******Demand Study of the National Aged Care Advocacy Program (NACAP)**

Final report for Department of Health

30 March 2022

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Glossary

| **Acronym** | **Full name** |
| --- | --- |
| AAT | Administrative Appeals Tribunal |
| ABS | Australian Bureau of Statistics |
| ACQSC | Aged Care Quality and Safety Commission |
| ADA | Aged and Disability Advocacy |
| ADACAS | ACT Disability, Aged and Carer Advocacy Service |
| AFDO | Australia Federation for Disability Organisations |
| AGNES | Australian Government National Economic Simulation |
| AHSRI | Australian Health Services Research Institute |
| AIHW | Australian Institute of Health and Welfare |
| ARC | Australian Research Council |
| ATDP | Advocate Training and Development Program |
| CALD | Culturally and Linguistically Diverse |
| CARF | Commission on Accreditation of Rehabilitation Facilities |
| CCF | Community Care Finder |
| CHSP | Commonwealth Home Support Programme |
| CIHI | Canadian Institute for Health Information |
| COTA | Council of the Ageing |
| CoS | Commonwealth Continuity of Support |
| CPI | Consumer Price Index |
| CPS | Conseil pour la protection des malades |
| DHB | District Health Board |
| DoLS | Deprivation of Liberty Safeguards |
| DVA | Department of Veterans’ Affairs |
| EAAA | Elder Abuse Action Australia |
| ELDAC | End of Life Direction for Aged Care |
| ESO | Ex-Service Organisation |
| FECCA | Federation of Ethnic Communities Councils of Australia |
| FTE | Full-time equivalent |
| HCP | Home Care Packages |
| HQSC | Health Quality and Safety Commission |
| IMCA | Independent Mental Capacity Advocate |
| IMHA | Independent Mental Health Advocacy |
| LASA | Leading Age Services Australia |
| LGBTIQ+ | Lesbian, gay, bisexual, trans/transgender, intersex and queer |
| LHS | Left-hand side |
| LTC | Long-term care |
| MHAS | Mental Health Advocacy Service |
| NACAP | National Aged Care Advocacy Program |
| NACCHO | National Aboriginal Community Controlled Health Organisation |
| NAGATSIAC | National Advisory Group for Aboriginal and Torres Strait Islander Aged Care |
| NDAF | National Disability Advocacy Framework |
| NDAP | National Disability Advocacy Program |
| NDIS | National Disability Insurance Scheme |
| NMDS | National Minimum Dataset |
| NSA | National Seniors Australia |
| NZACA | New Zealand Aged Care Association |
| OPAAL | Older People’s Advocacy Alliance |
| OPAN | Older Person Advocacy Network |
| OSA | Office of the Seniors Advocate |
| PHN | Primary Health Network |
| PIAC | Pathways in Aged Care |
| PICAC | Partners in Culturally Appropriate Care |
| PTSD | Post-traumatic stress disorder |
| QAMH | Queensland Alliance for Mental Health |
| RHS | Right-hand side |
| RSL | Returned Services League |
| SDAC | Survey of Disability, Ageing, and Carers |
| SDO | Service Delivery Organisation |
| TPI | Totally and Permanently Incapacitated veterans |
| VRB | Veteran Review Board |
| WPI | Wage Price Index |

|  |  |
| --- | --- |
| **Term** | **Description** |
| Met demand | The number of people within the NACAP target population who received a service |
| Special needs groups | As defined in *Aged Care Act 1997* |
| Supply | Services provided by the NACAP under current constraints |
| Target population | The population of older people who are eligible for NACAP services, defined as all recipients of aged care aged 65+ and Aboriginal and Torres Strait Islanders aged 50+ |
| Total demand | A measure of the total amount of demand for NACAP services that exists in the target population (met and unmet) based on illustrative total demand rates |
| Unmet demand | A measure of aged care users or potential users who would benefit from advocacy support but are not receiving a service |

1. Executive summary

The National Aged Care Advocacy Program (NACAP) is funded by the Australian Government under the *Aged Care Act 1997* (the Act). The NACAP provides free, independent, and confidential advocacy support, education, and information to older people (and their representatives) receiving, or seeking to receive, Australian Government funded aged care services.[[1]](#endnote-2) It also helps aged care service providers to understand their responsibilities and the consumer rights of the people they care for.[[2]](#endnote-3)

The Older Persons Advocacy Network (OPAN) is a national network of nine state and territory Service Delivery Organisations (SDOs) that deliver advocacy, information, and education services to older people and their families or representatives who are seeking or seeking to receive Commonwealth-funded aged care services.

The coverage among older people eligible for the NACAP was 1.9% as of 2020/21.[[3]](#endnote-4) The final report from the Royal Commission into Aged Care Quality and Safety, published in March 2021, recommended the Australian Government legislatively recognise the role of advocacy services in empowering older people during a complaints process, and fund advocacy services to support people navigating the complexities of aged care.[[4]](#endnote-5) The Royal Commission recommended “an immediate funding increase to enable a minimum of 5% of older people to access advocacy services”.

The Department of Health (the Department) has engaged Deloitte to consider the current and future demand for NACAP advocacy services, and the provision of these services.

A mixed methods approach has been used to undertake the demand study of the NACAP. This involved a combination of qualitative consultation, desktop research, and quantitative modelling to understand the current and future demand for NACAP services, and the supply of these services.

Current demand for NACAP

Key findings from the analysis of current demand included:

1. Several barriers to accessing NACAP exist
   * Approximately one-third of all NACAP information services are accessed by those outside of residential or community care
2. Of those who access NACAP, residential aged care recipients have scope for higher usage of advocacy services, compared to those who access it in the community
3. People living with dementia and experiencing elder abuse are low users of the service.

