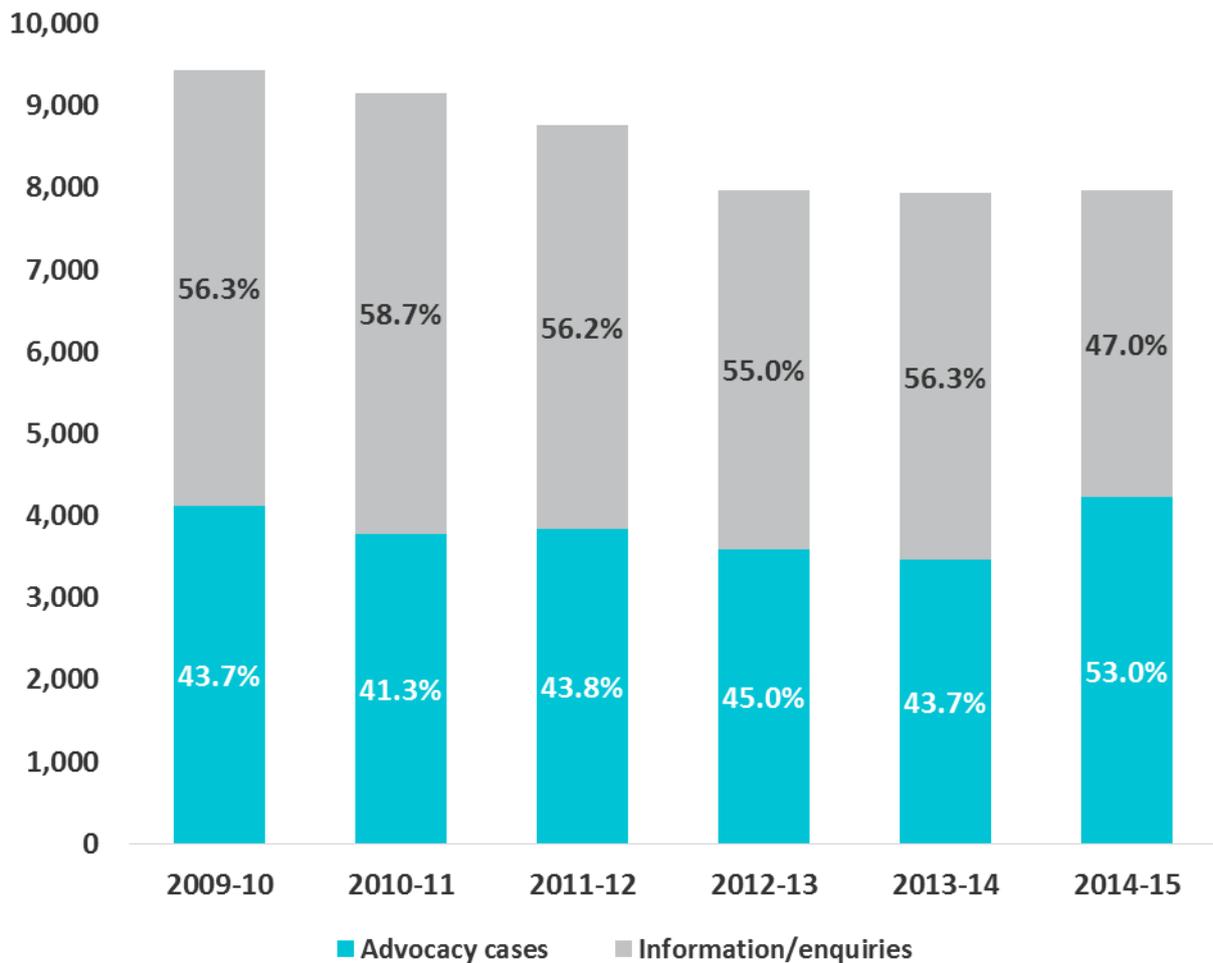


4. Current aged care advocacy service provision

Breakdown of advocacy cases and general information enquiries

Error! Reference source not found. shows the count of total contacts for each year between 2009–10 and 2014–15, split between advocacy cases and general information enquiries. The proportions of advocacy cases and general information enquiries has remained relatively steady over the six years, with the exception of 2014–15 in which a larger proportion of advocacy cases was reported.

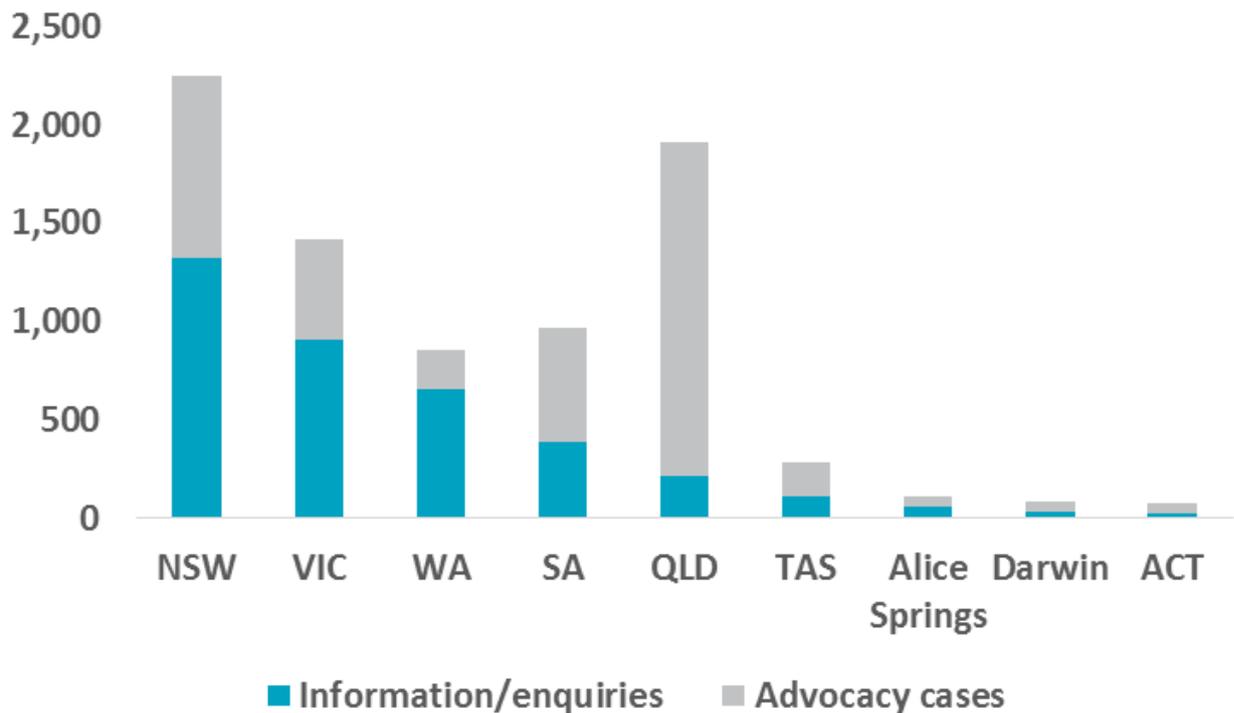
Figure 4-2: Proportions of advocacy cases and general information enquiries 2009-10 to 2014-15



4. Current aged care advocacy service provision

Error! Reference source not found. provides a breakdown of advocacy cases and general information enquiries across jurisdictions for the 2014–15 period. It reveals a high degree of variation between jurisdictions in terms of total contacts as well as the split between advocacy cases and general information enquiries.

Figure 4-3: All NACAP contacts by jurisdiction for the 2014-15 period



4.3.5. Variability in service design and delivery

There are some key differences in service design between NACAP providers. These differences are influenced by:

- The history of the organisation
- Other services offered by the organisation (e.g. legal aid services, disability or mental health advocacy)
- Resourcing
- Geography (e.g. proportion of rural/remote populations within the jurisdiction).

These differences are outlined in the following sections.

4.3.6. Service structure

As shown in **Error! Reference source not found.**, there is significant variability between the NACAP providers in terms of service structure and reach.

NACAP staff have indicated that they are able to support multiple offices provided they also receive funding to deliver other programs. It is reportedly not feasible for organisations that only receive

4. Current aged care advocacy service provision

NACAP funding (such as the Victorian NACAP provider (Elder Rights Advocacy)) to sustain more than a single capital city-based office with the funding available.

NACAP staff reported that the existence of regional offices improves access to services. This is not only due to physical proximity to consumers, but is also influenced by a perception that staff in the regional offices will better understand the needs of people in that region. For example, until 2000, Advocacy Tasmania had a single branch office in Hobart. They then expanded and established offices in Launceston and Devonport, as they recognised that, despite the small geographical size of the state, people from the North and North-West of the state were not likely to use services based in the South.

4.3.7. Staffing

Specialisation

There is variation in the number of advocates employed by the NACAPs across jurisdictions. In some jurisdictions, advocates specialise in either the HCP programme, the Residential Care Programme, or the CHSP (for those NACAPs delivering CHSP advocacy). Specialisation is justified by the providers on the basis that the regulations, networks and issues relating to each programme are unique. In other jurisdictions, advocates work across programmes, which is considered to assist with flexibility around staffing and to allow advocates to better support clients' journey and transitions through the aged care system. Commonly, the same NACAP staff provide individual advocacy services and deliver education sessions for consumers and staff.

Some jurisdictions employ advocates dedicated to working with Aboriginal and Torres Strait Islander, CALD (e.g. bilingual advocates) or LGBTI clients, which is noted to help with both access to, and appropriateness of, services.

Qualifications/background

The qualifications and backgrounds of advocates vary both within and between NACAP service providers and include psychology, social work, nursing, law and social science. A large number of these staff have worked within the NACAP services for many years and possess extensive knowledge, experience and skills in the delivery of advocacy services.

While there are no minimum qualification requirements, one NACAP provider indicated that a bachelor degree qualification is important in order to attain the respect of Nurse Unit Managers in residential care facilities.

A set of Core Competencies for Advocates was developed in 2008 as part of the programme guidance materials, and while it has not been updated, is still considered relatively accurate by the NACAP providers. Advocacy Tasmania has, however, more recently produced a set of competencies for recruitment and professional development purposes. This work has been undertaken independently of OPAN, and it is possible that other NACAP providers have undertaken similar processes (although no others were reported during consultations).

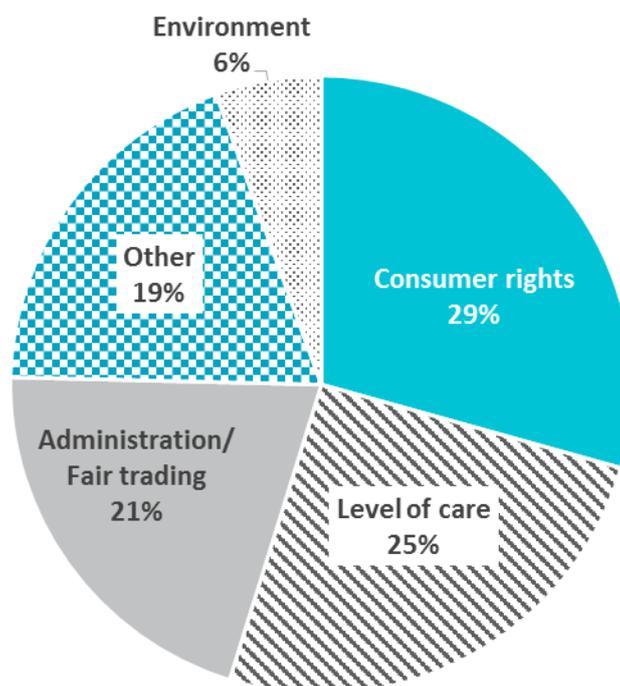
Professional development is generally approached on an individual basis, with advocates undertaking training according to perceived need and within resourcing constraints. Elder Rights Advocacy ensures that all advocates undertake mediation training as this has been identified as relevant to and beneficial for the role.

4. Current aged care advocacy service provision

4.3.8. Types of issues addressed

Detailed data on the types of issues addressed by NACAP advocates were not available for the 2014–15 period, but were for the preceding five-year period. **Error! Reference source not found.** shows that for 2013–2014, approximately one third of the issues raised pertained to consumer rights, one quarter to level of care and one fifth to administration and fair trading. This pattern was relatively consistent across previous reporting years.

Figure 4-4: Overarching categories of advocacy issues raised in 2013-14

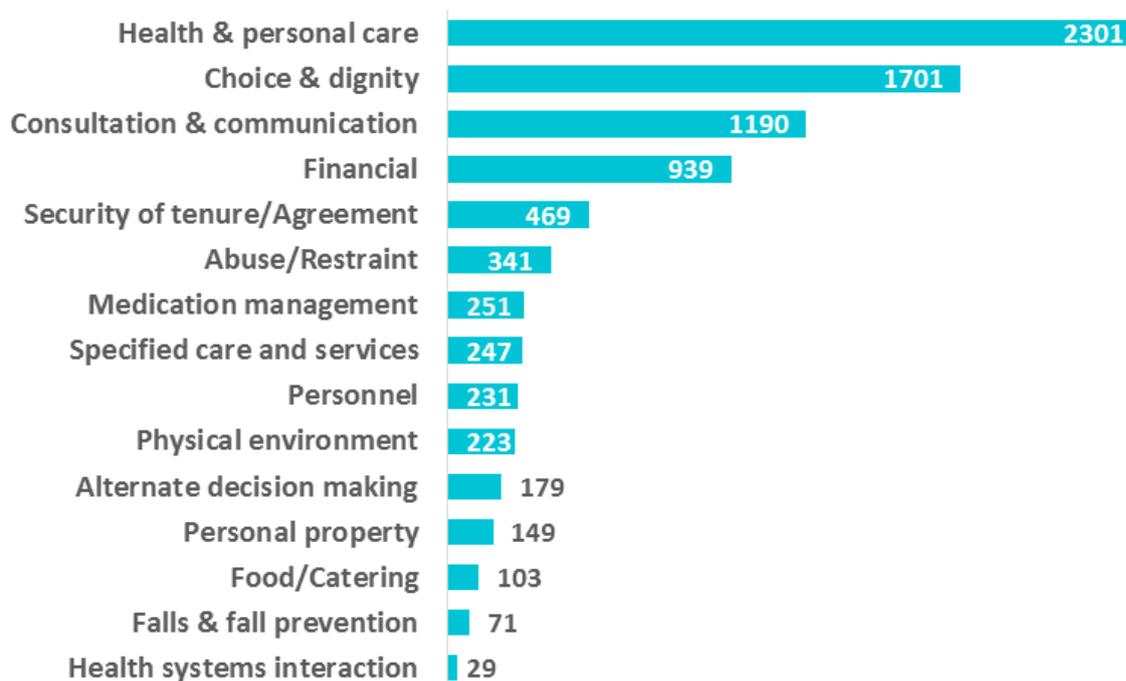


Advocacy issues were also recorded using a set of 72 more specific categories (which, due to the structure of the available data reports, do not represent sub-categories of the five broad areas in **Error! Reference source not found.**). The top 15 sub-categories of advocacy issue types recorded nationally in 2013–14 are displayed in *Figure 4-5: Types of advocacy issues nationally in 2013-14*

. Health and personal care, choice and dignity, and consultation and communication were the highest-ranking issues.

4. Current aged care advocacy service provision

Figure 4-5: Types of advocacy issues nationally in 2013-14



Consultations with NACAP representatives confirmed that a broad range of issues are dealt with in the course of their work, consistent with those shown in *Figure 4-5: Types of advocacy issues nationally in 2013-14*

. While the focus of all NACAP services is on upholding rights of consumers of aged care services, consultations with NACAP staff revealed some variability in the scope of issues addressed, as outlined below:

- While the NACAP documentation stipulates that services are available for ‘consumers or potential consumers of Australian Government-subsidised aged care, their representatives and their families’²⁴, there is lack of clarity around whether ‘potential consumers’ include only those assessed as eligible by an Aged Care Assessment Team (ACAT).²⁵ Most NACAP providers exercise flexibility in this regard.
- NACAP providers report that HCP consumers are increasingly requesting assistance in relation to CDC and that some of this assistance borders on legal advice. Those NACAP providers funded for legal services provide this advice in some instances, using staff from the legal services programs (but this is outside the formal remit of the NACAP).
- Some NACAP providers report spending a considerable amount of time assisting clients with filling out forms when entering or transitioning between services, especially for CDC agreements. There were mixed views as to whether this is within the scope of the programme.
- The level of general information provided to clients over the phone varies. Some NACAP providers offer a range of information about aged care service provision; others only offer information in relation to rights and responsibilities and refer clients to *My Aged Care* for more general information about the availability of aged care services.

²⁴ DSS, *NACAP Policy Guide 2013–2015*.

²⁵ ACATs are known as Aged Care Assessment Service (ACAS) in Victoria.

4. Current aged care advocacy service provision

- While the NACAP providers offer support in relation to CDC and residential care agreements, it is noted that the financial implications of the agreements are complex and usually necessitate referral to financial planning specialists.
- In the context of HCPs (and also for CHSP for those NACAP providers receiving CHSP funding), some advocates address issues not directly related to aged care service provision, but that may impact on consumers' ability to remain at home independently (e.g. accessing health services, housing issues, etc). ADACAS, for example, describes this work as 'reablement advocacy', acknowledging that this approach is feasible in the ACT because of the small size of the jurisdiction.
- Other (less common) issues addressed by NACAPs include assisting Aboriginal consumers to obtain identification documents or to return to country at end of life.
- In some instances, NACAP providers give advice and information to service providers in order to address situations in which service providers believe that the consumer's expectations are unrealistic. Problems are sometimes resolved by the advocate clarifying rights and responsibilities of both parties. The extent to which advocacy services work in this manner is influenced by the quality of the relationship between the advocacy service and the service provider. NACAP providers note that their independence from service providers also helps consumers accept the information they provide.

The scope of work undertaken by NACAP providers appears to be influenced by the existence of, and ease of referral to, other services. For example, the NACAP provider in Central Australia reported helping clients with a range of needs, including filling in forms for banking, accessing primary healthcare services and, in cases where housing quality is poor, helping clients address basic hygiene needs. This work is done because 'there is no one else who will do it'. While this approach is driven by a strong commitment to social justice, it is not within the current scope of NACAP as articulated in the policy documentation.

4.3.9. Focus on education and information sessions

All NACAP providers undertake information sessions (with residents/consumers) and education sessions (with staff) of aged care services. Nationally in 2014–15, three quarters of all education activities provided by NACAP providers were to residents (40%) and staff (36%) in aged care homes. Less than one quarter of all face-to-face educational activities in the 2014–15 period were delivered to staff and consumers of community care.

According to NACAP service staff, the ability to undertake educational activities is largely influenced by resourcing and geography. For example, Advocare (WA) staff explained it can take several months to arrange a visit to remote communities (in small planes at high cost) and that trips are sometimes cancelled at short notice due to bad weather or because of issues within the communities, such as 'sorry business'. In central Australia, the sole NACAP advocate is not permitted to travel to remote communities alone for safety reasons, so needs to wait until another service provider is also making the trip (e.g. an advocate from the NDAP). Advocates maximise the value of this travel by visiting as many services/clients as possible, but there can be logistical problems such as finding accommodation.

ADACAS (ACT) staff acknowledged that they have no such challenges due to the small size of the jurisdiction. As a result, they are able to visit facilities more frequently than required by their NACAP funding agreement, which enables the advocates to develop strong working relationships with the service providers.

4. Current aged care advocacy service provision

One rural Victorian stakeholder (not affiliated with Elder Rights Advocacy) noted that the geographical challenges of meeting the needs of the rural population in that state were often underestimated. While not as large or sparsely populated as other states, geography and the metropolitan-based nature of advocacy services still presented considerable barriers to providing face-to-face educational support.

While the NACAP providers report being generally well-received by service providers, they also report some instances of mistrust, and occasions in which staff did not have time to speak with them or were not receptive due to work demands. One advocate noted that some facilities *'only contact us when accreditation is coming up'*.

NACAP providers also highlighted that conducting information sessions with residents of aged care facilities can be challenging because it can be difficult to get a significant number of residents together at the same time due to mobility problems, sleep or health issues. Some advocates 'walk the floor' and speak to residents in their rooms to overcome this problem. A number of advocates reported that they usually stay for some time after the information session is finished, as residents often raise issues individually at this time. This approach is considered valuable because it helps to 'uncover' issues that would otherwise not be identified (as residents may not feel the issue is serious enough to phone an advocate, or because they weren't aware of the service). Several advocates acknowledged the importance of spending time talking informally with residents, because *'the initial issue raised is often not the main issue'*.