Barriers to accessing NACAP

In 2020/21 OPAN and its SDOs delivered services to 1.9% of Australians receiving aged care services. 11,849 cases of information, 8,826 cases of advocacy, and 1,310 sessions of education were delivered. The three SDOs in NSW, SA and Queensland delivered the most advocacy and information sessions, providing 55% of advocacy and 66% of information services nationally.

Key barriers in accessing NACAP that were identified in consultations included:

* A lack of awareness of both what advocacy means, and of NACAP and the support it can provide, both of which affect whether, and how, older people engage with the program
* Individuals not wanting to “make a fuss” or being seen to complain, due to a concern that this could negatively affect the care they receive
* Reliance on representatives to seek advocacy
* Informal carers (unpaid caregivers such as family members) who are also perpetrators of elder abuse, which may create barriers for older people seeking NACAP assistance
* Lack of trained staff in understanding and delivering advocacy support that is appropriate for the special needs groups (as defined in Section 1.1.1).

Residential aged care recipients have scope for greater usage of advocacy

Demand has been presented in **usage rate** terms, which represents the number of users of a service as a proportion of the total population in that cohort that is eligible for the services, by user characteristics. Stratifying the usage of NACAP services recipient by care type, (i.e., residential aged care, community care, and other) found that residential aged care recipients have scope for greater usage of advocacy (compared to community care) based on the current allocation. Provision of advocacy is higher in community care relative to residential aged care (Chart i).

* + 1. : Advocacy usage (2020/21) in residential aged care and community care, by age.

Source: OPAN unit record data; OPAN Progress Report 2020/21; modelling by Deloitte Access Economics

Those outside of residential aged care and community care received around one quarter of advocacy services and one third of information services

The usage rate of advocacy and information services is significantly lower in the population outside of residential aged care and community care. While those outside of residential or community care received around one-quarter of advocacy services and one-third of information services delivered in the NACAP, this still represents only a small proportion of the total number of people in the population who are not receiving formal care. As there is a large population of people not receiving formal care, this results in a low usage rate for both information and advocacy for the cohort outside of formal care.

Those experiencing dementia and elder abuse are low users of the service

Usage of advocacy service was low among people with dementia and those experiencing elder abuse across residential aged care and community care.

* + 1. : Advocacy usage among vulnerable populations

Source: OPAN unit record data; OPAN Progress Report 2020/21; modelling by Deloitte Access Economics.

Consultations suggested that older people with dementia often face barriers to seeking out advocacy for themselves, relying instead on carers and representatives to comprehend their requirements and find appropriate support. This places significant strain on the informal carer, who often is experiencing frailty and ageing themselves. In addition, older people with dementia who have no proper support network may face significant barriers to accessing aged care services.

Many of these issues can be exacerbated by intersectional challenges. Intersectionality refers to the way in which different aspects of a person’s identity (such as race, gender, class, disability, sexuality and more) interact to produce overlapping forms of discrimination or disadvantage. Intersectionality between critical cohorts with disability, dementia, language barriers, experiences of elder abuse, present some of the greatest needs for advocacy.

Future demand for NACAP

Key findings from the analysis of future demand included:

1. Several factors will influence the future demand for NACAP, including generational changes, demographic trends, government policy, growing complexity of care needs and an increase in the supply of aged care services.
2. The expanded NACAP funding boosts – scheduled to increase program funding from $12.9 million in 2021/22 to $41.4 million in 2024/25 – will alleviate some unmet demand for services in the short term. However, the gap in unmet demand will continue to grow over the longer term.
3. Education sessions will need to increase with the growth of residential aged care and community care use.

Factors influencing the future demand for NACAP

The demand for aged care advocacy is expected to grow over the coming years, as highlighted in consultations.

* 1. : Trends that are likely to influence the demand for advocacy

|  |  |
| --- | --- |
| **Trend** | **Implications for future demand** |
| **Improving health and growing longevity** such as higher life expectancies, and better recognition of health and disability needs. | Likely to increase |
| **Increasing prevalence of dementia** as more people live into very advanced ages where dementia becomes more common | Likely to increase |
| A greater proportion of older people from **special needs groups** (as defined in Section 1.1.1) entering old age will inform the support needed by older people | Likely to increase |
| The **complexity** in the aged care system through greater tailoring to the care needs of older people at the individual level | Likely to increase |
| **Government reforms and aged care policy**, including the introduction of new workforces to support navigation and awareness across the system (e.g. Community Care Finders); increased availability of services; and associated funding, governance, and quality and safety measures | Likely to increase during transition periods, however nature of advocacy will change to reflect reforms |
| The **program design**, the funding model, the obligations placed on providers, and the incentives inherent in the system (to encourage use of advocacy) have a major bearing on demand and are all within the control of government | Likely to increase |
| A **generational shift** from one that accepts the services provided and is reluctant to complain, to people who are more cognisant of their rights and willing to protect them | Uncertain |

Source: Deloitte Access Economics

The Royal Commission recommended “the National Aged Care Advocacy Program should be provided with an immediate funding increase to:

1. enable a minimum of 5% of older people to access advocacy services
2. enable advocacy networks to
   1. provide education;
   2. undertake systemic advocacy
3. support capacity building of the advocacy network through training of formal advocates and the development of clear guidelines and processes”.

Desktop research, qualitative research, and comparison of aged care advocacy in other jurisdictions did not reveal the ideal proportion of people who should be accessing advocacy services. Given the challenges in determining quantitative factors influencing demand, two scenarios were modelled, 1) unmet demand across the target population at 7% (rather than 5%) and 2) differentiated total demand rates across vulnerability groups. The model shows that even with the funding increase, a demand gap is shown to remain, particularly among recipients of advocacy in residential aged care.

* + 1. : Usage rates across both residential and community aged care, 2020/21 to 2031/32

Advocacy use has increased in both residential and community aged care since 2020/21, the increase is expected to continue to grow.

Source: Deloitte Access Economics based on OPAN and AIHW data.

Education sessions will need to increase with the growth of residential aged care and community care use. The current soft target set by SDOs of at least 2 sessions per residential facility per year will not be reached without additional funding or a reallocation of existing funding from advocacy and information to education.

Redesigning and targeting education sessions to individuals in community settings is also likely to be required. More than 75% of education sessions were delivered in residential aged care facilities in 2020/21, despite most of the target population residing in the community. Community care is also where system growth and complexity is expected to be concentrated over the coming years.

The demand analysis suggests that the funding increases will not be sufficient to meet anticipated demand. At these levels, there is forecast to be a significant demand gap across both residential and community aged care and across information and advocacy services.

Supply of the NACAP

The ability of the NACAP to meet the projected demand will depend on the supply of advocates and their capacity and capability to meet the advocacy needs of the aged care population. Funding to the program is increasing to help meet this anticipated demand. This funding boost will enable more advocates to be recruited and for investment in capacity building. The total number of full‑time equivalent (FTE) advocates nationally prior to expansion was 56, and this will increase to 145 by 2024/25.

It is noted that analysis of the FTE workers required to meet the projected demand would require data regarding the total FTE hours per instance of service to establish an average time spent per advocacy and information case. While advocacy hours were available in the unit record data provided by OPAN, this measure did not represent FTE hours. As such, FTE level analysis was not possible.

Notwithstanding this, stakeholder consultations revealed key supply factors affecting the use of NACAP aged care services are:

* Recruitment and Retention of advocates.
* Cultural, language, behavioural, and personal care needs.
* Providing services to regional and remote areas.

As NACAP expands it is also important that service design evolves to better meet the access and advocacy needs of its target population. Stakeholders noted a number of constraints in the current program design. For example, stakeholders highlighted the need for greater levels of proactive advocacy, however, noted that this was likely limited within the existing NACAP due to capacity constraints. Under the expanded NACAP, the Older Persons Homecare Vulnerability Check-in Project will address this to some extent, by providing advocacy support preventatively, and referrals to support organisations when an older person is deemed vulnerable due to social isolation, risk of harm or neglect. This is a notable change from the previous model, which provided advocacy support only when requested by a client. In addition, the expanded NACAP will also contain other activities that will help aged care service consumers and their families of choice to self-advocate for their aged care rights, and develop greater insight into complicated areas of the aged care sector such as Home Care service costs. The expanded NACAP will also include a Diversity Education Project for aged care providers on the delivery of culturally safe and inclusive services to people from diverse and marginalised groups.

Ongoing monitoring and evaluation will be key to ensuring that NACAP continues to meet the needs of target populations through its activities. Sound data capture practices will help the evaluation process. It is envisaged that through the current National Minimum Dataset (NMDS) project that a nationally consistent data collection process will be developed which will improve data and reporting capabilities across SDOs.

Future considerations

This report advances understanding of potential demand for advocacy services now and into the future.

The unit record data provided by SDOs presented significant gaps that impacted demand estimation for NACAP services (Table ii).

* 1. : Key data limitations in current unit record data

|  |  |  |
| --- | --- | --- |
| **Area** | **Limitations** | **Opportunities for future NACAP data collection** |
| **Comprehensiveness** | Data gaps for user characteristics across states prevented an accurate analysis of how NACAP was reaching vulnerable populations across States | Encourage the recording of key features of a user such as whether they are experiencing elder abuse or have dementia. Doing so will enable a better allocation of funding for NACAP services across user needs. |
| **Consistency** | Inconsistent data capture across states for optional fields (e.g., CALD status) meant that usage rates for certain populations might have been under- or overestimated, depending on the operations within the State | Adopt consistent data capture to ensure consistent capture of characteristics across SDOs. It is understood that the minimum dataset project will help to address this. |
| **Quality** | Instances of inaccurate data, with some records showing extreme values, impeded an understanding of the true user characteristics | Provide advocates with training on data definitions and data requirements and conduct periodic data checks at SDO level to better support prioritisation of needs. |
| **Clarity** | Lack of clarity around whether the unit record data captured the characteristics of older people or those calling on behalf of the older people reduced data accuracy | Provide an opportunity to capture information on the caller (in addition to the older person). Specifically, whether they are the older person seeking help or a family member, loved one or a representative. |

Source: Deloitte Access Economics

Since June 2021, the NMDS has been under development by OPAN. The NMDS will contain nationally consistent unit record data on aged care advocacy as part of the NACAP. It is anticipated that the data collection for the NMDS will begin in April 2022 for all SDOs. While the NMDS will help to address the identified issues in the current data collection it is important to keep the current data challenges and corresponding opportunities in mind as the NMDS is developed and implemented to ensure that future updates of this demand and supply analysis will be able to produce richer insights, such as state level projections.

Future work may also wish to explore the use of behaviourally informed approaches which can be low-cost and effective ways to increase program take-up through improving communications and accessibility.