4.3.10. Advocacy consumer characteristics

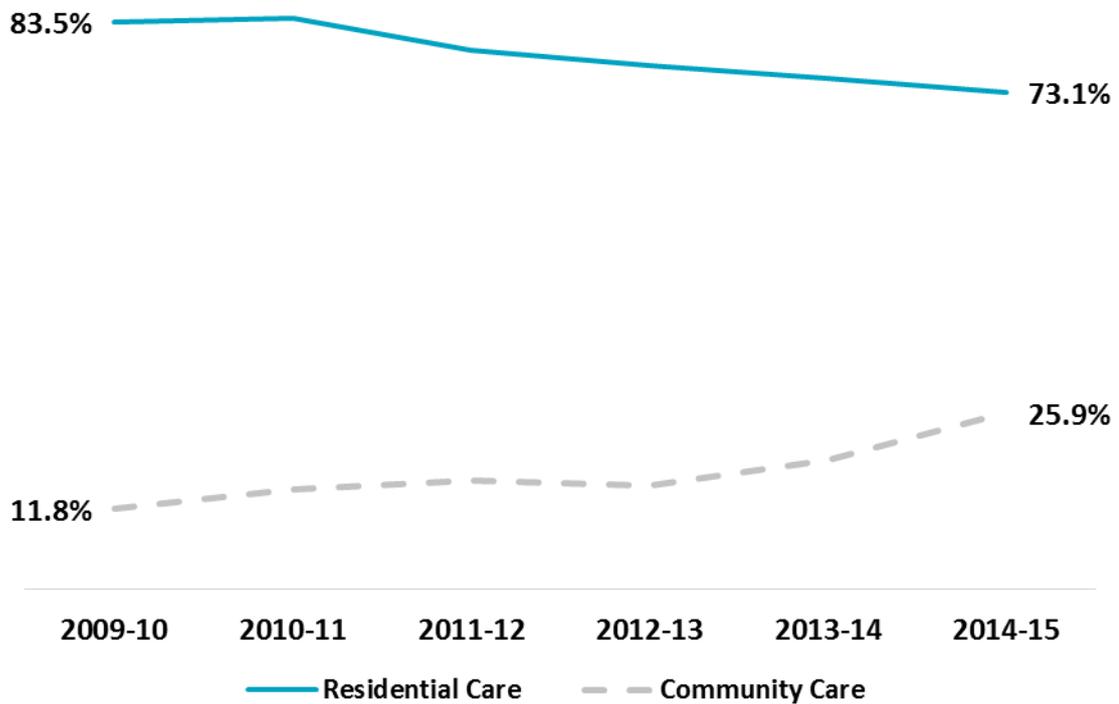
Type of aged care being received

Over the period from 2009–10 to 2014–15 there was a 10.4% decrease nationally in advocacy cases for those receiving residential care and a 14.1% increase for those receiving community care (see *Figure 4-6: Annual proportions of advocacy cases by residential and community care*

). Notably, between 2013–14 and 2014–15 there was a 66% increase in the number of advocacy cases for those receiving community care. It is possible that the increase in community-based advocacy work has been driven to some extent by the introduction of CDC. This is consistent with reports from NACAP providers that CDC has increased demand for advocacy support and that queries in relation to CDC are often complex and time-intensive. 'Emerging trends' data submitted by NACAP providers notes a range of advocacy issues arising from CDC, including administration costs imposed by providers, reductions in care hours, inadequate communication/explanation about contracts, and requests from consumers to change providers.

4. Current aged care advocacy service provision

Figure 4-6: Annual proportions of advocacy cases by residential and community care



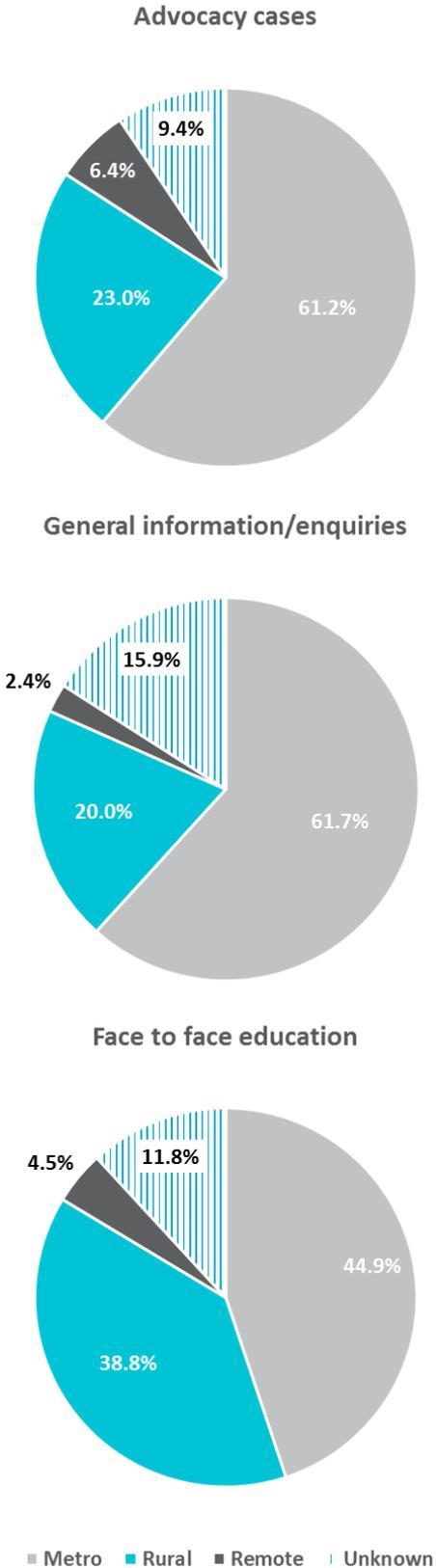
Note: This chart does not include the small proportions attributed to 'flexible', 'unknown' and 'not specified' categories.

Geographical location (of consumers)

In 2014–15, NACAP providers delivered advocacy services across metropolitan, rural and remote settings, as shown in *Figure 4-7: Geographical location of national advocacy cases, information enquiries and face-to-face education sessions in 2014-15*. It is not possible to compare this with previous years because of changes in the way data was collected.

4. Current aged care advocacy service provision

Figure 4-7: Geographical location of national advocacy cases, information enquiries and face-to-face education sessions in 2014-15



Note: Data on the geographical location of NACAP contacts for ADACAS (ACT) was not available for 2014–15.

4. Current aged care advocacy service provision

4.3.11. Service access and promotion

The NACAP providers use a range of approaches to promote service access, including:

- **Phone:** All NACAP providers have a formal intake system through which consumers are either provided with information over the phone or allocated an advocate. All services strive to avoid waiting lists *'as this is contrary to the consumer's rights'*, and inappropriate in crisis situations. If advocacy is required this is, wherever possible, conducted face-to-face.
- **Website:** Some consumers access NACAP providers via the organisations' websites, although differences in levels of sophistication of websites are noted.
- **Referrals** from:
 - **My Aged Care** call centre or website
 - the **Aged Care Complaints Scheme** (rare)
 - **other service providers** ('warm referrals')
- **Incidental contact:**
 - At information/education sessions (written resources are also distributed at these events)
 - Contact arising from NACAP providers' attendance at community events or expos.

Barriers to access

NACAP providers and other stakeholders have identified a range of barriers to access the NACAP, which include:

- A lack of awareness of the existence of the NACAP
- Limited understanding of what advocacy services are or how they can help (e.g. advocacy is commonly equated with legal services or 'lobbying')
- Problems with phone communication (e.g. hearing impaired, CALD, dementia)
- Reluctance to *'tell my story to a stranger'*
- Hesitance to raise issues for fear of being seen as a 'trouble-maker' or fear of retribution from service providers
- Technological/communication barriers – both for web-based information and, in some cases, phone-based (e.g. where there is a misconception that calls to NACAP providers will incur long-distance charges from a rural area)
- A fear of potential consequences of disclosing information (especially financial) to an organisation that may share it with other (government) agencies (e.g. fear that information disclosed to an advocate will affect an individual's pension).

NACAP providers work to facilitate multiple channels for access to assist in overcoming barriers to access.

4. Current aged care advocacy service provision

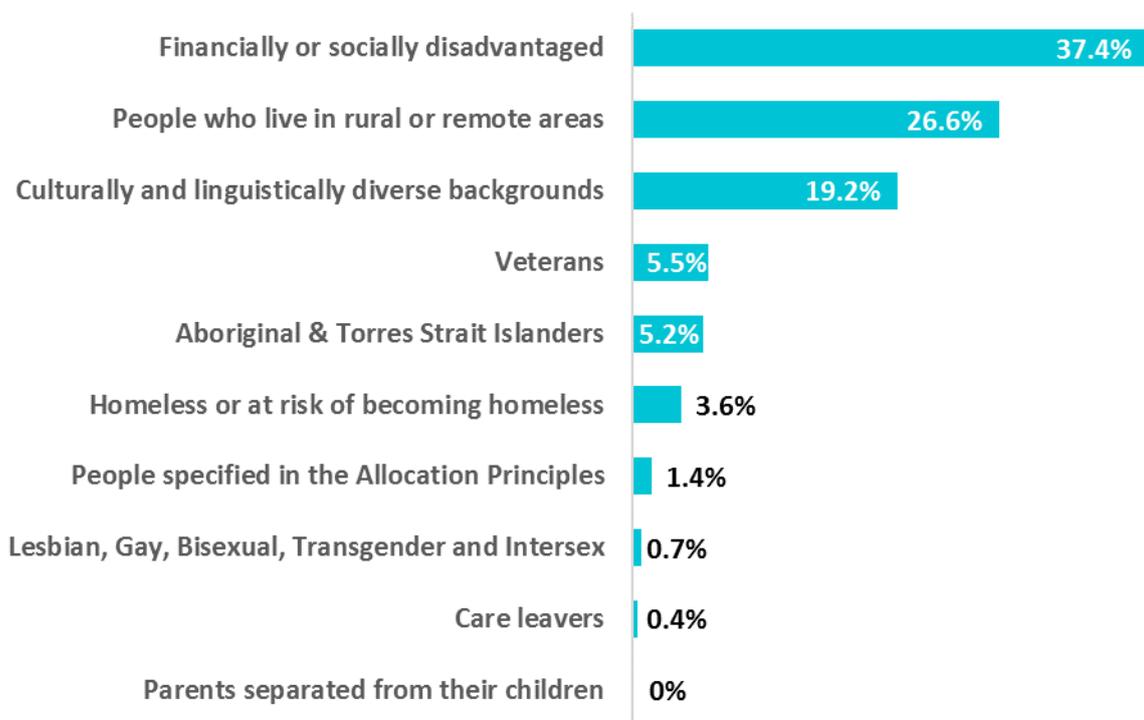
4.3.12. Approach to engaging with consumers from special needs groups

Stakeholders noted that the barriers described above are amplified for people from special needs groups. Most stakeholders believed that NACAP providers were working hard to engage with special needs groups, as evidenced through development of networks and involvement in consortia and working groups (including developing relationships with CHSP-funded service providers).

The NACAP providers collect information on special needs groups for advocacy activities only (i.e. not for general information enquiries or for educational activities).

The ten categories of special needs groups collected during the 2014–15 period are shown in **Error! Reference source not found.** (note that care recipients with disabilities and/or dementia were included in the category ‘People specified in the Allocation Principles’).

Figure 4-8: Reported NACAP special needs group of care recipient nationally in 2014-15



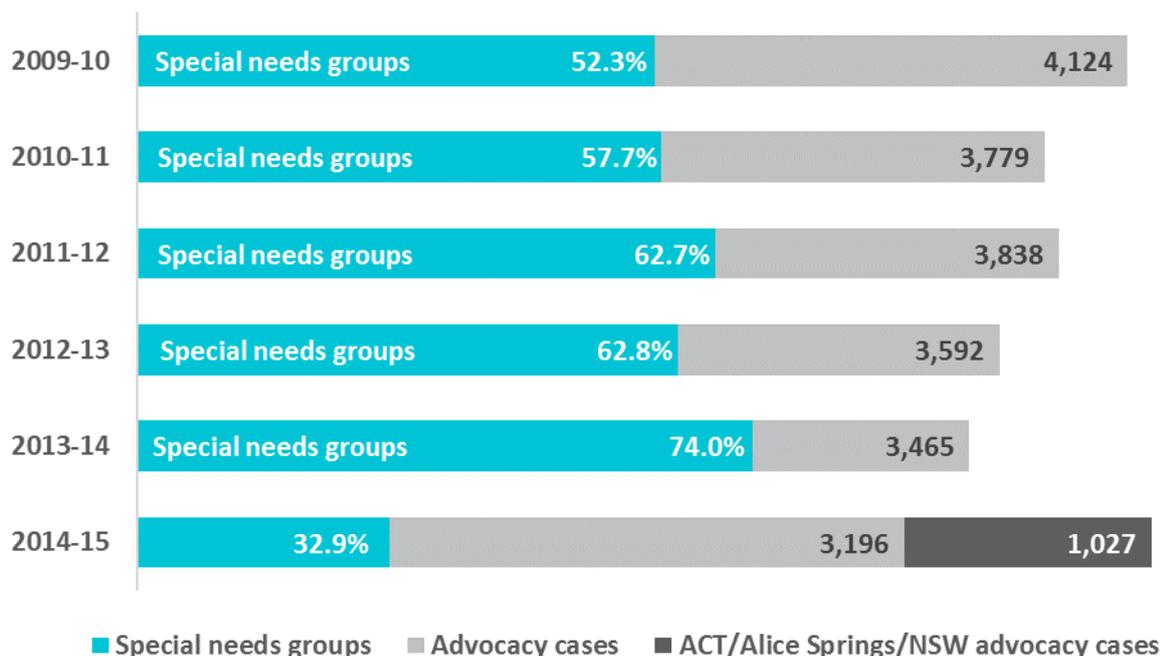
Note: Data on the special needs groups of care recipients for ADACAS (ACT) was not available for 2014–15.

The proportion of advocacy cases delivered to consumers from special needs groups also appears to have increased year on year between 2009–10 and 2013–14, as shown in *Figure 4-9: Special needs group as a proportion of advocacy cases nationally from 2009-2015*

(noting the 201415 data should be interpreted with caution). This suggests that individuals from special needs groups were either disclosing this information more readily, more easily identifiable, recorded more accurately in the NACAP data or sought advocacy services more often. It is also possible that as more categories of special needs group were added to the reporting framework (increasing from five to ten between 2009–10 and 2014–15), ‘special needs’ encompassed a greater proportion of the population.

4. Current aged care advocacy service provision

Figure 4-9: Special needs group as a proportion of advocacy cases nationally from 2009-2015



Notes:

- The count of advocacy cases nationally and special needs groups in 2014–15 excludes data from the ACT as it was unavailable, and Alice Springs and New South Wales due to inconsistencies in methods for recording special needs groups.
- The 2014–15 data on special needs groups should be interpreted with caution. During this period, jurisdictions used differing methods to record data pertaining to consumers in special needs groups. At least two jurisdictions reported that clients were counted in more than one category of special needs group (which inflated the total proportion of special needs groups consumers) and the method for counting special needs groups was modified mid year by one of the NACAP services.

While NACAP providers employ a range of strategies to reach people from special needs groups, some peak body representatives felt that effective engagement with special needs groups is beyond the capacity of the NACAP providers because of the time it takes to develop trust relationships with individuals and organisations, and the importance of face-to-face contact. Some peak body representatives described the NACAP providers as ‘too mainstream’ and not having the specialist knowledge and experience required to effectively engage with special needs groups.

Some of the issues raised by stakeholders in relation to each special needs group are outlined in **Error! Reference source not found.** When considering special needs groups, stakeholders stressed the importance of acknowledging the ‘diversity within the diversity’ (i.e. that the umbrella of ‘CALD’, for example, does not account for ethno-specific considerations). While these issues and strategies were raised primarily in relation to the NACAP, they are also consistent with the experiences of providers of CHSP-funded independent advocacy.

Table 4-3: Issues and approaches to addressing special needs groups

Special needs group	Key issues in relation to aged care services	Approaches used by NACAP and CHSP independent advocacy providers
---------------------	--	--

4. Current aged care advocacy service provision

Special needs group	Key issues in relation to aged care services	Approaches used by NACAP and CHSP independent advocacy providers
Aboriginal and Torres Strait Islanders	<ul style="list-style-type: none"> • Discrimination (real/perceived) • Reluctance to engage with mainstream services • Concerns about culturally appropriate aged care • Distrust of government • In some cases issues are compounded by living in rural/remote areas and complex social situations 	<ul style="list-style-type: none"> • Linkages/networks with Aboriginal community organisations for referral and promotion • Some NACAP organisations have Aboriginal advocates on staff
People from CALD backgrounds	<ul style="list-style-type: none"> • For some cultures, traditional reliance on family to provide aged care • Reluctance to 'speak up' or 'cause trouble' • Concerns about culturally appropriate aged care • Miscommunication (due to lack of English and/or cultural differences in use of language) 	<ul style="list-style-type: none"> • Many NACAP providers produce written resources in a number of languages other than English, as well as in braille • NACAP providers have access to interpreters (note that the time and cost involved in arranging an interpreter is seen by some as a barrier) • Networks and linkages with CALD community organisations for referral and promotion. Several NACAP providers receive regular in-house training from these organisations. • Some NACAP providers have advocates who work primarily with CALD clients (but ethno-specific advocates are rare) • Some NACAP providers have bilingual advocates
People who live in rural and remote areas	<ul style="list-style-type: none"> • Distance from advocacy services • Limited options in relation to aged care services and other social services • More limited access to web-based and tele-communications 	<ul style="list-style-type: none"> • Regionally based offices • Outreach to rural and remote areas • Referrals from other service providers servicing remote locations

4. Current aged care advocacy service provision

Special needs group	Key issues in relation to aged care services	Approaches used by NACAP and CHSP independent advocacy providers
People who are socially and financially disadvantaged	<ul style="list-style-type: none"> Financial barriers to accessing services Reluctance to access services 	<ul style="list-style-type: none"> NACAP service providers work to reach socially isolated consumers through community information activities but note that this group is difficult to link in with service provision No special approach to working with financial disadvantaged people is used, since a large proportion of consumers fall under this category
Veterans	<ul style="list-style-type: none"> Complex health and psychosocial issues 	<ul style="list-style-type: none"> Veterans are usually catered for in the course of standard service provision — no specific approaches identified
People who are homeless or at risk of becoming homeless	<ul style="list-style-type: none"> Difficulty/reluctance to engage with aged care services Often complex social/health issues Discrimination (real/perceived) 	<ul style="list-style-type: none"> Linkages/networks with services working with homeless people (e.g. Wintringham in Victoria) <p>NOTE: It is widely acknowledged that people who are homeless or at risk of homelessness are highly unlikely to have the capacity to contact NACAP providers without the help of service providers.</p>
Care-leavers (including Forgotten Australians and Former Child Migrants)	<ul style="list-style-type: none"> Lack of consideration (perceived/real) about implications of childhood experience on aged care experience (particularly residential care) Complex social, emotional and physical issues resulting from impacts of childhood experiences Some current aged care providers were also providers of out-of-home care (e.g. church-based organisations) 	<ul style="list-style-type: none"> NACAP providers acknowledged that they had not done a lot of work with care leavers at this stage. If required they would build linkages/networks with services working with care-leavers <p>NOTE: NACAP providers do not ask whether consumers are from this special needs group unless the consumer chooses to disclose this information.</p>
Parents separated from their children by forced adoption or removal	<ul style="list-style-type: none"> Reluctance to engage with/distrust of the healthcare/social services sector due to past experiences 	<ul style="list-style-type: none"> NACAPs acknowledge that they have not done a lot of work with this particular group. As needed, linkages/networks could be built with services working with care-leavers <p>NOTE: NACAP providers do not ask whether consumers are from this special needs group unless the consumer chooses to disclose this information.</p>

4. Current aged care advocacy service provision

Special needs group	Key issues in relation to aged care services	Approaches used by NACAP and CHSP independent advocacy providers
Lesbian, gay, bisexual, transgender and intersex people	<ul style="list-style-type: none"> • Discrimination (real/perceived) • Lack of awareness of rights and services to uphold them • Lack of recognition of discrimination • Not wanting to 'make trouble' 	<ul style="list-style-type: none"> • Some NACAP providers have a special interest in working with this group • Networks/linkages with LGBTI consumer groups/peak bodies (several NACAP providers receive regular in-house training from these groups/bodies)
People with dementia	<ul style="list-style-type: none"> • Vulnerable group with complex and changing needs 	<ul style="list-style-type: none"> • Network/linkages with dementia specific organisations • Advocacy work may involve working more directly with the carer or family members • In some jurisdictions specialised dementia advocacy programmes have been undertaken (e.g. Advocacy Tasmania's Supported Decision Making pilot programme)

4.3.13. Reporting and quality

The NACAP providers feel that their reporting obligations to DSS are not onerous, but question whether they are particularly valuable. Several noted the importance of having the opportunity to provide more detailed information on emerging issues in relation to aged care service quality, and the effect of policy changes, and suggested that mechanisms for this feedback could be improved.

Currently, NACAP providers are required to report on outputs only, rather than outcomes of their activities. Despite this, individual services have a number of approaches for determining and documenting outcomes. These include:

- Feedback/satisfaction surveys (which vary by jurisdiction)
- Follow-up with consumers by phone (the level of follow-up being undertaken by NACAP providers varies and is dependent on resources)
- Requesting consumers contact them to inform them of outcomes (and in particular, to inform them in the event of retribution by service providers).

Several providers currently use a common client management database but have suggested there may be benefit in all the NACAPs using the same system.

Currently, the NACAP service providers are not required to report against a quality framework. In the past they were required to report against two standards from the 2007 *National Aged Care Advocacy Manual of Standards*, however this has not been the case more recently.

4. Current aged care advocacy service provision

4.3.14. Relationship with the Aged Care Complaints Scheme (ACCS)

The strength of linkages between the NACAP and the ACCS varies between jurisdictions. Some NACAP services felt that ACCS staff did not have a very detailed understanding of the scope and processes of advocacy work. Conversely, some ACCS staff suggested that NACAP services were reluctant to refer consumers to the ACCS, in some cases not doing so until issues had escalated to such a level that resolution by the ACCS was very difficult. Other NACAP service staff reported good working relationships with the ACCS staff in their jurisdiction, with regular meetings held and referrals made between the two services wherever necessary.

4.3.15. Extent of collaboration between NACAP providers

While the *NACAP Policy Guide 2013–2015* provides for six-monthly network meetings or teleconferences with DSS, the NACAP providers report that such meetings are rare.

Nonetheless, the NACAP services report having a collegiate working relationship with frequent phone and email communication to discuss service delivery issues, and sharing of resources such as fact sheets and brochures. Where necessary, the NACAP services develop joint submissions to government under the banner of OPAN. Such submissions (including the submission to the Options Paper for this Review) demonstrate a commitment to working together, and a strongly aligned ethos.

At present, OPAN does not have a funded secretariat. The NACAP providers suggest that a secretariat would facilitate greater consistency between jurisdictions, allow more efficient information sharing and provide a mechanism through which broad issues of concern in relation to aged care service quality could be fed back to DSS.

Several NACAP service providers argued that it would be useful from a professional development perspective for advocates to come together periodically to discuss common issues and share learnings.

The lack of national 'branding' of the NACAP was considered by some stakeholders to be a missed opportunity to promote the programme. While some peak body stakeholders were aware of the organisation delivering the NACAP in their jurisdiction, they did not realise that it was a national, Commonwealth-funded program.

4.3.16. Emerging trends

In addition to the output data submitted by the NACAP-funded agencies, a summary of emerging trends is also developed. The emerging trends summaries from 2011–12 to 2014–15 paint a mixed picture of issues across the jurisdictions; however consistent findings included:

- Increasing concerns about elder abuse, and increased efforts to raise awareness about elder abuse
- Increasing complexity of issues dealt with (particularly for issues where the NACAP provider supports clients to work with the ACCS, or where clients have cognitive impairment or other 'capacity' issues)
- Increased demand for NACAP services due to the aged care reforms (introduction of CDC, *My Aged Care* and variations in the delivery of HCPs in the 2013–14 and 2014–15 reporting period).

4. Current aged care advocacy service provision

Issues relating to CDC included lengthy/complex contracts, clients wishing to change providers, administration costs, reduction in hours of care, and poor communication by providers.

- A shift towards more clients wishing to 'self-advocate', resulting in higher demand for education sessions
- Difficulties in finding time/financial resources for travel to remote areas (particularly for NT)
- Barriers to obtaining feedback from consumers/families, including a consumer's health (memory loss, sight impairment), educational or cultural issues, access to communications, or client death
- Fluctuations in levels of promotional activity/education sessions depending on organisational capacity
- Resistance from some aged care providers to education provided by advocacy services
- Issues relating to limited access to aged care facilities in rural and remote areas.

4.4. CHSP-funded advocacy

The activities undertaken through CHSP-funded advocacy vary widely between service providers and between jurisdictions, and as such, the service delivery model is less easy to characterise than NACAP advocacy. This has arisen in part from the variable evolution of the HACC programme in the states/territories, and the lack of clear definition of advocacy within the HACC Service Group 2. It is not possible to determine with certainty how many CHSP-funded providers conduct advocacy work as part of their CSIA funding, and no activity data were available for analysis. The findings below, while based on stakeholder consultation, are consistent with AHA's analysis of submissions made by CHSP providers to the CSIA questionnaire circulated by DSS (see *Section 2.3*).

Characteristics of CHSP-funded advocacy include:

- Advocacy is provided through a range of service providers, including those representing special needs groups (e.g. CALD, Aboriginal and Torres Strait Islander, dementia)
- Advocacy is sometimes provided by specialist advocates; in other cases, it is provided by CHSP service staff as a part of their service delivery
- Advocacy is generally provided on an individual basis. Occasionally, group advocacy is undertaken (e.g. on behalf of a CALD group)
- In most cases, CHSP advocacy services cover a broad range of issues including housing, transport, Centrelink and family disputes, which do not relate specifically to issues of aged care service quality. Some providers refer to this type of work as '*incidental advocacy*', or '*part and parcel of what we do*'. While some CHSP providers argue that this advocacy is consistent with the reablement concept because it helps maximise consumer independence, other stakeholders have pointed out that, in some cases, CHSP staff are 'doing for' the consumer rather than using an empowerment model
- Some of the issues dealt with by CHSP-funded advocacy services are complex and time-intensive (e.g. hoarding and squalor, over-crowding, and elder abuse)
- A common view among CHSP-funded services that work with special needs groups is that the mainstream advocacy services (i.e. NACAP-funded services) often do not have the resources or the capacity to provide advocacy services to individuals from these groups with the required level of intensity or specialisation

4. Current aged care advocacy service provision

- With some exceptions, CHSP-funded advocacy services are not provided independently of other aspects of CHSP service provision, and there is often no clear differentiation between advocacy, case management, and care coordination. Exceptions include:
 - CHSP advocacy delivered by organisations that also provide NACAP advocacy
 - Alzheimer’s Australia, which provides individual advocacy for clients with dementia
 - Organisations that have arranged to broker CHSP advocacy to independent advocacy providers, e.g.:
 - Partners 4 Health in Queensland brokers independent advocacy to Queensland Aged and Disability Advocacy (QADA) through a consortium model
 - Bankstown Area Multicultural Network (NSW) brokers services out to bilingual advocates that provide culturally appropriate support and referral into CHSP services. The Network provides training and peer support sessions for the bilingual workers
- A number of the stakeholders interviewed (including peak bodies, NACAP service providers and some CHSP service providers) argue that if advocacy is provided by the consumer’s primary aged care service provider, there is potential for conflicts of interest (both perceived and real). Consequently, independence from service delivery is considered an important element of advocacy services
- Because CHSP-funded advocacy is provided by organisations that have developed strong rapport and relationships with clients, it is described as consumer-focused, tailored and comprehensive. Some service providers described it as ‘reablement focused’ because it tends to be guided by clients’ goals
- CHSP advocacy providers use many of the approaches to addressing special needs groups outlined in ***Error! Reference source not found.***
- Many CHSP service providers report that they provide a crucial link between clients and more formalised mainstream (and independent) advocacy services.

4.5. Other aged care advocacy service models

While this Review focuses on advocacy provided through the NACAP and CHSP, it is acknowledged that aged care advocacy is also provided through a range of other means. This includes advocacy undertaken on a formal or informal basis by a range of other service providers at state/territory or local level. The case study below provides one example of other advocacy service models that attempt to address gaps in existing service provision.

4. Current aged care advocacy service provision

Case Study: Alpine Independent Aged Care Advocacy Service

In Victoria, the Alpine Independent Aged Care Advocacy Service is an incorporated association that provides volunteer-based individual advocacy for residential aged care clients in the Alpine Shire.

The aims of the service include 'standing beside' clients, protecting and promoting their rights, providing information, discussing options, empowering clients to speak for themselves, resolving issues, following up complaints and referring to other agencies where appropriate.

The service also provides education sessions to relevant community groups such as Probus and Men's Shed.

In many ways, this service appears to operate very similarly to NACAP-funded providers, and meets the needs of the local community through regular 'on the ground' contact with clients where this might not be feasible for NACAP-funded advocacy providers.

While the advocates are volunteers, training is provided and formal policies and procedures are in place to ensure correct handling of personal information and advocacy issues themselves.

Issues which are beyond the capability of the service are referred to other providers (e.g. legal issues).

4.6. Summary

As demonstrated in this chapter, Commonwealth-funded aged care advocacy services undertake a broad range of activity to support aged care consumers, using a range of approaches to service delivery. The following key points are noted:

- While limited activity data was available to inform analysis of CHSP advocacy services, NACAP activity data indicates that NACAP services are delivering a high volume of service with relatively low levels of funding. Variation in many aspects of service design and delivery between jurisdictions were noted. Due to the absence of outcomes data within the advocacy reporting system, it is not possible to draw conclusions on whether any services are delivering advocacy more efficiently than others
- The types of issues commonly addressed by NACAP providers include consumer rights, level of care and administration/fair trading. In CHSP-funded advocacy, the scope is often broadened to other issues and factors outside of aged care (e.g. housing, transport, etc)
- There is a trend towards increasing proportions of NACAP advocacy services delivered in community care, which is consistent with policy direction and the expansion of CDC
- Education and information sessions (for consumers and service providers) are consistent features of advocacy service
- Emerging issues identified by NACAP providers include: increasing demand for services, increasing complexity of cases, resource constraints (especially in providing access to rural and remote clients) and increasing concerns about elder abuse.

**5. Towards a national
framework for aged care
advocacy:
Stakeholder perspectives**

5.1. Introduction

Throughout the stakeholder consultations undertaken for the Review, there was strong support for the concept of a national framework to effectively support the delivery of an end-to-end aged care advocacy programme that includes the elements discussed in this chapter. It was also broadly agreed that a national entity (in which local advocacy groups were represented) that supported local advocacy would address some of the current inefficiencies and inconsistencies within the system.

Some stakeholders, however, expressed concern that a generalised framework may not adequately cater for the needs of diverse populations, and may be counter-productive if it sought to enforce conformity at the expense of locally appropriate and effective service provision. As one interviewee stated, it is important that “the issues and concerns of marginalised groups or at-risk populations are not diminished through the implementation of one-size-fits-all standardised policies and procedures”. It was felt, therefore, that the framework “needs to be broad enough to ensure fairness and consistency, without being so generalised as to only be useful in addressing a stereotypical ‘average’ consumer”.

Stakeholders’ viewpoints regarding key elements of a national framework were attained through initial consultations, and more substantially through analysis of responses to the Options Paper (O) and the subsequent workshop (O – O), and are discussed in this chapter.

The key elements of the national framework considered in the following sections are:

- Definitions
- Service delivery principles and priorities
- Outcomes sought and approaches to outcome reporting
- Objectives and service scope
- Service structure considerations
- Role of the Commonwealth government
- Service promotion
- Funding considerations.

5.2. Definitions

It was noted through early consultations that there was a lack of consistency in the way various forms of advocacy were defined, understood and described by stakeholders. Based on these consultations and the literature scan, a set of definitions was developed and included in the Options Paper for stakeholder feedback.

Overall, there was general support for the definitions presented. The various functions of advocacy could be described as consumer empowerment (i.e. information provision and consumer capacity building), representation, service provider education ('organisational' advocacy) and systemic advocacy. Inevitably, the scope of the future national aged care advocacy programme will need to be clearly and carefully defined, particularly because the current line between 'advocacy' and broader case management is somewhat blurred in a number of instances.

Where the proposed definitions referred to individual aged care advocacy services as generally providing one-to-one, short-term support to address a specific issue, it was noted that short-term support may be insufficient to meet the advocacy needs of some consumers (particularly for special needs groups such as people from CALD backgrounds or people with dementia). Similarly, the role of 'group advocacy' was also raised, as the concept of individual advocacy may not necessarily suit diverse cultures. Other comments on the definitions proposed in the Options Paper have been captured *Section 5.3*.

5.2.1. Updated definitions

Stakeholders' comments are further captured in the revised definitions presented below.

Advocacy is the process of supporting an individual so that their voice is heard.²⁶

Aged care advocacy services can be defined as independent and confidential services delivered for the benefit of people receiving (or potentially receiving) Commonwealth-subsidised aged care services to support them, their carers and other representatives to understand and exercise their rights and participate, to the maximum degree possible, in decisions affecting their care.

Consumer-directed care (CDC) is "a way of delivering services that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when".²⁷ In the context of aged care advocacy, CDC refers both to this approach to service provision, as well as the CDC packages of care funded by the Australian Government through the HCP programme.

Individual aged care advocacy supports consumers or potential consumers of aged care services (and their representatives) by:

- Supporting them to speak out on their own behalf (self-advocacy)
- Representing them in interactions with aged care service providers and other agencies

²⁶ QADA, 'What is Advocacy?', 2014, Accessed 27 May 2015, < <http://www.qada.org.au/about-qada/what-advocacy>>.

²⁷ Aged Care Services Australia, Council on the Ageing and Leading Aged Services Australia, 'Homecaretoday: Defining Characteristics of Consumer Directed Care', accessed 27 October 2015, < <http://ursa-media-homecare.s3.amazonaws.com/publicfiles/dmfile/CDC%20Defining%20Characteristics.pdf>>.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

- Referring them 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 representative. However, in some cases (e.g. for CALD populations or those with cognitive impairment) longer term or ongoing advocacy, or advocacy provided on behalf of groups (**group advocacy**), may be more appropriate.

Systemic advocacy focuses on influencing and changing systems – including government laws and policies, departmental procedures, community and other service practices – which may be adversely affecting people and their families.²⁸

Note: Although systemic advocacy is not a focus of this Review, there was a strong view among stakeholders and in the literature (see, for example, Pearson and Hill²⁹) that a mechanism through which individual issues can be fed into the systems/policy level is an essential component of a well-functioning individual advocacy system.

Organisational advocacy involves promoting consumer rights and interests (via education and training) to the staff of service providers and other organisations, in order to build the capacity of these organisations and embed the rights of consumers in service provision.

Consistent with the definitions of ‘resident’ in the Aged Care Act, all references to ‘aged care consumer’ are intended to cover the consumer’s representative as relevant. A **consumer’s representative** may be:

- A guardian appointed by a tribunal
- A person to whom the resident has formally delegated decision-making power (power of attorney)
- A person nominated by the consumer as his or her representative.

In addition, “in some circumstances, a person may nominate himself or herself as a resident’s representative. If the approved provider is satisfied that the person has a connection with the resident, and is concerned for the safety, health and well-being of the resident, the person may be regarded as the resident’s representative for some purposes. Such a person may be, for example, a family member or carer.”³⁰

‘End-to-end’ aged care advocacy refers to a service provided across the consumer journey, from initial consideration of Commonwealth-subsidised aged care options to permanent residential aged care, and encompassing transitions through the CHSP and the HCP programme and other Commonwealth-funded aged care services.

²⁸ Adapted from Tasmanian Government Department of Health and Human Services 2007, *The Role of Advocacy Services in the Tasmanian Disability Sector: An Information Booklet*, Tasmanian Government - Department of Health & Human Services, Hobart, <<https://books.google.com.au/books?id=mtXOoAEACAAJ>>.

²⁹ J Pearson & S Hill, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, Jenny Pearson & Associates Pty Ltd for the Department of Families, Housing, Community Services and Indigenous Affairs, 2009.

³⁰ Australian Government ‘Guide to Aged Care Law: Key terms used in the Guide to Aged Care Law’, 21 September 2015, accessed 12 October 2015, <<http://guides.dss.gov.au/guide-aged-care-law/1/1/1>>.

5.3. Service delivery principles and priorities

There was broad support for the principles and priorities highlighted by stakeholders throughout early consultations and presented in the Options Paper.

There was acknowledgement that the broader principle of consumer directed care (rather than the mechanism for delivering Commonwealth-subsidised HCPs) was very important. The principle of “nothing about me without me” was noted to have served the disability sector well, and its relevance to aged care confirmed.

While empowerment and self-advocacy may be considered the ‘gold standard’ for advocacy services, barriers to this ideal should be recognised and addressed and support provided to ensure consumers have a voice if they are unable to self-advocate. The importance of partnerships and ‘proactive engagement’ with consumers’ representatives (e.g. carers, family members, family of choice) in supporting decision making through individual advocacy was highlighted. At the same time, stakeholders noted a need to balance stakeholder involvement with consumers’ protection from elder abuse.

The diverse needs of the Australian aged care population were repeatedly highlighted by stakeholders. In particular, the challenges faced by special needs populations (as defined by the Act) and other ‘vulnerable’ populations (see *Section 5.6.2*) represented key concerns. Several peak bodies representing specific populations suggested that key barriers for each of those groups be highlighted within the principles.

5.3.1. Amended principles and priorities

Key principles and priorities consistently identified by stakeholders as supporting the delivery of high quality and effective aged care advocacy services include:

Key principles and priorities

- Advocacy services aim to ensure that the rights of consumers are supported, and that consumers (and their representatives) are empowered and enabled to exercise informed choice and self-advocate. This is particularly important for consumers who are living with dementia, experiencing cognitive decline or otherwise have a diminished capacity to exercise their rights (e.g. those with communication difficulties).
- Advocacy services are independent of service delivery and free of any real or perceived conflict of interest
- Advocacy services are available to consumers at all points along the aged care journey from initial consideration and contact with the Commonwealth-funded aged care service system to end-stage residential aged care
- Advocacy services ensure consumers are placed at the centre of the process, and the advocate acts at the consumer's direction
- Carers, family members, 'family of choice' and other representatives of aged care consumers are recognised as partners in care as well as partners in advocacy
- Advocacy services ensure that information and advocacy services are accessible to all potential consumers, with strategies in place to overcome barriers to access for those with diverse needs and to provide culturally safe, competent and sensitive services
- Advocacy services embed a strong emphasis on proactive/preventative advocacy by educating and strengthening the capacity of consumers, their representatives and the general community as well as educating and building the capacity of service providers to embed the rights of consumers in service provision
- Advocacy services use proven and tested practices delivered to a high standard by a competent and skilled workforce (paid and/or volunteer) and remain informed about the aged care system and broader sector environment
- Advocacy services contribute to other quality assurance mechanisms within the aged care system through analysis of the systemic trends which emerge through individual advocacy work
- Advocacy services have strong governance and management systems which ensure services are organised for safety, effectiveness and efficiency. The concept and practice of continuous improvement should be embraced by advocacy service providers, and a transparent mechanism for dealing with complaints developed.
- Advocacy services maintain constructive positive relationships with key stakeholders which, while upholding the independence of the programme, allow for collaborative approaches to improving quality of life and quality of care for aged care recipients.

5.4. Outcomes sought, measures and continuous quality improvement

There was general support among stakeholders regarding the proposed outcomes sought as articulated in the Options Paper.

Some stakeholders highlighted that the outcomes listed in the Options Paper were too broad (i.e. more 'vision statements' than measurable outcomes), potentially subjective, and not necessarily the responsibility of the advocacy system to address and achieve. Several of these broader statements may represent a vision for the aged care sector as a whole, rather than potential outcomes of an advocacy service. For example, an advocacy service may not be able to ensure that consumers' aged care needs are met, but rather, *can* ensure that consumers have their wishes and needs heard and acknowledged, that they are satisfied with the advocacy service and that their life circumstances are improved by having their issue addressed with advocacy assistance. Similarly, it was argued that ensuring service providers understand their obligations and responsibilities is the duty of the service provider and the funding body, rather than an advocacy service. Again, the advocacy service may *support* providers in this respect through consumer rights education (as is occurring in the current NACAP model).

Many felt that clearer, more precise outcomes would need to be defined (ideally collaboratively by the sector) to enable the development and measurement of KPIs and to provide guidance on how these outcomes might be achieved.

One respondent suggested that "the outcomes need to embed the rights of all aged care consumers within a human rights charter and go beyond the right to have needs met to the right of receiving a service that is flexible, culturally sensitive and appropriate to the needs of each consumer".

5.4.1. Amended and additional outcomes

Based on stakeholders' feedback, the outcomes presented in the Options Paper have been amended:

Amended and additional outcomes

- Consumers are enabled and empowered to make informed decisions about their care, exercise choice and are supported in reaching their wellbeing and reablement goals
- The rights of aged care consumers are better recognised and upheld
- Consumers' aged care needs are more optimally met due to the intervention of the aged care advocacy system
- Consumers are satisfied with the results they achieve as a result of engaging aged care advocacy services
- Aged care service providers are supported to understand and execute their obligations and responsibilities, and respect and embrace the rights of consumers
- Quality of aged care service (as experienced by consumers) is enhanced.

Additional outcomes suggested by stakeholders responding to the Options Paper included that:

- Older people are actively engaged in the evaluation of the advocacy framework to inform and measure continuous quality improvement
- The aged care system experiences significant and ongoing improvement as a result of the learnings at worker, organisational and system levels of the outcomes of the advocacy system

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

- Carers are able to receive advocacy support where a provider has not adhered to the principles of the Carers Recognition Act (e.g. 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)
- Linkages with consumers/providers within special needs groups are demonstrated to ensure those most vulnerable are being reached
- Younger people in residential care facilities find services better suited to their age where appropriate
- Mandatory education is provided to staff and aged care recipients in aged care facilities and other aged care workers regarding rights and responsibilities and concepts of Guardianship and Power of Attorney
- Consumers are well-informed regarding the services available to them
- The aged care system experiences significant and ongoing improvement as a result of the learnings at worker, organisational and system levels of the advocacy system.