# Introduction

## Background

Aged care advocacy has been delivered in Australia since it was recommended by the Ronalds Review in 1989.[[5]](#endnote-6) Under the Residential Advocacy Services Program, this Review resulted in funding for nine state and territory-based organisations to offer information and advocacy to persons receiving government-funded residential aged care. The program was renamed the National Aged Care Advocacy Program (NACAP) in 2002 to reflect the program's expansion to encompass people receiving non-residential aged care services. NACAP became a nationwide program overseen by Older Persons Advocacy Network (OPAN) in 2017, with services provided by nine state and territory-based organisations (SDOs).[[6]](#endnote-7)

### The National Aged Care Advocacy Program (NACAP)

The National Aged Care Advocacy Program (NACAP) is funded by the Australian Government under the *Aged Care Act 1997* (the Act). The NACAP provides free, independent, and confidential advocacy support, education, and information to older people (and their representatives) receiving, or seeking to receive, Australian Government funded aged care services.[[7]](#endnote-8)

The NACAP objectives are met through the following activities:

1. Advocacy support and information: independent and individually focused aged care advocacy support and information to older people (including their families of choice or representatives) including to older people in rural, regional, and remote areas, and diverse groups.
2. Outreach and education: outreach activities and education session to older people (including their families of choice or representatives) and aged care providers, to promote aged care consumer rights and raise awareness of elder abuse and prevention.
3. Advocacy community development, Home Care vulnerability check-ins and Home Care cost education: independent programs to support older people (including their families of choice or representatives).
4. Support for aged care reform and emergencies: additional advocacy, education, and information to support aged care reforms for aged care providers, and consumers; and respond to emergency management issues that affect consumers of aged care services, their families of choice and carers, including but not limited to COVID-19 responses.
5. Diversity education: education sessions to aged care providers and staff to understand and meet the needs of people from diverse background, characteristics, and life experiences in their care, including through online/digital systems.[[8]](#endnote-9)

The current total program grant funding is $30.59 million (excl. GST) in 2021/22 and will grow to $41.10 million in 2024/25 to deliver the above activities and expand the reach of services across Australia.

The NACAP is available to older people receiving Australian Government funded aged care services, people seeking to receive Australian Government funded aged care services (this may include prior to receiving an aged care assessment), and the families, loved ones or representatives of these groups. These groups form the **eligible population.**

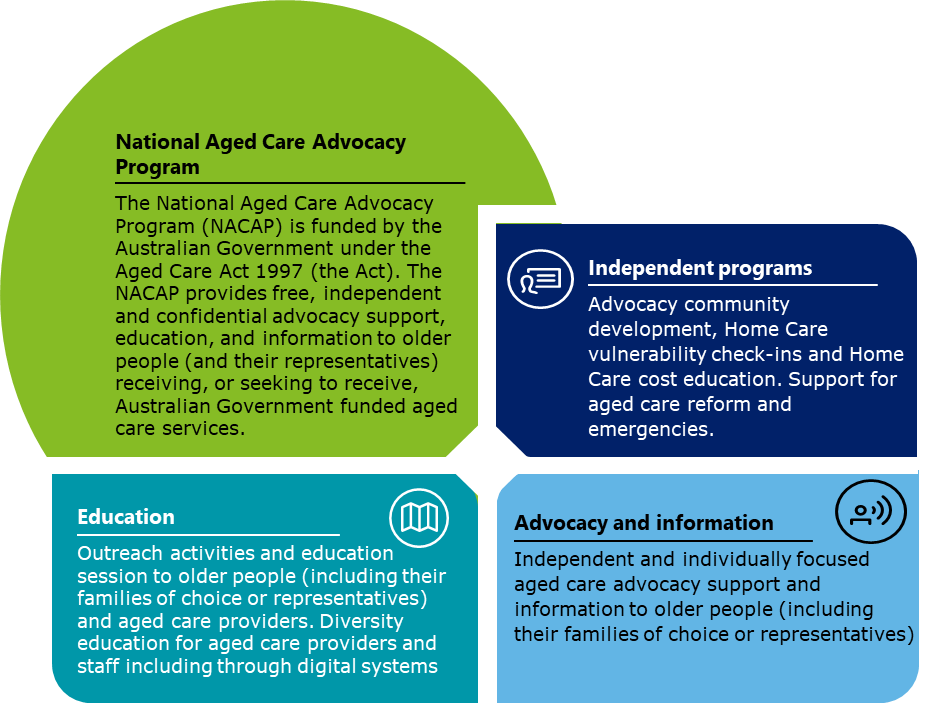
The program aims to ensure the support offered is inclusive, reflects the diversity of the community and meets people's diverse needs, including those who identify as being from “special needs” groups, as defined in the Act:

* people from Aboriginal and/or Torres Strait Islander communities
* people from culturally and linguistically diverse (CALD) backgrounds
* people who live in rural or remote areas
* people who are financially or socially disadvantaged
* people who are veterans of the Australian Defence Force or an allied defence force including the spouse, widow, or widower of a veteran
* people who are homeless, or at risk of becoming homeless
* people who are care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations)
* parents separated from their children by forced adoption or removal
* people from lesbian, gay, bisexual, trans/transgender, and intersex (LGBTI+) communities
* people who are deaf or hard of hearing
* people who are living with a disability
* people living with cognitive impairment including dementia or experiencing mental health conditions; and/or who have been exposed to significant trauma.[[9]](#endnote-10)

NACAP also delivers education and consumer rights and responsibilities to providers of Australian Government funded aged care services, which includes residential aged care; home care packages (HCPs); Commonwealth Home Support Programme (CHSP) services; Commonwealth Continuity of Support (CoS) Program; Commonwealth funded dementia services; and flexible care services.

An overview of the NACAP and its activities are summarised in Figure 1.1.

: Overview of expanded NACAP



### OPAN and SDOs

The Older Persons Advocacy Network (OPAN) is a national network of nine state and territory organisations that deliver advocacy, information, and education services to older people in metropolitan, regional, rural and remote Australia. OPAN is funded by the Australian Government to deliver the NACAP, via its Service Delivery Organisations (SDOs). There are nine SDOs – one in each state, the Australian Capital Territory, and two in the Northern Territory.

OPAN’s purpose is to facilitate an environment that promotes human rights of older people and the ability for all older Australians to live well and be respected.[[10]](#endnote-11)

OPAN aims to deliver a standardised, operationally efficient, highly connected service, enabling the consumer experience to be similar nationwide, while still responding to local issues and needs. NACAP is delivered physically and virtually, supported by a digital resource, a program website and 1800 telephone line.

Key principles underpinning the NACAP include:

1. Advancing human rights of older people, particularly those seeking and receiving care, and those who are marginalised and vulnerable
2. Supporting older people to bring their voices to the table, to advocate for themselves and to enable systemic advocacy based on their voices and experiences to drive the transformation of aged care
3. Supporting older people to make choices, decisions, and take action
4. Establishing strategic partnerships and alliances to enable OPAN to advance and uphold human rights of older people, and embrace diversity
5. Building OPAN’s capability and striving to provide a broad range of information, education and advocacy services for older people (and their families and representatives) that are culturally safe and respectful, trauma-informed and responsive
6. Working with the network to deliver information, education and advocacy for older people receiving or seeking care.[[11]](#endnote-12)

OPAN and its SDOs delivered services to 1.9% of Australians receiving aged care services in 2020/21. This represents an 11% increase on the previous year.[[12]](#endnote-13) The following services were provided across the network over 2020/21:

OPAN has progressed activities in 2020-21 with 23,019 information and advocacy service events, 1,658 education service events, 6,389 special needs groups and 958 education groups.

Source: OPAN Progress Report 2020/21

### The Royal Commission into Aged Care Quality and Safety

The Royal Commission (tabled 1 March 2021) identified the importance of advocacy services in strengthening the consumer voice. The Royal Commission recommended the Australian Government legislatively recognise the role of advocacy services in empowering these voices during a complaints process, and fund advocacy services to support people navigating the complexities of aged care.

Recommendation 106 (see Figure 1.2) indicated that “the NACAP should be provided with an immediate funding increase to enable a minimum of 5% of older people to access advocacy services”. The Australian Government has committed to this goal and has increased funding to support growth in services. Recommendation 106 also identified the need to determine the extent of unmet demand for prompt advocacy services by people seeking or receiving aged care services. identify the need for additional funding for the provision of education and systemic advocacy, and the capacity building of advocacy services.[[13]](#endnote-14)

: Royal Commission Recommendation 106

Recommendation 106: Enhanced advocacy

1. By 1 July 2022, the Australian Government should, through the implementation unit responsible for implementation of the Royal Commission’s recommendations, complete a consultation with the contracted provider of services under the National Aged Care Advocacy Program to determine the extent of unmet demand for prompt advocacy services by people seeking or receiving aged care services. The consultation should also consider the need for:
   1. additional funding for the provision of education and systemic advocacy by the contracted provider of services.
   2. capacity building of advocacy services.
2. In light of the conclusions reached by the implementation unit after that consultation, the Australian Government should increase the funding of the National Aged Care Advocacy Program to establish a sustainable funding base that provides for increased coverage of the program to meet currently unmet demand for prompt advocacy services, including education, and systemic advocacy, as well as the infrastructure required to support an effective national network of advocacy organisations.
3. As an interim measure, by 1 July 2021 the Australian Government should provide additional funding and other supports to enable the development of an effective national advocacy network. To this end, the National Aged Care Advocacy Program should be provided with an immediate funding increase to:
   1. enable a minimum of 5% of older people to access advocacy services
   2. enable advocacy networks to
      1. provide education;
      2. undertake systemic advocacy
   3. support capacity building of the advocacy network through training of formal advocates and the development of clear guidelines and processes to support a nationally consistent advocacy service.

## Project scope and objectives

The Department of Health (the Department) engaged Deloitte to inform an understanding of current and future demand for NACAP advocacy services, and the provision of these services.[[14]](#footnote-2) This project estimates the current met and unmet demand for NACAP services, the future demand for NACAP services until 2032/33, and the supply of NACAP services.

The intent of the project was to study:

* current met demand with comparisons to current estimated unmet demand, including across service offerings in advocacy support, information, education and outreach, and the range of case time across these categories of service
* emerging demographic impacts including changes in consumer behaviour and expectations
* impacts of an expanded NACAP (commencing 2021/22) with increased outreach, community development and education activities, and flexible and emerging models of individual advocacy
* anticipated impacts or learnings from other service systems and reform programs, including, but not limited to navigation supports, aged care consumer supports, disability and mental health advocacy, elder abuse hubs and the Aged Care Quality and Safety Commission (ACQSC).

A mixed methods approach was taken to make best use of the quantitative and qualitative data available. This involved the synthesis of insights from an extensive stakeholder consultation process with quantitative modelling outputs. The mixed methods approach allowed for a deeper understanding of demand and supply of the NACAP, especially given that several data limitations were identified throughout the project. Opportunities for future work once data limitations have been addressed – particularly through the implementation of the NMDS – are proposed at the end of this report.