5.4.2. Outcome measures

Robust evaluation of (intended and unintended) outcomes of advocacy services was universally supported, often in the context of a quality framework. There was a strongly held view that all stakeholders in the sector (including consumers) should contribute to the development of such a framework.

Given that desired outcomes include consumer satisfaction with the advocacy service and, more broadly, enhanced aged care service provision resulting from advocacy, the evaluation/reporting framework would likely include elements of both.

While the importance of standards and KPIs was noted by stakeholders, it was also acknowledged that some outcomes (particularly as currently outlined) would be difficult to measure. In particular, differentiating between contribution and attribution of results from consumer advocacy in determining improvements in service quality poses a challenge, particularly in terms of consumer empowerment and improved aged care service provision.

Several stakeholders noted the importance of outcomes measurement, as well as outputs, and the need to specifically evaluate services' responsiveness and effectiveness in serving special needs populations. In addition, consumer priorities will be important to consider in evaluating the advocacy service. For example, research undertaken by the Scottish Independent Advocacy Alliance showed that the 'soft' outcomes of improvement in sense of wellbeing resulting from being listened to, respected and having their wishes voiced was as valued by consumers as the 'hard', measurable outcomes (e.g. access to service, complaint resolved).³¹

Regarding whether and how these outcomes could be measured, stakeholders suggested utilising the following (acknowledging that some service providers already use some of these approaches):

- Consumer and representative feedback/satisfaction surveys (end-user quality assessment), assessing:

³¹ Scottish Independent Advocacy Alliance, *Advocacy is for the People*, Edinburgh, 2014.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

- Whether/extent to which consumers' goals were achieved as a result of their engagement with advocacy services
- Accessibility/appropriateness of advocacy services
- Likelihood of using advocacy services again in the future
- Impact on consumers' confidence, self esteem and self-efficacy
- Advocacy service output data reporting (e.g. client numbers, client type, timeliness, number of education sessions etc.) and analysis of trends over time (with specific reference to special needs groups)
- Advocacy service outcomes data (with specific reference to special needs groups)
- Workforce data (e.g. how many advocates are trained, their role, whether from a special needs group, CALD status)
- Existing sources of data (e.g. *My Aged Care*, ACCS).

Capturing such data would require the development of a robust quality management system clearly linked to reporting requirements that have a strong focus on measuring client outcomes. The introduction of a quality assurance process with a focus on continuous quality improvement could be considered in the future to further support service quality, depending on the level of sector readiness. Mutual recognition of standards from other relevant program areas (e.g. Home Care Common Standards, National Standards for Disability Services) would be important to minimise red tape and burden for service providers. The need for adequate resourcing to undertake such measurement, reporting and evaluation activities was raised by stakeholders as a key issue.

The NACAP Quality Standards (developed in 2000) were identified as a useful starting point for this work.

5.5. Advocacy objectives and service scope

5.5.1. Eligibility

A theme emerging from stakeholder consultations related to the issue of eligibility for Commonwealth aged care advocacy services. Stakeholders noted that many consumers are moving away from Commonwealth-subsidised aged care services and are increasingly using private providers (and are therefore not eligible for Commonwealth aged care advocacy), and that this trend is anticipated to continue.

Stakeholders also noted that the term 'potential consumers' should also be defined (see *Section 0* for other elements of advocacy definitions). While the current NACAP is technically available for those who have received an ACAT assessment but are yet to be allocated support services (noting that NACAP services exercise flexibility in this regard), there was consensus among stakeholders that a future model should be available from the time of initial consideration of aged care options. This approach was considered consistent with the notion of 'proactive advocacy' and the emphasis on supporting consumer choice during times of transition through and between services. Stakeholders noted possible resource implications of broadening eligibility in this way.

5.5.2. 'In-scope issues' for advocacy services

Currently, there is variation between advocacy services in terms of the type of issues they can help consumers address. While the scope of the NACAP is limited to the issues related to Commonwealth-subsidised aged care services (see *Section 4.3.8*), CHSP advocacy services have, in contrast, had a broader focus on addressing a broad range of issues that may impact consumers' ability to continue living in their own homes. These may include issues related to access to health care, transport, housing/tenancy and financial issues (see *Section 4.4*). Advocacy providers have also noted a growing number of issues relating to elder abuse and have suggested this problem requires a stronger, national response.

Stakeholders were supportive of broadening the scope of advocacy to address these wider issues, noting that such an approach is consistent with a holistic, consumer-led focus. However, stakeholders also noted the importance of ensuring that advocacy services develop and maintain strong networks of referral opportunities so that consumers' issues can be addressed by those with the requisite expertise, and to avoid the advocate's role from becoming that of a case manager. It was noted that the de-funding of case management in the new CHSP funding structure may lead to increased demand for advocacy services by consumers with complex and ongoing support needs.

5.6. Service structure considerations

5.6.1. Maximising geographical spread

Three options for maximising geographical spread of services were developed after initial consultation with key stakeholders, were presented in the Options paper for further comment.

Option 1: Establish a single, national, centralised aged care advocacy service with jurisdiction-based offices. This could potentially drive greater efficiency and consistency but could compromise the ability to develop flexible approaches tailored to local need.

Option 2: Retain the existing structure of nine separate jurisdiction-based organisations, and additional independent providers organised around special needs groups or specialist intervention.

Option 3: Expand the number of advocacy service providers by funding smaller, regionally-based providers (similar to the model used in the National Disability Advocacy Program (NDAP)). Population figures and remoteness variables would be considered in determining the number of providers. Such an approach may enable delivery of more localised services (and possibly better coverage of rural/remote areas), but with potential loss of national programme consistency, and possibly at higher cost. Stakeholders also indicated that quality assurance, reporting and administrative processes may carry a higher relative burden for smaller providers with fewer staff.

These options were presented in order to explore the trade-offs and benefits of each option in relation to efficiency, national consistency, access and flexibility to respond to local needs.

There was significant variation in responses from stakeholders. While the majority felt that Option 2 was the best of the three presented, almost all responses suggested elements of different models should be utilised in an 'ideal' model. The support for Option 2 reflected a general desire to consider a

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

jurisdiction-based model, similar to that of the existing NACAP, but emphasised the need to ensure linkages and connections with organisations or independent providers (where required) that would support special needs populations, rural and remote service delivery or specialist interventions. Stakeholders suggested that Option 2 provided a good balance between supporting national consistency and enabling localised flexibility.

It was noted that a number of existing advocacy services currently support branch offices or outreach workers (co-located with other relevant community services), and that this approach assists with extending geographical reach. Some advocacy providers suggested that such an approach is only cost-effective if the organisation also receives funding for other programmes/services because otherwise the overhead costs are prohibitive.

While Option 1 was the least favoured, a significant number of stakeholders agreed that elements of this option could be very useful, balancing facets of national coordination, consistency, efficiency and support with the flexibility to utilise local services and optimise local partnerships to meet local needs.

Therefore, the majority of stakeholder support was for a mix of the presented options that, in theory, managed trade-offs between national consistency and local flexibility. Several stakeholders spoke of the utility of a “hub and spokes” model, similar to that adopted by the NDAP, in supporting this approach.

One stakeholder noted that adopting the most locally-focused option (Option 3) need not compromise national consistency if good governance practices that comply with relevant standards and include quality reporting mechanisms were in place.

Volunteer service models were also raised for consideration in the context of a future aged care advocacy programme.

5.6.2. Access and appropriateness for special needs groups

Throughout consultations, stakeholders noted the importance of supporting marginalised consumers (e.g. those from CALD backgrounds, Aboriginal and Torres Strait Islander people, those with disabilities, those experiencing (or at risk of experiencing) elder abuse, etc.). In particular, addressing barriers to access and providing a culturally safe and sensitive service to such consumers and communities was felt to be of vital importance.

As one stakeholder commented, “due to the nature of vulnerability and disease among our aged, access for special needs will always require specific vigilance as well as creative solutions”. In particular, it was noted that contact through a website or 1800 number doesn’t facilitate access for most special needs populations.

Many stakeholders referred to the need to broaden the definition of ‘special needs’ populations beyond those described in the Act to include other vulnerable populations such as those:

- Over the age of 65 with a disability requiring specialist disability services (noting that this group may ‘fall through the cracks’ between aged care advocacy and the NDAP) under the age of 65 with a disability utilising aged care services
- With dementia living alone
- Without family or friends able to support their advocacy needs
- Experiencing (or at risk of experiencing) elder abuse

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

- With communication difficulties or who are otherwise less able to exercise their rights.

It was also noted that an individual identified as being from one special needs group may, in fact, ‘cut across’ multiple groups and face multiple barriers and forms of discrimination, again highlighting the role of formal policies and linkages between advocacy providers and other agencies to effectively deliver appropriate services to special needs populations.

A further issue is identification of individuals in special needs categories, as disclosure may not always occur (e.g. particularly for LGBTI individuals or care leavers), or may not occur early in interactions with the aged care system. This was noted to have implications for reporting.

To increase access and improve equity for special needs and other vulnerable populations, a number of strategies were presented in the Options Paper (informed by earlier stakeholder consultations), namely:

- Providing mandatory training for advocates on issues relating to special needs groups
- Including advocates with expertise in or affiliations with special needs groups on staff
- Delivering specific models of advocacy support to people from special needs groups (e.g. the Supported Decision Making model for people with dementia piloted by Advocacy Tasmania)
- Ensuring that advocacy service providers have ready access to interpreters (including funding/access to government-funded interpreter scheme)
- Supporting mechanisms for ‘warm referral’/‘supported referral’ of special needs consumers to advocacy services (noting that warm referral is acknowledged as essential to enabling consumers who are reluctant to engaging with services to do so), including:
 - Special needs groups speaking to the advocacy service on the consumer’s behalf and providing preliminary information (with the consumer’s consent)
 - Special needs groups following up with the consumer to ensure satisfactory outcomes have been achieved
- Targeting efforts to engage face-to-face with people from special needs groups, either via peak bodies or at community events
- Formalising brokerage arrangements to facilitate referral of people from special needs groups who require independent advocacy:
 - By advocacy services to specialist organisations (e.g. referral of clients with dementia to Alzheimer’s Australia)
 - To advocacy services for independent advocacy (e.g. the model used by Partners 4 Health (Queensland) through which CHSP clients received advocacy brokered through a specialised advocacy service).

Stakeholders were broadly supportive of these options outlined above. Again, formal linkages with local services and organisations were recommended to optimise access and acceptability of the service from the perspective of special needs groups, with two-way referrals useful to ensure these consumers’ needs are met most appropriately. Linkages between aged care advocacy services and primary and community health services, hospitals, and social housing were highlighted as opportunities worth pursuing.

While independence from government was considered an important feature of advocacy services for people from special needs groups (many of whom have had traumatic past experience with government

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

services), several stakeholders also raised that the delivery of advocacy services through national faith-based organisations may represent a barrier to access some people who have had negative past experiences with the church (e.g. care-leavers, Aboriginal and Torres Strait Islander peoples).

5.6.3. Mechanisms to inform systemic advocacy

While noting that it was outside of the scope of the current review and consultation process, stakeholders consistently advised that strong mechanisms must be in place to support the flow of information from individual advocacy services to systemic advocacy activities, and that these mechanisms must be appropriately resourced. For example, a number of NACAP providers have identified an increase in issues relating to elder abuse. Although addressing elder abuse is outside the current scope of the NACAP, providers felt that a mechanism through which to draw attention to this issue was important.

5.6.4. Viability of a centralised intake system

At the stakeholder workshop, participants discussed whether a centralised intake option, in addition to current access points, but independent from *My Aged Care* (in order to ensure independence from aged care service provision) could be an effective way of improving access to advocacy. There was a strong view that a website or centralised phone line alone would be ineffective in ensuring access to advocacy (particularly for those from special needs groups) and that a range of options (as described in *Section 5.6.2*) should be used. Participants also noted that there is currently a centralised phone number for the NACAP, but that this is not functioning well due to connectivity issues (e.g. cannot be reached from mobile phones).

5.6.5. Interface with National Disability Advocacy Programme and Aged Care Complaints Scheme

National Disability Advocacy Programme (NDAP)

The shared consumer rights-based ethos of both the NDAP and aged care advocacy programmes was acknowledged and discussed with stakeholders throughout the consultation process.

In the Options Paper, stakeholders were specifically asked whether there were strengths of the NDAP that should be considered in the redesigned aged care advocacy program, and whether synergies and improved interactions between the two models should be explored.

Stakeholders felt that aged care advocacy could benefit from aspects of the NDAP, with particular strengths identified including:

- Its shift of focus from agencies to consumers
- Its broader scope, assisting individuals with disabilities with a range of fundamental rights issues (not just service provision)
- The fact that it has been guided by the principles and objectives of key legislation, conventions, agreements and frameworks
- Its formal service certification requirements and funding for systemic advocacy
- Its 'hub and spoke' model providing national coverage.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

Stakeholders generally felt that there were important synergies and overlaps between the two schemes, that duplication is undesirable, and it was noted that some NACAP agencies already operate in both 'spaces' and take advantage of the resulting efficiencies. However, it was also noted that the aged care and disability sectors are currently in quite separate positions in their journeys of reform, and that simply combining the two programmes (at least at this point in time) may not be wise. There was some concern expressed that if the two advocacy sectors were combined, existing aged care advocacy services could be compromised.

Younger people with disabilities, including dementia, utilising (or potentially utilising) residential aged care facilities (due to lack of appropriate alternative services) and those over the age of 65 living with a disability are two key populations around which synergies and interactions between disability and aged care advocacy might be initially defined. A number of stakeholders noted the increasingly blurred line between disability and aged care services, with one stating the 'critical importance' of a single-entry system for those who are both aged and eligible for the National Disability Insurance Scheme (NDIS). The Futures Alliance, a collaboration of representatives from the disability and aged care sectors in NSW have been examining these issues, and identified the need to promote consistency, seamless service provision, 'no disadvantage', timely response and flexibility as key considerations. As another stakeholder noted, "an integrated framework that acknowledges the differences and interdependencies needs to be developed. An integrated model will improve efficiencies in the use of valuable resources while also providing a relevant service and, most importantly, positive outcomes for the individual".

More broadly, the importance of partnerships, linkages, referral pathways, brokerage arrangements, relationship-building and collaboration between agencies in aged care advocacy was highlighted including (but not limited to) the NDAP. One submission proposed that "a system of shared values and a less conflicted culture than exists at present will have to develop over time". Such linkages might include the NDAP as well as the disability sector more broadly, the health sector and non-Commonwealth funded aged care providers.

Overall, it was clear that there should be an interface between aged care advocacy and NDAP that maximises efficiencies but maintains flexibility and focus for the aged and disabled populations (and those spanning both).

Aged Care Complaints Scheme (ACCS)

Stakeholders noted the desirability of clearly articulating the interface between aged care advocacy services and the ACCS. As noted in *Section 4.3.14*, there is currently inconsistency between jurisdictions in relation to the number of referrals made between the ACCS and advocacy services, and reported variation in the strength of the working relationship between the NACAP services and the jurisdiction-based ACCS staff. Noting the important role independent advocacy services play in resolving low level complaints and preventing escalation to the ACCS, stakeholders identified a need to better communicate how and when issues should be referred from advocacy services to the ACCS and vice versa. Moreover, stakeholders noted the importance of ensuring consumers are aware of how to make complaints about the advocacy services they receive.

5.7. Role of the Commonwealth government

Stakeholders supported the role of government as primary funder of aged care advocacy. Moreover, they emphasised the role of the Commonwealth in driving the development of an Advocacy Framework. Other potential roles include:

- Supporting a formal mechanism for coordinated action by providing funding for secretariat support for advocacy service providers based on the model used by the existing OPAN. This would contribute to national consistency by providing a mechanism for sharing information, resources and learnings between service providers and advising government of key issues and trends (systemic advocacy)
- Advising service providers of developments in relation to aged care changes
- Advocacy service promotion (through a range of channels) including support for a national number for access and national branding of resources
- Analysing submitted advocacy data to refine the programme
- Using advocacy data in combination with data collected through other channels such as the ACCS or *My Aged Care* to contribute to ongoing monitoring of the quality of the aged care system.

However, many stakeholders emphasised the importance of advocacy services being delivered ‘at arms length’ from government, noting that some consumers (including many from the LGBTI, Aboriginal and Torres Strait Islander and Care Leaver special needs groups) can be distrustful of government due to historical experiences.

The model of publicly-funded, nation-wide, independent health and disability advocacy used in New Zealand, is worthy of exploration. In this model, an independent ‘Director of Advocacy’ (sitting within the Office of the Health and Disability Commissioner) is responsible for contracting advocacy services and monitoring their performance as well as overseeing all promotion and education activities. The use of contractual arrangements as a lever to drive advocacy service quality and consistency has been identified as a key strength of the New Zealand model.³² Other considerations may include ensuring advocacy service delivery sites are not co-located with government services or other aged care service delivery organisations.

5.8. Service promotion

Throughout the consultation process, the need for comprehensive, multi-channelled promotion of aged care advocacy services was emphasised. There was a strong view that the services should, with the assistance of the Commonwealth, be branded as a national advocacy programme.

A number of stakeholders identified the need to promote advocacy services through community channels (rather than aged care provider channels) in order to engage with *potential* consumers of aged care services, families/carers, and communities (particularly communities with special needs).

Stakeholders emphasised the need to better promote advocacy services at critical transition points through the aged care system. In particular, the need to ensure advocacy services are accessible to

³² Drage, J 2012, ‘New Zealand’s national health and disability advocacy service: a successful model of advocacy’, *Health and Human Rights: An International Journal*, vol. 14, no. 1, pp53-63.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

consumers as they transition from hospital to residential or home care is important, in order to ensure that they have support to make choices about their ongoing care options (consistent with the philosophy of consumer-directed care).

In addition, NACAP providers argued that national branding and marketing would improve awareness and understanding of an aged care advocacy programme. However, stakeholders stressed the importance of promoting the programme as independent of government (e.g. by ensuring consumers were aware that involvement of advocacy services would not have implications for their access to Commonwealth-funded services).

While advocacy services are currently using a number of approaches to promote their services (including many of those listed below), the following options could be considered as part of a multifaceted, Commonwealth-led promotional strategy:

- *My Aged Care* website and phone line and the Regional Assessment Service
- Aged care service providers (information sessions and inclusion of advocacy program information within other publications)
- Other service providers (e.g. health services, hospitals)
- Community settings (including CALD-specific social groups)
- Local radio/television
- Peak bodies
- Expos, events and conferences (attendance/presentations tailored to jurisdictional needs/opportunities)
- Information hubs (e.g. Ideas NSW).

5.8.1. Innovative approaches for promotion to special needs groups

A range of other opportunities for promotion were raised in the context of special needs/vulnerable groups. Central to this was the need to promote advocacy services through a range of relevant channels, including working with other organisations and communities that are active within vulnerable groups (not necessarily aged care). “Continual visibility” is required to ensure effective access. Innovative models should also be explored, including, for example:

- National promotion (similar to that undertaken for the Aged Care Complaints Scheme)
- Community and paid radio advertising through relevant (e.g. multicultural) stations
- Advertising on ‘meals on wheels’ packaging
- Forwarding regular advocacy updates to aged pensioners
- Stronger links with the Community Visitor Scheme.

5.9. Funding considerations

The funding model ultimately developed will, of course, be dependent to a large extent on the service structure decided. However, stakeholders felt that the funding model should reflect the ‘end-to-end’ nature of the advocacy service and consider the complexities of the sector.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

At a broad level, stakeholders felt that a high quality, consistent service should be made available free, or at low-cost to consumers. It was noted that there would be increasing demand for aged care advocacy due both to the ageing of the Australian population (and therefore greater need for and use of aged care services) and current developments in the aged care sector.

Some stakeholders recommended the retention of existing funding (i.e. pooled NACAP and CHSP advocacy funding) with current funding levels and service mix maintained and new monies used to fill in service gaps as they become available (noting current lack of CHSP advocacy funding in Victoria and central Australia). It was also suggested that, in the longer term, the new advocacy programme's funding would ideally represent an agreed percentage of the total funding allocated to aged care service provision, with models explored that might inform disbursement of these funds across jurisdictions.

Another stakeholder suggested all funding sources be considered in development of the model (e.g. government, consumer co-payment, leveraging public and private funding) and, again, that a collaborative approach across the system be encouraged to maximise outcomes for consumers.

Some stakeholders noted potential savings if a national aged care advocacy programme can, for example, help consumers stay at home longer or self-advocate and/or resolve issues without needing to call on other services (e.g. ACCS). It also may have the potential to reduce hospital admissions and eliminate overlap of advocacy service provision. In a similar vein, one stakeholder suggested that the cost of *not* delivering adequate and comprehensive aged care advocacy services be considered when determining funding levels.

In the short term, demand for advocacy is expected to be high with the defunding of case management services and disruption to services associated with the transition to an integrated aged care programme. Stakeholders stressed the growing need for advocacy services to support consumers as the aged care system evolves. For example, stakeholders identified CDC as a potential area where consumers will need support to understand the changes and exercise their rights. While CDC promotes greater choices for consumers it also requires more decision making. This will present challenges for some consumers as they attempt to navigate their way through the aged care system. The need for independent advocacy will be increasingly important in this environment.

Some individual elements of aged care advocacy service provision were highlighted by stakeholders as important considerations in funding model decisions. These are presented below.

Accessibility and special needs groups

It was noted that there is a wide variation in the level of advocacy services required by consumers across the spectrums of aged care needs, socioeconomic status and demographics, special needs groups (as currently defined) and other groups such as those with a disability. Clearly, more intensive and/or long-term advocacy services, or those delivered in rural and remote locations, will be more expensive than interactions consisting of a single phone call. However, most stakeholders felt strongly that for older people in general, and some specific populations in general, face-to-face support is ideal or even vital to effective service provision.

Overcoming barriers to access is an important principle and priority in aged care advocacy, and appropriate resourcing will be required to ensure access and appropriate service for all consumers. The majority of stakeholders felt that funding should allow for a flexible approach to local conditions, with funding to specifically facilitate access and appropriateness of service for special needs and other

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

vulnerable groups. For example, the particular costs associated with delivering services to rural and remote populations, engaging interpreter/translation services,³³ and ensuring responsiveness and capacity of service should all be considered.

Workforce development

Workforce development is an important consideration in ensuring service quality. It was felt that appropriate and ongoing training, support and supervision of staff should be explicit in the funding model to ensure advocates have the skills to deliver culturally appropriate, effective and respectful support. The use and training of volunteers was also raised in this context — while volunteers may represent an important resource, the quality of service provision is of paramount importance.

In addition, mandatory training of aged care service provider staff (e.g. in consumer rights, provider responsibilities, access to advocacy services for all, including special needs groups) was recommended as a key strategy for maximising the efficiency of aged care advocacy.

Proactive engagement

Consistent with the principle of proactive/preventative advocacy, it was noted that ongoing widespread community advertising and awareness-raising should be explicitly included in the funding model, with more specific and innovative methods of promotion considered to reach special needs and otherwise vulnerable groups. In addition, there was widespread support for the education sessions that NACAP services run in aged care facilities (or for providers of home-based care), and that the funding model should support this. Stakeholders noted that with the shift towards home-based care, this work may become increasingly time-intensive.

Partnerships

Noting the need to engage and support special needs groups, the funding model could consider enabling and supporting such functions through supporting partnerships with relevant organisations. In particular, the function and activities of other national service providers could be considered (as a number of peak bodies provide individual advocacy services for those in particular populations), along with co-funding opportunities.

Innovation

Some stakeholders noted that there should be some capacity to trial and assess innovative technologies (e.g. videoconferencing) and alternative models (e.g. volunteer, peer or collaborative advocacy services) that may improve access to services. One stakeholder suggested the development of a clearinghouse to centralise national and international research, resources and tools to promote best practice and share innovative approaches.

Administration

It was recommended that sufficient resourcing for reporting requirements, administration and evaluation costs should be included in the funding model, as stakeholders expressed concern that

³³ One stakeholder noted that while aged care service providers currently have access to free interpretation services, advocacy providers do not.

5. Towards a national framework for aged care advocacy: Stakeholder perspectives

compliance requirements could constitute a significant administrative function that diverts resources from client contact.

5.10. Summary

As detailed in this chapter, there is strong stakeholder support for the development of a nationally consistent, end-to-end advocacy service delivery model. A national framework, which focuses on meaningful and measurable outcomes, was supported as a means for driving national consistency. Key findings from this chapter have informed the development of recommendations in *Chapter 6*.

6. Conclusions, Options and Considerations

6.1. Summary of key findings

The following key findings were identified through the Review.

6.1.1. Current advocacy service provision

The Review identified the following points in relation to how advocacy services are currently being delivered:

- Variations exist in interpretations of the nature of advocacy work among aged care service providers, peak bodies, and even some services that report undertaking advocacy.
- NACAP activity data indicates that NACAP services are delivering a high volume of service with relatively low levels of funding. Variation in many aspects of service design and delivery between jurisdictions were noted. Due to the absence of outcomes data within the NACAP reporting system, it is not possible to draw conclusions on whether any services are delivering advocacy more efficiently than others. The Review was unable to undertake the same analysis for CHSP advocacy services due to the limited data available.
- NACAP providers endeavour to avoid waiting lists for advocacy and usually achieve this. To accommodate fluctuations in demand for advocacy, providers report that they adjust the number of education sessions or networking activities they undertake.
- The types of issues commonly addressed by NACAP providers include consumer rights, and level and quality of care. In CHSP advocacy, the scope is frequently broadened to include issues and factors outside of aged care (e.g. housing, transport, etc.).
- An increasing proportion of NACAP service is being delivered in community care settings, which is consistent with the Government's policy direction toward expansion of Consumer-Directed Care (CDC). NACAP services reported that advocacy cases relating to CDC are often complex and time-consuming.
- NACAP providers identified the following emerging challenges to delivering services:
 - Increasing demand for services
 - Increasing complexity of cases
 - Resource constraints (especially in providing access to rural and remote clients)
 - Growing concerns about elder abuse.
- Education and information sessions on consumer rights (targeting service providers and/or consumers) are a consistent and highly regarded feature of advocacy service provision. These sessions are noted to often result in consumers seeking advocacy assistance.

6.1.2. Stakeholder perspectives and priorities

The following themes emerged through consultations with advocacy providers, aged care service providers, peak bodies, government representatives and consumers:

- There is strong support for an integrated, end-to-end programme of aged care advocacy that supports consumers in their transitions through, and between, aged care services.
- Individual advocacy must be linked with, and inform, systemic advocacy processes in order to contribute to improvements in the aged care system.

6. Conclusions, Options and Considerations

- Existing independent advocacy services were recognised as providing a quality service to aged care consumers (within resource constraints).
- Some challenges in ensuring that all consumers can access advocacy were also identified, including challenges ensuring access to and appropriateness of services for people from special needs groups and other vulnerable populations, and geographical challenges related to Australia's size and population distribution.
- A key strength of the work undertaken by independent advocacy organisations is the development of local linkages with (and referral of consumers to) relevant peak bodies and other service providers. These networks play a particularly important role in supporting special needs populations.
- Opportunities exist to build consistency in the aged care advocacy service delivery model through the development of a national framework. Building consistency in aged care advocacy could drive service quality, national coverage and efficiency. However, national consistency should not be sought at the expense of local flexibility.

6.2. Options and Considerations

Based on the findings of the Review process, the following options are presented for consideration by the Department of Health in designing a nationally consistent, end-to-end aged care advocacy service model.

1. A National Framework for aged care advocacy

A National Framework for aged care advocacy could be developed to promote national consistency.

The Framework could include:

- Definitions as described in *Section 5.2.1*
- Principles and priorities as described in *Section 0*
- Clear processes for data collection and reporting with tools to support providers to identify and report on outcomes
- A quality assurance process with a focus on continuous quality improvement. The process would need to consider options for mutual recognition of standards from other relevant program areas (e.g. Home Care Common Standards, National Standards for Disability Services) to minimise red tape and burden for service providers
- An approach for connecting with local stakeholders and service providers to optimise appropriate referral pathways, particularly for special needs populations
- Clearly articulated processes for interaction with other services, including the Aged Care Complaints Scheme (ACCS) and the National Disability Advocacy Program (NDAP)
- A set of competencies for aged care advocates to support recruitment, professional development and training (competencies developed by Advocacy Tasmania, and those included in the 2008 NACAP program materials, could be reviewed as a starting point).

6. Conclusions, Options and Considerations

2. A mechanism for coordinated action

Development of a formal alliance of advocacy providers could be considered, based on the model used by the existing Older Person's Advocacy Network (OPAN). The secretariat role for the alliance could rotate between group members in order to maintain independence from government.

Such an alliance could enhance national consistency by:

- Providing a forum for sharing information, resources, practices and learnings
- Enabling coordinated feedback to government around systemic issues and trends in relation to both advocacy and aged care service delivery
- Creating opportunities for professional development and training
- Strengthening relationships and networks with other stakeholders (including the ACCS, national peak bodies and aged care service providers).

3. Aged care advocacy model

The model of advocacy employed by the aged care advocacy programme should centre on issue-based, individual advocacy.

The model could include consideration of:

- The role of proactive/preventative advocacy and the benefits of low-level resolution of issues
- Ways to ensure that appropriate service options are available to meet the needs of individuals from special needs groups
- The importance of face-to-face interactions for many in the aged population, and particularly those from special needs groups
- The role that information provision and education plays in facilitating consumer choice and supporting self-advocacy as consumers transition through the aged care system
- Group advocacy in some circumstances where a number of people have shared issues (e.g. for some people from Culturally And Linguistically Diverse (CALD) backgrounds)
- The benefits of educating service providers about the rights of consumers (organisational advocacy)
- Expanded models of more intensive advocacy in specific cases (the Supported Decision Making model used by Advocacy Tasmania could be further explored with a view to expanding this initiative)
- The scope of issues addressed, for example, the feasibility of extending beyond those relating to aged care service provision to encompass other concerns that may affect the ability of CHSP or Home Care Package (HCP) consumers to continue living in their own homes (should they wish to do so); where appropriate, advocacy services should refer consumers to other organisations with the requisite expertise (e.g. for financial or legal issues).

6. Conclusions, Options and Considerations

4. Service structure

The following factors could be considered in developing a future service structure (noting that the optimal number and spread of aged care advocacy organisations has not been determined):

- Aged care advocacy should ideally be provided independently from aged care services, due to the possibility of perceived/real conflicts of interest
- Independence from government and faith-based organisations should also be considered, in order to maximise acceptability
- Opportunities to increase national consistency in aged care advocacy could drive service quality, national coverage and efficiency, but should not come at the expense of local flexibility.
- A new aged care advocacy programme should, wherever possible, seek to build on existing expertise and networks with other organisations and services (including those involved with people from special needs groups)
- Options for maximising the geographical reach of advocacy services include:
 - Establishing multiple branch offices within advocacy organisations or co-locating advocacy outlets with other complementary organisations (including those appropriate to people from special needs groups)
 - Continuing support (and sufficient resourcing) for outreach visits by advocacy services to rural/remote areas.

Options provided in *Section 5.6.2* could be considered to ensure access to, and appropriateness of, advocacy services to people from special needs groups.

5. Service promotion

The advocacy programme could be branded as a national programme in order to increase visibility and minimise consumer confusion. Consistency of messaging in all communication materials developed under the national brand should be encouraged.

Given that lack of awareness of advocacy services, and misconceptions about the nature of individual advocacy can be key barriers to uptake, promotional materials should include a focus on educating the public about the role of advocacy in upholding consumer rights and the potential benefits of engaging with advocacy services.

The range of opportunities for promotion described in *Section 5.8* could be considered, including approaches to maximise access for people from special needs groups.

6. Conclusions, Options and Considerations

6. Funding considerations

Funding decisions for a future advocacy programme could take into account the following (noting that the funding model will largely be dependent on the agreed service structure — and, to some extent, vice versa):

- The predicted increase in the proportion, and absolute numbers, of people aged over 65 years of age is likely to drive higher demand for advocacy services. At a minimum, funding could increase in line with these projections and inflation to maintain current service levels. In tandem, advocacy services may need to adapt their service models to meet growing demand
- Funding could include support for ongoing provision of educational activities (with service providers and consumers) as well as networking and proactive engagement with other organisations, as these are considered key to effective advocacy service provision
- The funding model should reflect the increased advocacy support that will be required to support consumers to exercise their rights to informed choice, given the expansion of community-based aged care and the roll-out of CDC
- The funding model should account for the proportion of special needs (including rural/remote) populations, because providing services to these groups is resource-intensive
- Given that a core aim of aged care advocacy is to support those who are ‘hard to reach’, particularly vulnerable, or with complex needs (and for whom advocacy support may be more resource-intensive), any efforts to drive efficiency should be balanced with the need to ensure quality, accessibility and responsiveness for all eligible consumers
- Regardless of the funding model, greater certainty around ongoing funding would assist organisations in forward planning and staff retention.

Appendix A. Terms of Reference for Review

Review of Commonwealth Aged Care Advocacy Services: Terms of Reference

1. Review Rationale

A review of Commonwealth aged care advocacy services is being undertaken to inform the Commonwealth on how individual advocacy services can best support consumers to:

- effectively interact with the aged care system;
- better transition between service types; and
- be empowered to apply informed decision making and actively exercise choice.

From a consumer perspective, the focus of current changes to the aged care system is centred on embedding greater choice, control and flexibility. This is being effected through:

- consumers being viewed as active partners throughout their aged care experience;
- supporting empowerment so that consumers can exercise individual responsibility in making decisions about their care;
- implementation of Consumer Directed Care (CDC) services; and
- incorporating a restorative approach as the key philosophy to the design of the Commonwealth Home Support Programme which focuses on wellness and reablement.

2. Review Objectives

It is recognised that the shift in the way aged care operates is creating an environment where individual advocacy services have been identified as fundamental in supporting older people through the aged care system.

The Australian Government currently funds individual advocacy services for aged care consumers through two programmes:

1. the National Aged Care Advocacy Programme (NACAP); and
2. the Commonwealth Home and Community Care (HACC) Programme, Service Group 2.

The review will seek to:

- explore how individual advocacy is currently being delivered across residential, home care and Commonwealth HACC services;
- consider what is working well, what could be improved, current challenges and gaps;
- identify differing client needs, including those from special needs groups;
- define individual and independent advocacy services; and
- consider how consumer choice, decision making and the protection of consumer rights can best be supported by a Commonwealth funded individual advocacy programme.

Consideration of systemic advocacy is not in scope for the outcome of this review.

3. Review Outcomes

The review will present options to inform the Department's design of a nationally consistent, end to end aged care advocacy service model focussed on individual advocacy support.

Based on the Productivity Commission's inquiry report - '*Caring for Older Australians*', the aged care system is undergoing major changes.

The Government has signalled that the current system will need further changes that continue to focus on consumer empowerment into the future.

This increases the need to develop an end to end, individual advocacy programme that incorporates a number of key priorities including:

- the provision of independent and individual advocacy support for consumers of residential, home care and Commonwealth Home Support aged care services;
- that supports consumers to exercise consumer directed care as well as be able to benefit from the CHSP restorative, wellness and enablement approach;
- that can ensure access by all consumers nationally; and
- that addresses current client needs to assist consumers to transition through the system, while also ensuring that consumers can continue to be supported, empowered and have their rights protected, during ongoing change and within an evolving aged care system.

Appendix B. Key Review Questions

Key Review Questions

Table B-1: Key Review Questions

Theme	Component of the Review
<p>Current Commonwealth-funded advocacy services</p>	<ul style="list-style-type: none"> • How does the NACAP currently operate? <ul style="list-style-type: none"> – What is the scope? – What is the relationship between the NACAP and other state/territory level programmes? – What is working well? – What could be improved? – What are the challenges? • How does advocacy for HACC clients currently operate? <ul style="list-style-type: none"> – What is the scope? – What is the relationship between the HACC-funded advocacy services and other state/territory level programmes? – What is working well? – What could be improved? – What are the challenges? – What are the different definitions for advocacy services including individual, systemic and group advocacy? is the role of each advocacy type? • What is the Government’s role in supporting advocacy for consumers? • Is current programme design and delivery efficient? <ul style="list-style-type: none"> – What elements influence value for money within this environment? – What are the critical success factors in delivering advocacy services efficiently? • Are the programmes meeting the advocacy requirements of people with special needs? • What are the differences between NACAP and HACC advocacy service provision? <ul style="list-style-type: none"> – What are the key differences in the service models? – Are clients’ needs or presenting issues different/more complex in one programme than the other? – Do clients’ issues require multidisciplinary input? – Are there service gaps (or duplications)? • How is advocacy different when the focus of care is reablement (for Home Support clients) compared to ‘ongoing care’ (for HCP and residential care clients)? • What are the pros and cons of delivering information and education sessions

Theme	Component of the Review
	<p>to providers and recipients of HACC services and HCPs?</p> <ul style="list-style-type: none"> • What is the relationship between the Commonwealth-funded aged care advocacy services, the Aged Care Complaints Scheme and any similar services provided through the Department of Veterans Affairs?
<p>Other models of advocacy services</p>	<ul style="list-style-type: none"> • What are the key features of effective individual, systemic and group advocacy? • What models exist for effective end-to-end aged care advocacy services? • In the NDAP, what models are used for individual, group and systemic advocacy service provision? <ul style="list-style-type: none"> – Are there any overlaps with the current Commonwealth-funded aged care advocacy services?
<p>Moving to a new system</p>	<ul style="list-style-type: none"> • How will the current funding quantum meet the needs of current clients and anticipated growth in client numbers? • How can advocacy services support aged care clients within a consumer-directed care model? • How can future programme outputs be nationally consistent while still considering contextual factors in each jurisdiction? • How could internal DSS program management processes be made more streamlined and efficient? • What issues need to be considered in determining a viable funding model for aged care advocacy? • How can funding arrangements best account for different client needs, including variability for specific client groups (e.g. culturally and linguistically diverse) as well as the impact of geographical location? • What factors would need to be considered in advocacy programme funding being subject to contestability and long-term funding arrangements? • What factors need to be considered to ensure the service model is efficient and sustainable (including the role of the Commonwealth in ensuring market failure is avoided)? • What service delivery model options exist for an integrated, independent end-to-end aged care advocacy service? <ul style="list-style-type: none"> – How would success be measured? – What options could work for different types of consumers in different contexts? – What processes for Quality Assurance should be considered?

Appendix C. List of Stakeholders Consulted

List of Stakeholders Consulted

Organisation	Round 1: In-depth Interview	Round 2: Options Paper submission	Round 3: Consultation Workshop
NACAP-funded organisations			
Older Persons Advocacy Network (OPAN)		✓ (Advocacy TAS, on behalf of OPAN)	
The Aged-care Rights Services Inc (TARS)	✓	✓	✓
Elder Rights Advocacy (ERA)	✓	✓	✓
QLD Aged and Disability Advocacy Inc (QADA)	✓	✓	✓
Aged Rights Advocacy Services Inc (ARAS)	✓	✓	✓
Advocare Inc	✓	✓	✓
Advocacy Tasmania Inc	✓	✓	✓
Darwin Community Legal Service (Aged and Disability Advocacy Service (ADAS)	✓	✓	
CatholicCare NT	✓	✓	✓
ACT Disability Aged and Carer Advocacy Service (ADACAS)	✓	✓	✓
HACC/CHSP-funded organisations			
Ozcare Qld	✓		
Footprints Brisbane	✓		✓
City of Tea Tree Gully	✓		
Inner South West Community Development	✓		
COTA TAS	✓		
City of Salisbury	✓		
Bankstown area multicultural network	✓	✓	
City of Marion	✓		✓
Catholic Healthcare NSW ACT	✓		
IDEAS NSW	✓		✓
Tangentyere Council	✓		✓
Alzheimer Aust (ACT)	✓		
Mosman Community Council	✓	✓	✓
Partners 4 Health QLD	✓		✓
Central Hume Primary Care Partnership	✓		✓
Ethnic Community Services Cooperative		✓	

Appendix C: List of Stakeholders Consulted

Organisation	Round 1: In-depth Interview	Round 2: Options Paper submission	Round 3: Consultation Workshop
integratedliving Australia		✓	
Northside Community Forum		✓	
Southern Sydney Community Care		✓	
The Multicultural Network		✓	
Willoughby City Council			✓
Diversicare QLD			✓
Peak Bodies			
Aged and Community Services Australia (ACSA)	✓	✓	
Australian Blindness Forum		✓	
Alzheimer's Australia	✓	✓	✓
Alzheimer's Australia ACT			✓
Alzheimer's Australia NSW		✓	
Australian Red Cross	✓		
Alliance for Forgotten Australians	✓		✓
Carers Australia	✓	✓	✓
Carers Queensland		✓	
Care Leavers Australia Network (CLAN)	✓		
Combined Pensioners and Superannuants Association of NSW (CPSA)		✓	
Council of the Ageing (COTA)	✓	✓	✓
Federation of Ethnic Communities' Councils of Australia (FECCA)		✓	✓
Illawarra Forum		✓	✓
Leading Aged Care Services Australia	✓	✓	✓
National LGBTI Health Alliance	✓	✓	✓
National Seniors Australia	✓	✓	
Speech Pathology Australia		✓	
Val's Café/Australian Research Centre in Sex, Health & Society (ARCSHS)	✓	✓	
Vision Australia		✓	
Aged Care Services Providers			
Catholic Healthcare Australia	✓	✓	✓
Anglicare Australia	✓		

Appendix C: List of Stakeholders Consulted

Organisation	Round 1: In-depth Interview	Round 2: Options Paper submission	Round 3: Consultation Workshop
Anglicare Southern QLD			✓
Wintringham	✓		
Australian Nursing Home Foundation Limited	✓		
CareConnect	✓		
UnitingCare Australia	✓		✓
DutchCare	✓		
Salvation Army	✓		
Home Instead Senior Care		✓	
Resthaven Incorporated		✓	
DSS Internal Representatives			
DSS Home Care Packages Programme	✓		
DSS CHSP Home Support Policy	✓		
DSS Commonwealth HACC Programmes: Home Support Programmes	✓		
DSS National Disability Advocacy Programme	✓		
DSS National Disability Advocacy Programme – Quality Reporting	✓		
DSS Aged Care Quality Standards	✓		
DSS NACAP Grant Management	✓		
DSS Aged Care Complaints Scheme	✓		
DSS Multicultural Access and Equity Section	✓		
DSS Aged Care Programmes Qld	✓	✓	
DSS Aged Care Programmes NT	✓		
DSS Aged Care Programmes NSW/ACT	✓	✓	
DSS Aged Care Programmes Tas	✓		
DSS Aged Care Programmes SA	✓		
Partners in Culturally Appropriate Care (PICAC)			
Multicultural Communities Council of Illawarra	✓		
Multicultural Aged Care Incorporated	✓		
Other			
Disability Advocacy Network Australia	✓		
Office of the Aged Care Commissioner	✓	✓	✓

Appendix C: List of Stakeholders Consulted

Organisation	Round 1: In-depth Interview	Round 2: Options Paper submission	Round 3: Consultation Workshop
Office of the Health and Disability Commissioner NZ	✓		
Consumer/Carer		✓	
Volunteer Advocate, Alzheimer's Australia		✓	
Consumer/Advocate		✓	
Consumer		✓	
Consumer		✓	
Aged Care Crisis		✓	
Aged Care Finance Solutions and Reverse Mortgage Finance Solutions		✓	
Youngcare		✓	
Alpine Independent Aged Care Advocacy Service		✓	
Disability Advocacy NSW		✓	✓

Appendix D. Previous Reviews of the NACAP

Previous Reviews of the NACAP

This section summarises two previous reviews/evaluations of the NACAP. The first was conducted by external evaluators (Allen Consulting Group) in 2006.³⁴ The second was an internal administrative review undertaken in 2011.³⁵

2006 external evaluation

The purpose of the 2006 evaluation was to assess the effectiveness of the NACAP program against its stated objectives and identify potential areas of improvement for future arrangements, particularly in the areas of quality assurance and accountability. The evaluation was conducted over a five month period (February to June 2006) and included consultations with each NACAP program manager, Complaints Resolution Scheme (CRS) officers in each DHA State and Territory office and the Commissioner for Complaints.