## Scope of this report

This report includes findings from the current demand analysis, future demand analysis, supply analysis, and insights on the additional support required to meet future demands. This report also includes selected findings from the extensive consultations with aged care advocacy stakeholders. An overview of the consultation approach is in Appendix A. Full details of the consultation and its findings are available in the *Early Findings Report – November 2021.*

# Overview of approach and methodology

This chapter provides an overview of the approach used, including how qualitative and quantitative analysis was synthesised to provide insights on current demand, future demand, and supply.

## Overview of approach

A mixed methods approach was used to undertake the demand study of the NACAP. This involved a combination of stakeholder consultations, desktop research, and quantitative modelling to understand the current and future demand for NACAP services, and the supply of these services.

### Qualitative input

The qualitative aspects of the methodology primarily involved desktop research and stakeholder consultation. The desktop research involved a targeted review of publicly available literature and data, as well as documents and data provided by OPAN, the SDOs and other project stakeholders. This was complemented by an extensive consultation process with aged care advocacy stakeholders, including aged care peak bodies, aged care consumer and carer advocacy groups, organisations representing care issues for older Australians (e.g., mental health, disability etc.), relevant Commonwealth and jurisdictional government bodies, and subject matter experts (see Table A.1 for list of stakeholder organisations and interview guide). Consultations were conducted as virtual sessions over Microsoft Teams as focus groups or individual organisation interviews and the sessions were guided by semi-structured interview scripts containing the questions for discussion. The qualitative consultations captured stakeholder perspectives regarding the issues subject to consideration.

### Quantitative input

The quantitative aspects of the methodology involved data gathering, cleansing, and analysis to enable the modelling of demand for and supply of the NACAP. Data were sourced primarily from OPAN (program data in the form of a unit record), the Australian Bureau of Statistics (ABS) (population data), and Australian Institute of Health (AIHW) (GEN Aged Care data). A methodology workshop was conducted with the Project Governance Group (PGG) in the early stages of the methodology development to test the approach and determine the availability of data. The approach was subsequently refined to reflect feedback from the workshop and consultations. As with any modelling approach there are limits to what can be suitably and reliability quantified and for this project this was especially the case due to the limited data available on some key demographic characteristics. Where this is the case, we have combined qualitative insights to contextualise, complement and extend the quantitative findings.

Figure 2.1 presents an overarching methodology framework for the project, demonstrating how the different components of the analysis fit together. The analysis estimates the extent of current and future demand (both met and unmet) and NACAP’s ability to meet the demand for aged care advocacy.

Figure 2.1: Methodology framework

Methodology of reviewing the program.

Source: Deloitte Access Economics.

For the purposes of this report, the older population captures Aboriginal and Torres Strait Islander peoples aged 50 and over and non-Aboriginal and Torres Strait Islander people aged 65 and over. The population eligible for NACAP services are either people receiving Australian Government funded aged care services, or people seeking to receive Australian Government funded aged care services (this may include prior to receiving an aged care assessment), and families, loved ones and representatives of the above.

## Current demand

The current demand for NACAP services comprises current met and unmet demand for NACAP in FY-2020/21. Current met demand is the demand that has been satisfied by the provision of NACAP services. Current unmet demand is the NACAP demand that has not been addressed in the current provision of services, due to supply restrictions or unknown demand. Demand was measured in terms of usage rates, capturing the number of NACAP service users as a proportion of the eligible population in the cohort. The total eligible population was sourced from publicly available data inclusive of demographic characteristics and interactions with the aged care system.

### Current met demand

The current demand for NACAP services comprises current met and unmet demand for NACAP in FY-2020/21. Current met demand is the demand that has been satisfied by the provision of NACAP services. Current unmet demand is the NACAP demand that has not been satisfied by the program due to supply restrictions or unknown demand.

Figure 2.2: Overview of current demand analysis

Current met demand was estimated using the unit record data received and progress report data received from OPAN. 

Current met demandwas estimated using the unit record data received from SDOs and progress report data received from OPAN. The number of users derived from these datasets were compared to the total eligible population (i.e., older people interacting with aged care services) to understand how the current usage rates of NACAP services compares to the minimum 5% usage target recommended by the Royal Commission.

The demand was measured in **usage rate** terms, which captures the number of users of a service as a proportion of the total population in that cohort that is eligible for the services, by user characteristic. Usage rates were used as they are a useful metric to convey the uptake of the services among the eligible population, by key demographic characteristics. This enables an analysis of unmet demand across population cohorts. A summary of the relevant characteristics captured in the unit record data is provided in Table 2.1.

: Summary of relevant characteristics in available data and corresponding data fields

|  |  |
| --- | --- |
| **Characteristic** | **Fields** |
| **Service type** | ‘Information’, ‘Advocacy’, ‘Education’ |
| **Care type** | ‘Residential aged care’, ‘Community care’, ‘Other’ |
| **Location** | ‘Metro’, ‘Regional’ |
| **Age** | ‘<50’, ‘50-54’, ‘55-59’, ‘60-64’, ‘65-69’, ‘70-74’, ‘75-79’, ‘80-84’, ‘85-89’, ‘90-94’, ‘95-99’, ‘100+’ |
| **Gender** | ‘Female’, ‘Male’, ‘Other’ |
| **Dementia** | ‘Yes’, ‘No’ |
| **Aboriginal and Torres Strait Islander** | ‘Yes’, ‘No’ |
| **Elder abuse** | ‘Yes’, ‘No’ |
| **CALD** | ‘Yes’, ‘No’ |

Source: OPAN unit record data with recoding by Deloitte Access Economics.

Given significant data gaps in the unit record data, two key assumptions were made.