Assessing the effectiveness of NACAP services was hindered by an absence of outcome data with the result that program outputs had to be used to measure the extent to which program objectives were met. Inconsistency in the reporting and collection of data across States and Territories posed further limitations.

When services were mapped against the the program's objectives, three of the four NACAP objectives were addressed (providing information, supporting decision making, and helping to resolve problems and complaints). No service provider was found to specifically address the fourth objective of promoting the rights of older people to the wider community, although the evaluators acknowledged this is most likely an outcome of other activities. Service providers differed considerably in terms of their service activity mix and the proportion of the potential client population served.

Efficiency was assessed by comparing funding to outputs. Considerable variation was evident in the efficiency of service delivery across and within NACAP providers.

NACAP accountability and quality assurance arrangements were found to have four major shortcomings:

- The NACAP objectives were not clear
- The NACAP Strategic Plan was not directly linked to the program's objectives
- The indicators used in the strategic plan did not provide clear measures of outcomes and outputs
- Some specific areas of reporting could be further defined and therefore more useful for analysis of service provision.

The 12 recommendations arising from this evaluation were grouped under three categories:

1. **Managing the NACAP.** Recommendations in this category included:
 - a. Utilising program administration approaches such as management-based approaches to case work services and performance based approaches to NACAP information and education based activities

³⁴ Allen Consulting Group, *Evaluation of the National Aged Care Advocacy Program*, Sydney, 2006.

³⁵ Australian Government Department of Social Services, *Internal Administrative Review of the National Aged Care Advocacy Program (NACAP)*, Canberra, 2011.

- b. A standardised referral process to the CRS and third parties
2. **Monitoring the NACAP.** The Manual of Standards for Advocacy Agencies developed by Aged Rights Advocacy Service in South Australia was recommended to be adopted as the basis for the NACAP quality assurance framework and that the standards be reviewed in line with any decisions about the future framework of NACAP quality assurance and accountability arrangements
3. **Reporting for the NACAP.** Eight of the 12 recommendations were listed in this category and included:
 - a. Collection of data on client outcomes
 - b. Reviewing and clarifying in the NACAP program objectives
 - c. Standardising intake processes for case work
 - d. Service providers using a standardised feedback form to collect data from aged care service providers
 - e. Establishing an independent complaints mechanism
 - f. Improving reporting measures, including refining the definition of 'a case' and developing measures for the total number and distribution of education sessions on consumer rights and responsibilities delivered at individual residential aged care facilities
 - g. Establishing base line activity targets
 - h. Developing annual performance reporting that compares NACAP service provider outputs and outcomes on selected performance measures
 - i. Investigating the impacts on program funding arrangements in light of possible changes to the strategic directions and objectives of the program.

2011 Internal Review

The internal review conducted in 2011 was based on information gathered through desktop research (including the previous NACAP and the Aged Care Complaints Investigation Scheme reviews) and input from Departmental program staff. At this point in time, the NACAP had been in place for more than 17 years and program administration had moved from the State Offices to Central Office in July 2008.

The review found a number of non-compliances in current practices in relation to the Commonwealth Grant Guidelines and recommended that program management and administrative practices be put in place for the following funding round and that multi-year agreements be established so the Department could link payments to deliverables.

Appendix E. Learnings from the literature

Introduction

AHA undertook a brief scan of the Australian and international literature for current learnings and evidence regarding the efficacy of advocacy service models for consumers and carers in the aged care sector. The focus was on exploring contemporary definitions of advocacy (including individual, systemic and group advocacy) across a range of comparable sectors.

The literature scan specifically focused on addressing the following key questions in this review:

- How is advocacy different when the focus of care is ‘reablement’ (HACC/CHSP) compared with ‘ongoing care’ (HCPs and Residential Care)?
- What are the key features of individual, systemic and group advocacy, as described in the literature?
- How can advocacy services support aged care clients within a consumer-directed care model?
- What models exist for effective end-to-end aged care advocacy services?
 - What funding models are used for these services?
- What is the role of government in supporting advocacy for consumers?

The literature scan findings section has been grouped according to these key questions.

The scan was an iterative process. That is, after each step in the methodology, review of the appropriateness of databases, terms, exclusion criteria, abstract review etc was undertaken to ensure the relevance and quality of the material collected. Search strategies were adjusted as required. References identified by stakeholders during the consultation process were also reviewed and included where relevant.

Literature scan findings

The search results from the published literature provided few references that had a specific focus on advocacy in the aged care sector. Of those identified, the majority focused on systemic or social justice advocacy. Williams et al. note that there *‘is a lack of robust evidence-based research around “what works” in relation to [information, advice and advocacy and] the literature...is rarely empirically grounded and therefore seldom offers robust evidence about whether or not these models actually “work”’* (Williams et al. 2009, p. 49).

Grey literature, including government reports, peak body reports and consultant reports provided more detailed discussion of the key questions, i.e. definitions of advocacy, models of service provision etc. The findings from the peer reviewed and grey literature have been combined below and discussed under each key question.

How is advocacy different when the focus of care is ‘reablement’ compared with ‘ongoing care’ (HCPs and residential care)?

No literature was identified that compared models of advocacy provision that focussed on reablement to those geared toward ‘ongoing care’. One study examined whether a ‘reablement’ type intervention compared to standard care could improve self-advocacy amongst a group of patients with mental illness. The randomised controlled trial compared the propensity of patients to self-advocate following either a peer-led mental illness self-management intervention (Wellness Recovery Action Planning –

WRAP) to those who received usual care. The study found a *'beneficial impact on patient self-advocacy'* in the WRAP-receiving group and that *'the more WRAP people received, the more positive patient self-advocacy attitudes and behaviours they reported'* (Jonikas et al. 2013, p. 266).

In some instances where care provision had a reablement focus the literature noted that providers became de facto advocates for their clients, though this was not their primary role, nor was there any comparison to other modes of care provision.

Meador et al. noted that the social worker case managers in their study became client advocates across a broad range of areas, dependent on the needs of the client. This activity was incidental to achieving particular goals and workers served as *'client advocates by contributing expert advice, realistic perspective, and flexible services'* (Meador et al. 2011, p. 10).

Caffrey reports that independent nurses working with the frail elderly living at home became advocates for clients in their dealings with other health professionals, particularly with physicians (Caffrey 2005).

What are the key features of individual, systemic and group advocacy, as described in the literature?

At its core, advocacy can be thought of as *'[drawing] attention to any problems needing resolution'* (Huber 2008, p. 4) or *'standing up for the rights of people who are being treated unfairly'* (Parsons 1994, p. 10). Despite these descriptions suggesting that the concept of advocacy is relatively straightforward, many types of advocacy are described in the literature, with terms, descriptions and features that are often overlapping. Even what constitutes 'advocacy' and the role/s of an advocate more broadly are ill-defined, with Drage noting that *'while the word "advocacy" is commonly used in an extensive range of settings, there is little consensus or in-depth analysis of how advocacy is used in practice, or what it is to be an advocate'* (Drage 2012, p. 54). The main approaches in the literature to grouping and defining advocacy services can be thought of in terms of:

- who the advocacy is for (e.g. an individual or a group)
- the capacity of the advocacy recipient (i.e. instructed or non-instructed advocacy)
- who provides the advocacy (e.g. a trained citizen, a lawyer, the individual themselves)
- the approach used to provide the advocacy (e.g. assistance, support/empowerment advocacy, or representation)
- how the advocacy is funded (e.g. volunteer, paid).

As previously noted these definitions and terms and the features of these advocacy types often overlap, and one type of advocacy may result in another. For example, empowerment advocacy (an approach to advocacy delivery), which focuses on sharing resources and information, aims to empower individuals to be able to advocate for themselves (self-advocacy) (Wealleans 1998).

Bearing this complexity in mind, a detailed discussion of each of the three advocacy types of interest (individual, systemic and group) is provided below, drawn from what consensus exists in the literature, as well as a brief discussion of the other types of advocacy identified. It should be noted that the majority of the literature and discussion around these advocacy types is drawn from the disability rather than aged care literature, as little such material exists.

Individual advocacy

The Tasmanian Government Department of Health and Human Services noted that:

'Individual advocacy focuses on the specific needs and rights of individuals and provides an environment in which individuals...can assert their rights, to challenge the decisions and actions which restrict their opportunities and to obtain justice and equality in their daily lives. (Tasmanian Government - Department of Health & Human Services 2007, p. 10)

Similarly, Pearson and Hill describe individual advocacy as upholding *'the rights and interests of people...on a one-on-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people...on a short-term and issue-specific basis'* (Pearson & Hill 2009, Appendix F, p. 1).

Who is it for?

Individual advocacy, as its name suggests, is provided to or on behalf of individuals, by individuals, in a one-on-one manner and is used for *'supporting and promoting the rights and interests of individuals'* (Muldowney 2011, p. 7).

What is the capacity of the recipient?

The advocacy can be either instructed or non-instructed. Instructed advocacy occurs when the recipient is able to instruct the advocate about their wishes, needs or concerns. In contrast, non-instructed advocacy refers to advocacy *'for people who lack capacity or who have severe communication needs'* (The Scottish Independent Advocacy Alliance 2008a, p. 5).

"Non-instructed advocacy is.....taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person's rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives" (Henderson 2006, p. 7).

Who provides the advocacy?

Advocacy is provided in a one-on-one setting, usually by an advocate that works as part of an advocacy agency or organisation. Individual advocacy may also be undertaken by a friend or associate. Advocacy provided by a family member is often classed separately as family advocacy (Dunning 2005; Muldowney 2011). Family carers often play a vital role in assisting care recipients to exercise choice, plan for their care and make complaints where required (Carers WA), and the national *Carer Recognition Act 2010* highlights the role of unpaid carers (most commonly spouses/partners, parents, or children of the care recipient) as partners in care (DSS 2011).

What is the approach?

There can be multiple approaches, depending on the needs of the recipient, i.e. assistance, support/empowerment advocacy, or representation.

The Department of Health and Human Services in Tasmania describe these three approaches (in the context of disability advocacy) as follows:

- **Assistance** – ‘standing beside’ people, for example, accompanying them to meetings, assisting them to clarify their goals, advocating their views
- **Support** – ‘standing behind’ people, for example, providing training for the person to advocate for themselves (empowering them), supporting them to speak up
- **Representation** – ‘standing before’ people, for example, speaking for or acting on behalf of people (Tasmanian Government - Department of Health & Human Services 2007).

How is the advocacy funded?

Advocates can either be paid or unpaid (volunteer) advocates.

Systemic advocacy

Systemic advocacy attempts to influence change within the ‘system’ (government policies, regulations, provider systems and broader public attitudes and discourse) in response to individual or group needs (Almog-Bar & Schmid 2013; Dunlop & Fawcett 2008; Mosley 2013). It is also referred to in the literature as public policy advocacy (Weafer & Woods 2003). More broadly, such attempts across the social welfare spectrum are referred to as social justice advocacy or social welfare activism (McNutt & Menon 2008), i.e. ‘advocating for the public good’ (Martinson, Minkler & Garcia 2013, p. 352).

In an Australian context, Pearson and Hill describe it as seeking ‘*to influence or secure positive long term changes that remove discriminatory barriers to ensure the rights and interests of groups of people...are upheld*’ (Pearson & Hill 2009, Appendix F, p. 1), whilst the Tasmanian Department of Health and Human Services note that it ‘*focuses on influencing and changing the systems – including government laws and policies, departmental procedures, generic community and [other] service practices – which may be adversely affecting people...[and] their families*’ (Tasmanian Government - Department of Health & Human Services 2007, p. 10).

Who is it for?

Systemic advocacy is generally undertaken on behalf of a group of people or a community with shared issues or concerns.

What is the capacity of the recipient?

The recipient’s capacity is not usually irrelevant, as the advocacy is not undertaken on behalf of an individual.

Who provides the advocacy?

Individual advocacy service providers, peak bodies, professional associations, citizens, non-government organisations, charities and lobby groups commonly undertake systemic advocacy.

What is the approach?

Approaches to systemic activity vary considerably according to cause, advocacy group and intended outcome. Strategies may include collective advocacy, community development, community education, resources development and lobbying (Family Advocacy 2015), such as submissions to government.

Systemic advocacy is increasingly occurring outside of the traditional means of approaching government (e.g. lobbying, submissions etc) and is moving online to get *'issues on the public agenda, [using] social marketing [and] policy-related research to influence decision makers'* (Dunlop & Fawcett 2008, p. 143). This rise in the use of technology in the field of advocacy has been described as *'cyberactivism'* (McNutt & Menon 2008), and a recent example in the aged care field is YourLifeChoices partnering with GetUp to campaign against proposed changes to the aged pension (GetUp 2015).

How is the advocacy funded?

Systemic advocacy can be either paid or unpaid.

Group advocacy

Discussion of group advocacy (also described as collective advocacy) was almost entirely absent from the literature. . Dunning describes group advocacy as *'self-advocacy groups and organisations that provide mutual support, skill development and a common call for change'* (Dunning 2005, p. 10), whilst Weafer and Woods describe it as *'a group of people campaigning on behalf of themselves or others to try and change things'* (Weafer & Woods 2003, p. 37). It could also be described as a simple variation on individual advocacy in situations where a group of individuals have shared needs or concerns (Disability Advocacy Resource Unit (DARU), n.d.).

Who is it for?

Group advocacy is undertaken on behalf of groups of individuals with common concerns or issues.

What is the capacity of the recipient?

Recipients within groups may be able to provide instruction, but this is not necessary.

Who provides the advocacy?

The advocacy can be provided by an independent advocate to a group, or it *'enables a peer group of people, as well as a wider community with shared interests, to represent their [own] views, preferences and experiences'* (NHS Highland 2015).

What is the approach?

Depending on the issue and the group being represented, systemic advocacy approaches or individual advocacy approaches may be required.

How is the advocacy funded?

Group advocacy can be either paid or unpaid.

Other advocacy types

The literature identified a multitude of other types of advocacy, the most common other types being:

- **Citizen advocacy** – The approach was founded by Wolf Wolfensburger in the 1960s in the area of intellectual disability (Pearson & Hill 2009). The advocacy is a *‘one-to-one, long-term partnership between an independent, unpaid ‘ordinary person’ and a disadvantaged ‘partner’* (Dunning 2005, p. 10).
- **Family advocacy** – is similar to individual advocacy in that it champions the interests of an individual, however the advocate *‘works with parents and family members [of that individual] to enable them to act as advocates on behalf of a family member. Family advocates work with parent and family members on a short-term and issue-specific basis’* (Pearson & Hill 2009, Appendix F, p. 2).
- **Legal advocacy** – *‘Is the most established and widely recognised form of advocacy and is undertaken by trained lawyers’* (Dunning 2005, p. 10) who *‘defend the rights and interests of people...on a one-on-one basis through the...legal system’* (Pearson & Hill 2009, Appendix F, p. 2).
- **Peer advocacy** – occurs when *‘one person advocates for another who shares a common experience, difficulty or discrimination’* (Dunning 2005, p. 10).
- **Professional advocacy** – advocacy undertaken by a professional as part of their job, but is not their specific role, e.g. nurse, social worker (Bliss 2015).
- **Self-advocacy** - There is a strong self-advocacy movement within the intellectual disability movement, which encourages *‘speaking up for yourself’* to represent your own needs, wishes and interests’ (Dunning 2005, p. 10). Self advocacy encourages *‘making informed decisions and taking responsibility for those decisions’* (Merchant & Gajar 1997, p. 223)
- **Informal advocacy** – This type of unpaid advocacy occurs most commonly when families, friends and carers advocate for those they care for or about. *‘This form of advocacy may require an investment of time and effort and at times the advocate may be perceived as not completely independent in pursuing the best interests of the consumer if potential conflicts of interest exist in the relationship’* (Health Consumers Queensland 2011).

What models exist for effective end-to-end aged care advocacy services? What funding models are used for these services?

Models

There is little detailed information available about end-to-end aged care advocacy services and as noted previously, there *'is a lack of robust evidence-based research around "what works"'* (Williams et al. 2009, p. 49). The little information available does not allow for effectiveness to be determined, although it has been noted that the process of advocacy can promote consumer empowerment, provide practical support and facilitate the development of relationships (Stewart & MacIntyre, 2013).

However, Action for Advocacy outline ten key themes for good practice in advocacy more broadly. These are:

1. Putting people first
2. Empowerment
3. Equal opportunity
4. Clarity of purpose
5. Independence
6. Accessibility
7. Accountability
8. Support of advocates
9. Confidentiality
10. A complaints mechanism (Action for Advocacy 2006).

As an example, the governing guidelines of New Zealand's Health and Disability Advocacy Service model resonate with the themes described above, including empowerment, low-level resolution, quality and compliance with a code of practice, accessibility, systemic advocacy, priority populations and advocate support (King 2005). The model 'operates through a national contract between the director of advocacy in the Health and Disability Commissioner's office (a publicly-funded crown entity) and the National Advocacy Trust (the governing body)' (Drage 2012, p. 55).

While not a regulatory body, The Scottish Independent Advocacy Alliance (SIAA) is a peak body that supports independent advocacy organisations across sectors. The SIAA has developed principles and standards for independent advocacy, a code of practice, an evaluation framework and indicators for individual advocates and advocacy organisations, and specific guidelines for elder abuse advocacy. The principles reflect consumer-directed advocacy, accountability, independence and accessibility (The Scottish Independent Advocacy Alliance 2008b).

Funding

Little information is available that details the funding models used to provide aged care advocacy services, beyond that government is the most common provider of such funding, particularly in an

Australian context. The particular mechanisms for this funding, and funding agreements were not readily available for review.

Consideration of the importance of independence leads to a number of potential funding scenarios including:

- Central (e.g. government) funding
- Local administration of funds (e.g. from a pooled budget)
- Funding from a central body with specialist initiatives
- Multi-source funding (sought by service providers)
- 'No strings attached' funding allocation (Stewart & MacIntyre, 2013).

While the New Zealand National Health and Disability Advocacy Service is publicly-funded, it operates independently of government agencies and service providers (Drage 2012). Wright notes that in the UK, funding of advocacy services for care home residents often comes from multiple sources, including different levels of government or government funded bodies, such as '*local authorities and health care trusts*' as well as chariTable sources, such as '*the Community Fund or Comic Relief*' (Wright 2005, p. 12). ChariTable funding was identified as a common funding source for advocacy services, particularly in the UK. For example:

- In Wales, Age Cymru note that approximately 20% of advocacy funding comes from chariTable trusts, including the Big Lottery AdvantAGE Fund for Wales (Age Cymru 2011).
- The Big Lottery Fund in the UK provides funding to the Older People's Advocacy Alliance (OPAAL), to conduct specific aged care advocacy projects. The Big Lottery Fund is responsible for distributing over £650 million each year in National Lottery money, via grants, to '*community groups and projects that improve health, education and the environment*' (The Big Lottery Group 2015a). OPAAL received a grant to conduct a project titled *Advocacy on the Wards*, which aimed to '*to guide older cancer patients through care in hospitals and homes across England*' (The Big Lottery Group 2015b).
- In Western Australia, Advocare is supported by LotteryWest grants (Advocare Incorporated 2015).

The grant funding model is, however, not specific to aged care advocacy, or even advocacy more broadly.

Two themes emerged from the literature in regard to funding; first that independently-funded advocacy was important (Drage 2012; Dunning 2005) and second, that funding uncertainty was a concern for a number of advocacy service providers (Age Cymru 2011; Older People's Advocacy Alliance UK 2004; Wright 2005) - '*all advocacy schemes struggle for financial stability*' (Older People's Advocacy Alliance UK 2004, p. 30).

How can advocacy services support aged care clients within a consumer-directed care model?

The literature did not include any material with a specific focus on aged care advocacy services that support a consumer-directed care model, however we note that NACAP-funded organisations already provide advocacy services for clients that receive support within such a framework.

However, as described above, ‘putting people first’ and empowerment are consistently highlighted as key principals in advocacy service provision.

The SIAA has documented research into the impact of independent advocacy that suggested it can help older people maintain independence, access information and address any power imbalance. It can also provide vital support to those suffering from physical or cognitive impairment, and safeguard the rights of older people (The Scottish Independent Advocacy Alliance 2014).

Outside of the aged care sector, but still within an Australian context, the NDIS offers another model of support in which a consumer-directed approach is a key objective. Monitoring how advocacy services work with NDIS clients across the current trial sites may provide an area of future best practice to draw upon for developing such a service in the aged care sector.

AHA also notes that the draft *Good Practice Guide for Restorative Care Approaches (incorporating Wellness, and Reablement)* details that Home Support clients will be supported ‘to have access to independent and confidential advocacy services (pending implementation of the reviewed National Aged Care Advocacy Programme from 1 July 2016)’ (Australian Government Department of Social Services 2015).

What is the role of government in supporting advocacy for consumers?

None of the literature identified addressed this question, however in Australia, New Zealand and the UK, the role of government appears to primarily be in providing funding for independent advocacy services, across a range of settings (e.g. disability, aged care). Indeed, this independence from government as well as service providers has been highlighted as a key feature of New Zealand’s Health and Disability Advocacy Service (Drage 2012).

Literature scan methodology

Databases

AHA searched the following databases:

- **AgeLine**
Specifically 50 plus focus, on issues of aging. Includes social gerontology literature with aging-related content from the health sciences, psychology, sociology, social work, economics and public policy.
- **CINHAL**
Database has a nursing focus, but also covers biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines.
- **Cochrane Library**
Comprises seven databases, containing ‘high-quality, independent evidence to inform healthcare decision-making’ and about Cochrane groups.

Appendix E: Learnings from the literature

- **PubMed**

Provides access to MEDLINE®, which covers medical, nursing, dental, veterinary, health care, and preclinical sciences.

- **Social Sciences Citation Index (SSCI)**

Database that includes anthropology, sociology, urban studies, business and communication, criminology, penology, law, nursing, rehabilitation, and information and library sciences.

- **SCOPUS**

The largest abstract and citation database of peer-reviewed literature including scientific journals, books and conference proceedings across the fields of science, technology, medicine, social sciences, and arts and humanities.

Key search terms

The following search terms, in various combinations with Boolean Operators, formed the basis for the first round of searching, undertaken in March 2015:

Advocacy keywords	Aged care keywords	Reablement keywords
<ul style="list-style-type: none">• Advocacy• Consumer Advocacy• Patient Advocacy• Advoca*	<ul style="list-style-type: none">• Aged• Age*	<ul style="list-style-type: none">• Re-ablement/reablement• Prevention• Restorative• Active service model• Independence/Independent• Client focussed• Strength based• Advice and support• Wellness.

Exclusion criteria

The following exclusion criteria were used to focus the search:

- English language only
- Previous 10 years (2005 – 2015)
- Limited to USA, UK, Canada, Australia, New Zealand, Sweden, Ireland, Norway, Denmark, Finland
- Exclusion of various terms, depending on the database, including HIV, AIDS etc

Article review

The abstract of articles that match the above criteria were reviewed for relevance and those that fell outside of the scope of the review will be discarded.

Snowballing

Additional references were sought via 'snowballing' (Jalali & Wohlin 2012), that is, reviewing the reference list of key papers and obtaining pertinent articles that have were not identified via the searching detailed above.

Grey literature

In addition to examination of peer-reviewed published literature, searches were conducted to identify reports and evaluations in the grey literature. Information and strategic documents of relevance to understanding recent progress and identifying effective interventions included:

- **Online reports and evaluations of advocacy services** for people utilising or intending to utilise aged care services at the state/provincial and national levels such as:
 - Government reports and guidelines, reports from health services, conference proceedings, theses and unpublished studies
 - Evaluations of programs that aim to address relevant advocacy needs
- **Websites of research institutes, health organisations, professional organisations (e.g., colleges) and other relevant non-government organisations** involved in aged care advocacy-related activities.

Stakeholder identification

References identified by stakeholders through the consultation process were also included as relevant.

References

Action for Advocacy 2006, *Quality standards for advocacy schemes*, Action for Advocacy, London.

Advocare Incorporated 2015, *Advocare Incorporated Homepage*, Advocare Incorporated, viewed 24 April 2015.

Age Cymru 2011, *Advocacy Counts 3: The third report on advocacy provision for older people in Wales*, Age Cymru, Cardiff.

Almog-Bar, M & Schmid, H 2013, 'Advocacy activities of nonprofit human service organizations: A critical review', *Nonprofit and Voluntary Sector Quarterly*, vol. 43, no. 11, pp. 11-35.

Australian Government Department of Social Services 2015, *Discussion Paper for the Commonwealth Home Support Programme: Good Practice Guide for Restorative Care Approaches (incorporating Welless, and Reablement)*, Australian Government Department of Social Services, Canberra.

Bliss, D 2015, 'Using the Social Work Advocacy Practice Model to Find Our Voices in Service of Advocacy', *Human Service Organizations: Management, Leadership & Governance*, vol. 39, no. 1.

Caffrey, RA 2005, 'Community care gerontological nursing: the independent nurse's role', *Journal of gerontological nursing*, vol. 31, no. 7, p. 18.

Carers WA, Support packs for families whose loved one is entering residential aged care, viewed 16 September 2015, <http://www.carerswa.asn.au/resources/Residential-Aged-Care-folder_web-version.pdf>.

Department of Social Services (DSS) 2011, *National Carer Strategy Evidence Base October 2011*, Commonwealth of Australia, Canberra.

Disability Advocacy Resource Unit (DARU), no date, 'What is Advocacy', <http://www.daru.org.au/what-is-advocacy>; viewed 20 August 2010, <http://www.daru.org.au/what-is-advocacy>>

Drage, J 2012, 'New Zealand's national health and disability advocacy service: a successful model of advocacy', *Health and Human Rights: An International Journal*, vol. 14, no. 1, pp53-63.

Dunlop, JM & Fawcett, G 2008, 'Technology-based approaches to social work and social justice', *Journal of Policy Practice*, vol. 7, no. 2-3, pp. 140-54.

Dunning, A 2005, 'Information, advice and advocacy for older people', *Joseph Rowntree Foundation*.

Family Advocacy 2015, *Systemic Advocacy*, Family Advocacy, viewed 25 April 2015, <<http://www.family-advocacy.com/our-work/systemic-advocacy/%3E>>.

GetUp 2015, *Protect the Aged Pension*, GetUp, viewed April 25 2015, <<https://http://www.getup.org.au/campaigns/pensions/pensions-petition--2/protect-the-age-pension%3E>>.

Health Consumers Queensland, *Health Advocacy Framework: Strengthening Health Advocacy in Queensland*. Queensland Government, Brisbane, 2011, p.18.

Henderson, R 2006, 'Defining non-instructed advocacy', *Planet Advocacy*, vol. 18, pp. 5-7.

Appendix E: Learnings from the literature

Huber, R 2008, *Elder advocacy : essential knowledge and skills across settings*, Thomson Brooks/Cole, Belmont, CA.

Jalali, S & Wohlin, C 2012, 'Systematic literature studies: database searches vs. backward snowballing', in *Proceedings of the ACM-IEEE international symposium on Empirical software engineering and measurement*, pp. 29-38.

King, A 2005, *Advocacy guidelines for the NAtionwide Advocacy Service*, viewed 16 September 2015, <<http://advocacy.hdc.org.nz/resources/advocacy-guidelines>>.

Jonikas, JA, Grey, DD, Copeland, ME, Razzano, LA, Hamilton, MM, Floyd, CB, Hudson, WB & Cook, JA 2013, 'Improving propensity for patient self-advocacy through wellness recovery action planning: results of a randomized controlled trial', *Community mental health journal*, vol. 49, no. 3, pp. 260-9.

Martinson, M, Minkler, M & Garcia, A 2013, 'Honoring, Training, and Building a Statewide Network of Elder Activists: The California Senior Leaders Program (2002–2012)', *Journal of Community Practice*, vol. 21, no. 4, pp. 327-55.

McNutt, JG & Menon, GM 2008, 'The rise of cyberactivism: Implications for the future of advocacy in the human services', *Families in Society: The Journal of Contemporary Social Services*, vol. 89, no. 1, pp. 33-8.

Meador, R, Chen, E, Schultz, L, Norton, A, Henderson, C, Jr. & Pillemer, K 2011, 'Going Home: Identifying and Overcoming Barriers to Nursing Home Discharge', *Care Management Journals*, vol. 12, no. 1, pp. 2-11.

Merchant, DJ & Gajar, A 1997, 'A review of the literature on self advocacy components in transition programs for students with learning disabilities', *Journal of Vocational Rehabilitation*, vol. 8, no. 3, pp. 223-31.

Mosley, J 2013, 'Recognizing new opportunities: Reconceptualizing policy advocacy in everyday organizational practice', *Social work*, vol. 58, no. 3, pp. 231-9.

Muldowney, A 2011, *Discussion paper on Individual Advocacy and Caring Families*, Carers Association Victoria, Footscray.

NHS Highland 2015, *Independent Advocacy*, NHS Highland, viewed 25 April 2015, <<http://www.nhshighland.scot.nhs.uk/Services/ASC/IndependentAdvocacy/Pages/welcome.aspx%3E>>.

Older People's Advocacy Alliance UK 2004, *Advocacy- who cares for older people? Regional Development Programme June 2004 to December 2004*, Older People's Advocacy Alliance UK, London.

Parsons, I 1994, *Oliver Twist has asked for more: The politics and practice of getting justice for people with disabilities*, Villamanta Publishing Service, Geelong.

Pearson, J & Hill, S 2009, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, Jenny Pearson & Associates Pty Ltd for the Department of Families, Housing, Community Services and Indigenous Affairs.

Stewart, A & MacIntyre G, 2013, *Advocacy: models and effectiveness*, Institute for Research and Innovation in Social Services, Glasgow.

Tasmanian Government - Department of Health & Human Services 2007, *The Role of Advocacy Services in the Tasmanian Disability Sector: An Information Booklet*, 9780980518894, Tasmanian Government -

Appendix E: Learnings from the literature

Department of Health & Human Services, Hobart,
<<https://books.google.com.au/books?id=mtXOoAEACAAJ>>.

The Big Lottery Group 2015a, *About Big Lottery Fund*, The Big Lottery Group, viewed 24 April 2015,
<<https://http://www.biglotteryfund.org.uk/about-big%3E>.

— 2015b, *The Big Blog*, The Big Lottery Group,, viewed 24 April 2015 2015,
<<http://bigblog.org.uk/2013/05/14/cancer-older-people-and-advocacy/%3E>.

The Scottish Independent Advocacy Alliance (SIAA) 2008a, *Elder Abuse Advocacy Guidelines*, SIAA, Edinburgh.

The Scottish Independent Advocacy Alliance (SIAA) 2008b, *Principles and Standards for Independent Advocacy*, SIAA, Edinburgh.

Weafer, JA & Woods, M 2003, *Jigsaw of Advocacy: A Research Report*, Comhairle, Dublin.

Wealleans, N 1998, 'The quest for consumer voice: An evaluation of the implementation and outcomes of the Health and Disability Commissioner Act 1994', *Master of Social Work thesis*, p. 58.

Williams, C, Harris, J, Hind, T & Uppal, S 2009, *Transforming Adult Social Care: Access to Information, Advice and Advocacy*, Improvement and Development Agency, London.

Wright, F 2005, 'Explaining about.... advocacy and care home residents', *Working with Older People*, vol. 9, no. 1, pp. 9-12.

Appendix F. Options Paper

Department of Social Services Review of Commonwealth Aged Care Advocacy Services **Options Paper** August 2015



List of abbreviations

Abbreviation	Definition
AHA	Australian Healthcare Associates
CDC	Consumer-Directed Care
CHSP	Commonwealth Home Support Programme
DSS	Department of Social Services
HACC	Home and Community Care
HCP	Home Care Package
NACAP	National Aged Care Advocacy Programme
NDAP	National Disability Advocacy Program

Introduction

Australian Healthcare Associates (AHA) were engaged in February 2015 by the Department of Social Services (DSS) to undertake a review of Commonwealth Aged Care Advocacy Services (the review).

The aim of the Review is to inform the future service delivery model for an end-to-end individual advocacy programme that can best support consumers to:

- Effectively interact with the aged care system
- Better transition between service types
- Be empowered to apply informed decision making and actively exercise choice.

This options paper has been developed as part of the Review process.

It should be noted that, for the purpose of the review the term ‘end-to-end’ has been adopted to demonstrate that the future aged care advocacy programme will be accessible to consumers across the spectrum of Commonwealth aged care services. .

Current Commonwealth aged care advocacy

The Australian Government currently funds individual advocacy services for aged care consumers through :

- the National Aged Care Advocacy Programme (NACAP)
- the Commonwealth Home Support Programme (CHSP).

NACAP services are provided by a single independent organisation in each state/territory (with the exception of the Northern Territory, where there are two NACAP providers).

It should be noted that from 1 July 2015, the Commonwealth Home and Community Care (HACC) Programme transitioned to the CHSP.

While the two programmes operate separately, the core focus of providing individual advocacy support is consistent across both programmes, however to a certain extent, the delivery varies across programmes and jurisdictions. The implementation of a single end to end programme will enhance consistency and define advocacy service delivery across the aged care spectrum.

Purpose

This 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 focused 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 this 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 are listed at the end of each section of the options paper. Please respond to these questions using the feedback form that accompanies this paper. 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 on 03 9663 1950 or:

jill.waddell@ahaconsulting.com.au

tracey.higlett@ahaconsulting.com.au

Future options

Definitions of advocacy

The following definitions are proposed to guide the delivery of a nationally consistent end-to-end aged care advocacy service that is focussed on individual support:

Advocacy is the process of supporting an individual so that their voice is heard.³⁶

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 to understand and uphold their rights and participate in decisions affecting their care.

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.

Systemic advocacy focuses on influencing and changing systems – including government laws and policies, departmental procedures, community and other service practices – which may be adversely affecting people and their families.³⁷

Note: Although systemic advocacy is not the subject of this review, there is a strong view among stakeholders interviewed and in the literature; (see for example Pearson and Hill³⁸) that a mechanism through which individual issues can be fed into the systems/policy level is an essential component of a well-functioning individual advocacy system.

Discussion question:

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?

³⁶ QADA, What is Advocacy? < <http://www.qada.org.au/about-qada/what-advocacy> > Viewed 27 May 2015

³⁷ Adapted from Tasmanian Government Department of Health and Human Services 2007, *The Role of Advocacy Services in the Tasmanian Disability Sector: An Information Booklet*, 9780980518894, Tasmanian Government - Department of Health & Human Services, Hobart, < <https://books.google.com.au/books?id=mtXOoAEACAAJ> >.

³⁸ Pearson, J & Hill, S 2009, *Research of the Models of Advocacy Funded under the National Disability Advocacy Program*, Jenny Pearson & Associates Pty Ltd for the Department of Families, Housing, Community Services and Indigenous Affairs.

Development of a national framework

The development of a national service delivery framework has been identified as a potential option for guiding a nationally consistent approach to delivering aged care advocacy. The framework would potentially include:

- Agreed definitions for advocacy
- The guiding principles for the provision of advocacy
- The objectives and aims of the programme
- Clear expectations for service and client outcomes (Standards and/or practice implications)
- Quality assurance and reporting requirements for service providers
- Mechanisms for sharing information, training and resources between services
- Formalised networks with relevant areas of DSS and the Aged Care Complaints Scheme. .

Discussion questions:

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

What other considerations should be given to developing a framework?

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

Key principles and priorities consistently identified by stakeholders as supporting the delivery of high quality and effective aged care advocacy services include:

- Advocacy services are independent of service delivery and free of any perceived conflict of interest
 - Advocacy services ensure consumers are placed at the centre of process
 - Advocacy services aim to ensure that the rights of consumers in receiving consumer directed care (CDC) services are supported, and that consumers can be empowered to exercise informed choice and self-advocate. This is particularly important for consumers who are experiencing cognitive decline
- Advocacy services focus on ensuring access to services for people with diverse needs groups and those who may face barriers to accessing services (i.e. 'go to where they go; don't expect them to come to you')
- Advocacy services embed a strong emphasis on proactive/preventative advocacy support by strengthening and building the capacity of consumers as well as educating and building the capacity of services providers to uphold the rights of consumers
 - Advocacy services use proven and tested practices and are delivered to a high standard by a competent and skilled workforce

- Advocacy services contribute to other quality assurance mechanisms within the aged care system through **analysis of the systemic trends** which emerge through individual advocacy work
- Advocacy services have strong governance and management systems which ensure services are organised for safety, effectiveness and efficiency
- Advocacy services maintain constructive **positive relationships** with key stakeholders which, while recognising the independence of the programme, allows for collaborative approaches to improving quality of life and quality of care for aged care recipients.

Discussion questions:

Do these principles represent good practice for the programme?

Are there other principles or key priorities that are critical to the success of an end-to-end aged care advocacy service delivery model?

Objectives and service scope

The following objectives are identified as framing the core elements of an effective aged care advocacy programme:

4. Assist people receiving all Commonwealth aged care services or their representatives to resolve problems or complaints in relation to aged care services, through the provision of individual advocacy
5. Support people receiving aged care services to be involved in decisions that affect their life, and empowering them to exercise their rights and increased choice
6. Provide people receiving aged care services with information and advice about their rights and responsibilities
7. Promote the rights of people receiving aged care services to aged care providers
8. Support consumers to address issues that impact their ability to live in their own homes, with the aim of preventing premature admission to aged care facilities. Consumers who are experiencing cognitive decline receive particular focus, so that they are provided the care they want/need to support their ability to remain at home, if they wish to do so.
9. Promote and support consumers to achieve their restorative wellness and reablement goals
10. Proactively assist consumers as they move through the aged care system to make decisions about how, where and from whom they receive care, and to understand the financial implications of these options
11. Be **accessible** to all consumers of Commonwealth funded aged care services and their representatives
12. Ensure open and constructive **communication, consultation and feedback** mechanisms and clear points of contact.

Discussion questions:

Are these objectives appropriate for an end-to-end aged care advocacy model?

Are there other objectives that should be included?

Outcomes sought

Stakeholders have proposed that an aged care advocacy system should achieve the following outcomes:

- The rights of all aged care consumers are prioritised and upheld
- Consumers have their aged care needs met and satisfied with the advocacy services received
- Consumers are empowered to participate in decisions about their care, exercise choice and are supported in reaching their wellbeing and reablement goals
- Service providers understand their obligations and responsibilities, as well as the rights of consumers, in relation to aged care service provision
- Quality of aged care service provision is enhanced

Discussion questions:

Are there other outcomes that an end-to-end aged care advocacy service should aim to achieve?

Can these outcomes be effectively measured?

Eligible client populations

It is proposed that eligibility for a future end-to-end aged care advocacy service include all consumers (as well as their representatives) of Commonwealth funded aged care services, as well as people who are seeking to receive aged care services but are yet to enter the system.

Discussion question:

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

Service structure

Number of funded organisations and geographical spread

The following options are proposed in order to further explore stakeholder views on how a future aged care advocacy programme could be structured – noting that there are inherent trade-offs and benefits for each option in relation to efficiency, national consistency, access and flexibility to respond to local needs.

Option 1: Establish a single, national, centralised aged care advocacy service with jurisdiction-based offices. This could potentially drive greater efficiency and consistency but could compromise the ability to develop flexible approaches tailored to local need.