1. The distribution of NACAP services across the user characteristics were assumed to be the same as that in Queensland’s Aged and Disability Advocacy (ADA) for all jurisdictions.
2. Given the missing unit record data for NT, ACT and Tasmania, the distribution of NACAP services from Queensland was applied to the total instances of services captured in the progress reports, to derive a full dataset.

State-based variations in data are likely a result of the different accounting rules for data collection across states, as well as resource differences. Historical differences in funding across states has enabled some SDOs, such as Queensland (ADA) to allocate more resources to delivering NACAP services. This is reflected in the higher servicing rate relative to the older population in the state, when compared to other states such as NSW’s Senior Rights Service (SRS) and might also have resulted in better data capture for users.

#### Population characteristics

The eligible population with a given set of characteristics was derived by combining publicly available data from the ABS and AIHW. The total target population was first split by care type using AIHW GEN Aged Care data. These data enabled age- and gender-specific usage rates of aged care to be calculated and subsequently applied to the projected population base (from ABS). The size of the CALD, Aboriginal and Torres Strait Islander, elder abuse, and dementia population groups were estimated by applying prevalence rates to the overall recipient population. The data sources for each of these population groups is provided in Table 2.2.

: Summary of data sources for population estimates

| **Characteristic** | **Description** | **Source** |
| --- | --- | --- |
| **Care type** | The number of recipients of residential or community aged care. | AIHW (2021), GEN Aged Care – People using aged care 30 June 2020 |
| **CALD** | The number of recipients of residential or community aged care who are identified as being of a culturally or linguistically diverse background. | AIHW (2021), GEN Aged Care – People using aged care 30 June 2020 |
| **Aboriginal and Torres Strait Islander** | The number of recipients of residential or community aged care who are identified as being of an Aboriginal or Torres Strait Islander background. | AIHW (2021), GEN Aged Care – People using aged care 30 June 2020 |
| **Elder Abuse** | The number of recipients of residential or community aged care who are subjected to elder abuse. | Australian Institute of Family Studies (2021), National Elder Abuse Prevalence Study; Post et al (2010) |
| **Dementia** | The number of recipients of residential or community aged care who are living with dementia. | AIHW (2021), Dementia in Australia |

Source: As listed in table.

### Current unmet demand

Quantitative and qualitative approaches were used to analyse current unmet demand. Current unmet demand was estimated as the difference between the usage rate in FY21 and a 5% target, which is based on the Royal Commission’s recommendation of an “immediate funding increase to enable a minimum of 5% of older people to access advocacy services”.[[15]](#endnote-15) This quantitative analysis was complemented by the consultation process detailed in 2.1.1 to identify where unmet demand is most likely to exist at present.

## Future demand for information and advocacy

The future demand for NACAP services was estimated by combining the analysis of the unit record data for current met demand with projections of the NACAP target population going forward. The target population was established by projecting the number of recipients of aged care between 2020/21 and 2031/32. The number of services delivered each year (supply) was estimated by accounting for the forthcoming increase in funding, adjusted for growth in the cost of delivering services. This process is discussed further below.

: Overview of approach to the future demand analysis

Illustration of the approach to future demand.

### Total demand

The future total demand was estimated by establishing the size of the NACAP **target population** in each year between now and 2031/32 and multiplying by the relevant **maximum total demand rate**.

The **NACAP target population** was used as the basis for determining the total demand for NACAP services over the coming years. The target population is based on the number of recipients of aged care – both residential and community-based. It was estimated by projecting the size of the aged care sector between 2020/21 and 2031/32.

As Australia’s population ages, so too does NACAP’s target population. Over time, more older Australians will be eligible to receive services through the NACAP and these individuals will be older, on average, than they are today. We used population projections from various sources to estimate the size of the future target population. Data for the target population were extracted from ABS Series B Population Projections for non-Indigenous Australians and from the ARC Centre of Excellence in Population Ageing Research for Indigenous Australians. Data for the aged care systems were taken from AIHW’s Gen Aged Care Data.

Chart 2.1 shows how the age distribution of the NACAP target population will change between now and 2031/32. The share of the target population in all age groups above 80, except for 85-89, will grow by between 0.5 and 1.9 percentage points. In contrast, all age groups below the age of 80 will comprise a smaller share of the target population by the end of the forecast period.

: Composition of the NACAP target population, by age

Age distribution of the NACAP target population will change, the share of the target population in all age groups above 80, except for 85-89, will grow by between 0.5 and 1.9 percentage points.

Source: GEN Aged Care data; StewartBrown Aged Care Financial Performance Survey Sector Report (June 2021).

Chart 2.2 presents the same target population data distributed by care type. Rapid growth is expected in the community care system over the next few years as new packages are added to the system. This is reflected in the chart, with most of the compositional change projected to take place between now and 2023/24. This captures the additional 80,000 home care packages that are scheduled to be released over the 2021/22 and 2022/23 financial years as well as the nearly 40,000 packages that were added in the 2020/21 financial year. By the end of the forecast period, the composition of Australia’s aged care system will have shifted from a 45/55 split to 40/60.

: Composition of the NACAP target population, by care type

Care type population remains constant.

Source: GEN Aged Care data; StewartBrown Aged Care Financial Performance Survey Sector Report (June 2021).

Chart 2.3 presents projections of the size of the NACAP target population from the present year until the end of the forecast period. The figures in this chart account for **population growth and ageing, and the planned expansion of the home care system by applying an additional growth factor to home care recipients**. A corresponding offset was applied to the residential aged care population.

The target population is projected to grow from around 420,000 to nearly 700,000 over this time. Most growth will occur in the community care system, with a rapid expansion in the number of available home care places to occur over the next few years. Growth in residential aged care will be much more subdued, as the focus of aged care delivery shifts more towards recipient’s homes and the community.