Option 2: Retain the existing structure of nine separate jurisdiction-based organisations, and additional independent providers organised around special needs groups or specialist intervention.

Option 3: Expand the number of advocacy service providers by funding smaller, regionally-based providers (similar to the model used in the National Disability Advocacy Program (NDAP)). Population figures and remoteness variables would be considered in determining the number of providers. Such an approach may enable delivery of more localised services (and possibly better coverage of rural/remote areas), but with potential loss of national programme consistency, and possibly at higher cost. Stakeholders also indicated that quality assurance, reporting and administrative processes may carry a higher relative burden for smaller providers with fewer staff.

Discussion questions:

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?

In the preferred option, how can the trade-offs be minimised?

Are there other options to consider?

Funding considerations

Consistent with the definitions provided in Section 2.1, it is suggested that funding for aged care advocacy should be reserved for those services providing individual, independent advocacy.

The funding model for the advocacy programme should be explicit, and account for the costs associated with delivering advocacy services to rural/remote consumers and people from other special needs groups.

Discussion question:

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

Ensuring access and appropriateness for people from special needs groups

Ideas to ensure appropriate and accessible services to people from special needs groups are listed below.

These ideas are complementary rather than mutually exclusive, and services would ideally include most or all as part of advocacy service provision:

- Providing mandatory training for advocates on issues relating to special needs groups
- Including advocates with expertise in or affiliations with special needs groups on staff
- Delivering specific models of advocacy support to people from special needs groups (e.g. the Supported Decision Making model for people with dementia piloted by Advocacy Tasmania)
- Ensuring that advocacy service providers have ready access to interpreters (including funding/access to government-funded interpreter scheme)
- Supporting mechanisms for ‘warm referral’/‘supported referral’ of special needs consumers to advocacy services, including:
 - Special needs groups speaking to the advocacy service on the consumer’s behalf and providing preliminary information (with the consumer’s consent)
 - Special needs groups following up with the consumer to ensure satisfactory outcomes have been achieved
- Warm referral is acknowledged as essential to enabling consumers who are reluctant to engaging with services to do so
- Targeting efforts to engage face-to-face with people from special needs groups, either via peak bodies or at community events
- Formalising brokerage arrangements to facilitate referral of people from special needs groups who require independent advocacy:
 - By advocacy services to specialist organisations (e.g. referral of clients with dementia to Alzheimer’s Australia)
 - To advocacy services for independent advocacy (e.g. the model used by Partners 4 Health (Qld) through which CHSP clients received advocacy brokered through a specialised advocacy services)

Discussion questions:

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

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?

Interface with other services

In order to deliver quality, consumer-focussed advocacy services, advocacy providers reported the importance of developing and maintaining a range of stakeholder relationships, through formal or informal arrangements. These include but are not limited to:

- Aged care service providers
- Peak bodies representing aged care consumers and the interests of special needs groups
- The Aged Care Complaints Scheme*
- Regional Assessment Services and My Aged Care
- Relevant DSS branches
- Specialist service providers in a range of other areas including those relating to housing, healthcare, legal services and financial services.

** From 1 January 2016, responsibility for the Aged Care Complaints Scheme will transfer to the Aged Care Commissioner. This transfer is increasing the independence of the aged care complaints handling mechanism and build sector confidence in the complaints process.*

Interface with Disability Advocacy Services

The shared consumer rights-based ethos of both the NDAP and aged care advocacy programmes is acknowledged. Additionally it is noted that the aged care sector is building on the learnings of the disability sector in relation to consumer choice and empowerment. This review is seeking to further explore the extent to which the strengths of the NDAP could be applied to aged care advocacy, and vice versa.

Discussion questions:

Are there any strengths of the NDAP that could be considered in a future aged care advocacy model or conversely from aged care advocacy with the NDAP?

Are there synergies and improved interactions between the existing programmes that should be considered?

Summary and next steps

This options paper has considered a range of stakeholder priorities for a nationally consistent end-to-end aged care advocacy model. It has presented a range of options for consideration in the development of a future model, and seeks stakeholder views on these options. It is important to note that many components of such a model already exist, and that the achievements of the existing advocacy service providers over the past 25 years are recognised.

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.

Appendix G. Stakeholder Workshop: Agenda

Review of Commonwealth Aged Care Advocacy Services

Consultation workshop: Agenda

Date: Thursday 24 September 2015

Time: 10am – 3pm

Location: Stamford Plaza, Sydney Airport

Forum aims:

1. To provide an overview of key findings from the Options Paper consultation process
2. To build on the Options Paper process by discussing possible key elements for the design of a national aged care advocacy service delivery model, including trade-offs and benefits of the options proposed
3. To provide participants with an opportunity to explain their perspectives in more detail.

Please note that the forum is not intended as a means of making definitive decisions about the service delivery model for aged care advocacy. Rather, the aim is to gather further information on stakeholder perspectives in order to guide decision-making within the Department of Social Services.

Time	Item	Discussion lead
10.00	Morning tea on arrival	
10.10	Welcome	AHA
10.25	Introductory activity	AHA
10.35	Background and context	DSS
10.45	Consultation process and key findings	AHA
11.10	Discussion Session 1: Desired outcomes of a national aged care advocacy model	All
12.00	Discussion Session 2: Special Needs Groups and service scope	All
12.45	Lunch	
1.15	Discussion Session 3: Service Structure	All
2.25	Revisiting key issues raised during the workshop	All
2.45	Summary and next steps	AHA and DSS
2.55	Meeting close	AHA

Appendix H. Briefing Paper

Review of Commonwealth Aged Care Advocacy Services

Consultation workshop: Briefing paper

Introduction

This paper has been developed to support the consultation workshop for the Review of Commonwealth Aged Care Advocacy Services. It provides participants with some high level feedback from the Options Paper consultation process, and outlines the key areas for discussion at the workshop.

It is noted that with the focus of change to the aged care system centred on embedding increased choice for consumers, individual advocacy has been identified as fundamental in supporting consumers effectively interact with the aged care system. It is important to note that individual advocacy is only one element of a suite of possible and/or necessary supports for consumers to assist them with exercising choice and control. This review is focussing on developing an effective individual advocacy programme that will form part of a broader approach to supporting consumer empowerment. The Aged Care Sector Committee through its work on the Aged Care Roadmap will consider what shape this additional consumer support might take.

Workshop Aims

The aims of the workshop are:

1. To provide an overview of key findings from the Options Paper consultation process
2. To build on the Options Paper process by discussing possible key elements for the design of a national aged care advocacy service delivery model, including trade-offs and benefits of the options proposed
3. To provide participants with an opportunity to explain their perspectives in more detail.

Note: The forum is not intended as a means of making definitive decisions about the service delivery model for aged care advocacy. Rather, the aim is to gather further information on stakeholder perspectives in order to guide decision-making by the Department.

Options Paper consultation process: high level findings

The following key themes emerged through the Options Paper consultation:

- Aged care advocacy is vital to upholding the rights of aged care consumers
- Access to services by people from special needs groups requires ongoing effort
- Advocacy must be independent from aged care service provision
- Individual advocacy must be linked with, and inform, systemic advocacy processes
- Opportunities to strengthen linkages with grass-roots/community organisations should be explored

- A national framework for aged care advocacy was supported as a means for driving consistency
- A national framework should focus on meaningful and measurable outcomes.

While there was relatively strong consensus in these areas, responses to some other questions revealed divergent views. These topics have been prioritised for discussion at the workshop. The sections below outline the workshop discussion topics and include a brief overview of the issues raised to date, and prompts to guide the discussion.

Discussion Session 1: Desired outcomes of a national aged care advocacy model

Overview

There was general support for the proposed outcomes suggested for the aged care advocacy model, with minor amendments suggested by a number of stakeholders. Many respondents raised issues relating to measurement of the outcomes of aged care advocacy services. Based on the feedback provided, the following set of outcomes is proposed (note that these are not final but rather intended to stimulate discussion):

- Consumers are supported to have their aged care wishes and needs heard and acknowledged
- Consumers are empowered to make informed decisions about their care and to exercise choice
- Consumers are supported in reaching their wellness and reablement potential
- Service providers are supported to understand their obligations and responsibilities, as well as the rights of consumers, in relation to aged care provision

Note: in this context 'consumer' includes both current and potential consumers of Commonwealth aged care services.

Discussion prompts

1. Are these the outcomes expected of an aged care advocacy model?
2. What measures could be used to demonstrate that these outcomes have been achieved?

Discussion Session 2: Special needs groups and service scope

Overview

It was noted that many independent advocacy organisations already employ a range of strategies to cater for special needs groups and vulnerable clients (within resource constraints). A number of respondents identified a need to include a specific focus on clients with limited supports and those who may be experiencing particularly complex needs, and others pointed out the need to acknowledge the diversity within special needs groups, as well as the fact that some clients may span multiple special needs groups.

In addition, respondents raised the range of issues that could be considered 'in-scope' for aged care advocacy, noting that these may extend beyond issues related to aged care services. While the

eligibility for aged care advocacy is intended to remain ‘consumers or potential consumers of Commonwealth-funded aged care services’, we are interested in discussing the connection between advocacy and other services that could support consumers to address a broader range of issues that may impact on their ability to remain at home.

Discussion prompts

1. Thinking about the special needs groups you work with, how should they be best supported to access independent advocacy services?
2. In what ways can the links between advocacy services and organisations representing special needs groups be strengthened to ensure advocacy services are appropriate and responsive to the diverse needs of consumers?
3. Acknowledging there are a number of issues for which older people may seek advocacy services, what could be an appropriate/reasonable scope of services for an end to end advocacy programme?

Discussion Session 3: Service Structure

Overview

A range of views emerged on the options presented for possible service structures for a future advocacy model. We would like to further explore the option of a centralised (national) intake system for advocacy services, with a view to supporting opportunities for maximising geographical reach of services, noting the challenges inherent in providing advocacy services to people living in remote parts of Australia.

Further, there was strong consensus that while a future advocacy service delivery model under consideration in this Review would focus on individual advocacy, mechanisms should be put in place to harness the capacity of individual advocacy services to inform systemic advocacy.

Discussion prompts

1. What options could be incorporated to maximise geographical reach? How could a centralised intake system support this?
2. What practical mechanisms could be put in place within a programme focussed on individual advocacy to inform broader aged care reforms that are focussed around consumer empowerment and the ability to exercise choice?

Thank you for taking time to consider these questions. We look forward to hearing your perspectives on these issues at the workshop.

Appendix I. Workshop Summary Report

Review of Commonwealth Aged Care Advocacy Services

Consultation workshop: Summary

Introduction

Australian Healthcare Associates (AHA) held a consultation workshop on 24 September 2015 with key stakeholders from across Australia to further explore key issues raised in feedback received through the Options Paper consultation process.

This summary has been developed for workshop attendees as a high-level record of the issues and themes discussed at the meeting.

Summary of Workshop Aims

It was noted that the focus of change to the aged care system is centred on embedding increased choice for consumers. Within this context, individual advocacy has been identified as fundamental in supporting consumers to effectively interact with the aged care system. The review of Commonwealth aged care advocacy services forms one part of a broader focus on the supports that people might need to assist them with exercising choice and control as they transition through the aged care system.

Consistent with this focus, the workshop was designed to achieve the following aims:

- To provide an overview of key findings from the Options Paper consultation process
- To build on the Options Paper consultation process by discussing possible key elements for the design of a national aged care advocacy service delivery model (including trade-offs and benefits of the options proposed)
- To provide participants with an opportunity to explain their views in more detail.

Discussion Session 1

Discussion Session 1 was focused on informing the development of outcomes and measures for a national aged care advocacy model. AHA proposed four outcomes for the purpose of discussion, and asked participants to workshop potential measures for these outcomes. The outcomes were:

4. Consumers are supported to have their aged care wishes and needs heard and acknowledged
5. Consumers are empowered to make informed decisions about their care and to exercise choice
6. Consumers are supported in reaching their wellness and reablement potential
7. Service providers are supported to understand their obligations and responsibilities, as well as the rights of consumers, in relation to aged care provision

Key discussion points

Overall, participants indicated that the outcomes proposed by AHA were generally suitable, with some modifications of wording and order of outcomes. In particular, concerns were raised about the use of

the word 'wishes' and participants suggested there needed to be a stronger emphasis on entitlements and individual rights.

Issues were raised about Outcome 4 in terms of being clear that the role of the advocacy services is not to help service providers understand their obligations. Rather, that the focus should be on helping providers to understand the rights of consumers.

A range of suggestions were made for measuring the outcomes of advocacy, including through:

- Assessment of consumer satisfaction (e.g. surveys)
- Levels of community awareness of advocacy services
- Measures of the extent to which consumers and aged care service providers understand their rights and responsibilities
- Assessing whether consumers accomplished what they set out to achieve by engaging advocacy services
- Assessment of outcomes of training sessions for service providers
- Monitoring of number of complaints made to the Aged Care Complaints Scheme.

Other themes discussed included:

- Service providers may need support and training to ensure advocacy is available to consumers
- Outcomes were noted to be important, but difficult to measure. Outputs and associated process measures are also necessary, including numerical data such as the number of pamphlets provided, follow up phone calls and wait times for service
- The importance of ensuring outcome measures assess the extent to which advocacy services are meeting the needs of people from special needs groups.

Discussion Session 2

Discussion Session 2 focused on service scope and special needs groups. It was noted that people from special needs groups often have complex needs, and individuals may span more than one particular special needs area. AHA acknowledged that existing independent aged care advocacy services are seen by many stakeholders to be doing a good job on this front already, however ensuring access and appropriateness of services is an ongoing challenge.

Key Discussion Points

AHA provided each Table with a special needs group to focus their discussion (noting that these did not cover the full range of special needs groups of concern to advocacy services). The following key themes emerged in relation to barriers to people from special needs groups accessing advocacy services.

Care Leavers and Forgotten Australians

Participants raised a broad range of barriers faced by this group, including distrust of institutions, trauma (past and present), fear of disempowerment and difficulties accessing information through websites and 1800 numbers (lack of access to computers, telephones and a lack of literacy to use these services).

People from Aboriginal and Torres Strait Islander communities

Barriers identified included a lack of access to culturally competent/culturally safe services, remoteness of some communities and the associated lack of trust and relationship building. The complex nature of the problems impacting on many Indigenous communities – including housing, health, and drug and alcohol issues – was acknowledged. It was noted that organisations and advocates must understand the needs of individual communities because Aboriginal and Torres Strait Islander communities are not homogenous. Participants also raised the point that few advocates are Indigenous, and noted a lack of culturally appropriate promotional/educational material.

People with Dementia

Participants noted that people with dementia often require intensive and ongoing support to exercise their rights to make informed choices. It was argued that that advocacy has often been delivered in a reactive manner historically, and that for this group particularly, proactive and preventative advocacy is key. Promising models for providing this early support were discussed.

People from Culturally and Linguistically Diverse (CALD) Backgrounds

Participants identified several key access barriers for people from CALD backgrounds, including family and cultural restrictions, first language regression (particularly for patients also suffering from dementia), and lack of computer skills and literacy issues. It was also noted that communication by telephone could be a barrier as the absence of non-verbal communication can be problematic. Participants also noted the importance of developing strong, trusted relationships.

Lesbian, Gay, Bisexual, Transgender and Intersex people (LGBTI)

Key barriers identified centred on real and perceived discrimination against LGBTI-identified people. It was noted that people may not necessarily identify as LGBTI and consequently the importance of ensuring that advocacy services can respond to the unique needs of individuals (regardless of whether they belong to a special needs group).

People with a Disability

Participants discussed the importance of linkages between disability advocacy services and aged care advocacy services because lack of awareness of aged care advocacy services was considered to be a barrier to access. They also discussed the importance of ensuring that advocacy services can access expertise relating to specific disabilities to ensure appropriateness.

Overcoming Barriers

The methods for overcoming these barriers particularly focused around strengthening collaboration with relevant special needs organisations, ensuring that culturally appropriate materials are available and promoted, and developing a ‘no wrong door policy’. Participants also discussed the importance of ensuring staff are sufficiently trained to address the complex needs of people from special needs groups, and also that services retain sufficient flexibility to develop localised responses.

Participants also discussed data collection issues in relation to special needs groups, noting that people from special needs groups do not necessarily identify as such, or disclose this information to service providers (which may lead to under-reporting). Some participants felt that the emphasis on collecting data on special needs group affiliation at the individual level is excessive and that the focus should

rather be on ensuring services are accessible to all older people, regardless of a consumer's special needs .

Discussion Session 3

Discussion session 3 focused on service structure. Part 1 related to maximising geographical reach and the potential benefits and limitations of including a centralised intake system as part of the service model. Part 2 explored the linkages between individual and systemic advocacy.

Key Discussion Points

Part One – Geographical Reach and Centralised Intake

Participants noted that a 1800 number for the NACAP is already available and could potentially form the basis of a centralised system, however there are connectivity issues (e.g. not accessible from mobile phones). Participants suggested that a centralised phone-based or web-based intake system could be useful, but only if it formed one part of a broader suite of options for consumers to access services. A 'No wrong door policy' was considered important.

There was concern that a detached, third party intake system may hinder development of localised, tailored responses. Others suggested that My Aged Care could potentially be used to streamline intake to advocacy services – although it was noted that this may lead to a perception that the independence of advocacy services was compromised. Overall, participants identified a mixed model of some central functions with local, flexible options as ideal.

A number of suggestions for improving geographical reach were made, including exploring opportunities for harnessing technology (e.g. developing apps, national web services which redirect to local websites, skype and webinars) and providing outreach staff co-located with like-minded organisations (e.g. hub and spoke model).

Participants raised the importance of the model for aged care advocacy being nationally consistent but remaining locally relevant.

Part 2 – Individual advocacy informing aged care reforms

Participants suggested ideas and options for individual advocacy to feed into systemic advocacy and aged care reforms. Suggestions included:

- Opportunities to report systemic issues should be built into potential reporting requirements
- The Older Persons' Advocacy Network (OPAN) could function as a national secretariat to consolidate issues and feed back to policy makers and systemic advocacy processes

In this session, participants also discussed opportunities to better promote advocacy services at a national level.

Review of Key Issues

Throughout the workshop, AHA tabled issues raised by participants that fell outside the scope of the initial discussions or that were not easily resolved. These were revisited at the end of the workshop, and the following key issues were noted for consideration by DSS.

- **Eligibility**
 - Carefully define ‘potential recipients’ – noting the important role that advocacy can play as individuals enter the aged care system
 - Consider the role that carers play in facilitating access to advocacy
- **Promotion**
 - Culturally appropriate
 - Range of formats, but consistent messaging
 - To broader public as well as aged care consumers
- **Ability to respond to the reform agenda**
 - The service model developed for aged care advocacy will need to be sufficiently agile to ensure it can respond to the changes and impacts resulting in the reform agenda
 - It is important to consider the broader range of supports that consumers and carers will need to exercise choice
- **Data collection**
 - Requires adequate resourcing
 - Issues regarding disclosure by individuals from special needs groups
 - Data should be used to inform policy

AHA would like to thank all attendees for their valuable contributions at the workshop, and look forward to including these in our final report to the Department.

Consultation workshop: Participants

Name	Organisation
Melinda Paterson	IDEAS
Greg Mahney	Advocare
Mary Lyttle	Elder Rights Advocacy (ERA)
Geoff Rowe	QADA
Rima Sallis	City of Marion
Cathy Wiseman	City of Marion
Viv Daniels	Office of Aged Care Commissioner
Samantha Edmonds	Ageing and Aged Care Project National LGBTI Health Alliance
Anita Ghose	Mercy Health (Catholic Healthcare)
Lance Thomas	Illawarra Forum
Kay Richards	Leading Age Services Australia
Ken Hardaker	Advocacy Tasmania
Louise Geaghan	Willoughby City Council
Caroline Carroll	Alliance for Forgotten Australians
Kelly Jones	Anglicare Southern Queensland
John Ferguson	Alzheimer's Australia (ACT)
Dini Liyanarachchi	FECCA
Jayne Stinton	CatholicCare NT
Sonia DiMezza	ADACAS
Cherylee Treloar	Footprints Qld
Kazu Imai	Mosman Council
Lyn Kelleher	Mosman Council
Jenny Houston	UnitingCare
Pat Joyce	TARS
Craig Gear	TARS
Russell Westacott	TARS
Shelley Kleinhans	PHN Brisbane North
Marilyn Crabtree	ARAS
Richard Farrell	Tangentyere Council NT
Corey Irlam	Council on the Ageing
Vivienne McDonald	Diversicare Qld
Darcy Burgess	Disability Advocacy NSW

Name	Organisation
Yve Gritschner	Carers Australia
Jenny Ashby	Central Hume Primary Care Partnership VIC
Carlo Krikowa	Alzheimer's Australia
Andrew Campbell	DSS Canberra
Sally Burgess	DSS Canberra
Sarah McLelland	DSS Canberra
Nadia Arrage	DSS NSW State Office
Jill Waddell	AHA
Maree Kulkens	AHA
Tracey Higlett	AHA
Zoe Holmes	AHA