: Projected NACAP target population from 2020/21 to 2031/32, by care type

Project target population by care type constantly increases into the projected time.

Source: Deloitte Access Economics analysis of AIHW data.

The total demand rate was taken to be a constant 5% in each year of projections. The 5% figure is based on the recommendations of the Aged Care Royal Commission, which suggested an “immediate funding increase to enable a minimum of 5% of older people to access advocacy services”.[[16]](#endnote-16) Consultations and international and sectoral comparisons did not reveal what an optimal level of advocacy should be. In recognition that the 5% recommendation in the Royal Commission was described as a minimum, we also conducted scenario analysis considering a higher target usage rate. The scenario modelling conducted considered two different demand rates to the 5% - the first scenario was a 7% maximum demand rate, and the second scenario was a cohort dependent usage rate.

Box 2.1: Estimating total demand for aged care advocacy

The NACAP is being expanded in response to Recommendation 106 of the Aged Care Royal Commission. This recommendation was based on findings within the report that the consumer voice in aged care is relatively weak and that the coverage of organisations that support these consumers is insufficient. The recommendation included – among other things – an “immediate funding increase to enable a minimum of 5% of older people to access advocacy services”.

Based on the target population projections presented in Chart 2.3, this would be equivalent to nearly 20,000 older people living in residential aged care and 23,000 recipients of community care. This will rise to over 27,000 residential care and 46,000 community care recipients by 2031/32.

One of the aims of this study was to estimate the level of unmet demand for aged care advocacy that may exist at present and in future years. While it is recognised that the Royal Commission recommended a *minimum* 5% of older people to have access to the NACAP, this 5% level has been used as an illustrative upper bound to which met demand can be compared. This means that the estimates of unmet demand are built on a consistent 5% of the NACAP target population over the forecast period.

The consultation process did not identify an alternative “optimal” level of demand for advocacy. Unmet demand that may exist at present has been almost completely unobserved. Moreover, it is likely to be largely unobservable. Consumers generally do not become aware of advocacy services until they have a critical need for them. This means that the usual tool through which unmet demand would be measured – a survey – is not feasible. Respondents to such a survey would not have sufficient information to understand whether they have an unmet need.

Future work could be undertaken by OPAN with the aim of understanding the awareness and usage of the NACAP by older persons. This would give a clearer view of the extent of unmet demand for the NACAP that exists in the aged care population. However, it is critical that any such research is complemented by improved program data collection through the NMDS.

### Met demand

Future met demand equates to the number of services delivered in a year. The number of services delivered in a year is calculated as total funding in that year divided by the cost of service.

* Total funding in a particular year is based on the forward estimates for the NACAP total agreement funding. For this analysis, COVID support (2020/21 only), Emergency & Additional Reform Advocacy, and Diversity Education Project funding were excluded. The NACAP budget that has been used to inform the modelling for the Demand Study is $148.99 (GST exclusive) over the period 2020-21 to 2024-25. Note, the total budget for the NACAP over this period is $165.75 million (GST exclusive), however this includes $10.6 million (GST exclusive) for emergency responses during times of crisis and $6.16 million (GST exclusive) for diversity education for aged care providers. For this study, funding for these two activities is excluded from the NACAP budget as they are distinct from the provision of general advocacy support, education and information. Forward estimates covered the years 2020/21 through 2024/25. Accounting for the exclusions, total agreement funding is budgeted to rise from around $12 million in 2020/21 to nearly $38 million by 2024/25. As the forecast horizon went beyond the forward estimates, the out years assumed that funding grows in line with the size of the aged care system (i.e., the number of recipients). Detailed program expenditure information is provided at Appendix B.
* A current cost per service was calculated by dividing the available funding in FY21 by the number of services delivered in FY21. This cost per service was then inflated using a weighted measure of the consumer price index (CPI) and the wage price index (WPI) to determine a cost per service for each year of the forecast period. This was done to approximate increases in the unit cost of delivering services for providers. A weighted average of wages growth and inflation was used to proxy for the cost structure of service providers.

Chart 2.4 shows the relationship between the NACAP Core Business Activity Funding and the number of services that will be delivered. The largest increase in core funding occurs between 2020/21 and 2021/22, with the total budget rising from around $12 million to over $30 million. Adjusted for the cost of delivering services, this sees service delivery rise from 20,679 to 52,796. Substantial growth will also be realised in 2022/23, with the number of services delivered rising again to 66,168. More gradual growth is observed beyond that.

: NACAP total agreement funding (less exclusions) and forecast service delivery, 2020/21 to 2031/32

Funding forecast for the OPAN service is expected to increase aligned to delivery requirements.

Source: Department of Health (2021); data provided by OPAN; Australian Bureau of Statistics CPI and WPI data.  
Note: LHS = left-hand side; RHS = right-hand side.

Once total number of services delivered were determined, the current demand profile presented in Section 3.1 was used to distribute the total number of services delivered (i.e., the projected met demand) over the coming years. This means that it is assumed the current distribution of services (for example, across care types and service types) remains constant between now and 2031/32. It is possible that adjustments to this distribution will be made over the forecast period to address areas with greater unmet demand, but this type of shift is not captured in the projections.

### Unmet demand

Future unmet demand was approximated by subtracting the met demand from the estimated total demand in each year of the projections. This means that the main parameters affecting unmet demand are the rate of maximum demand and the NACAP total agreement funding (less exclusions). Unmet demand rises with the total demand rate and falls as more funding is provided.

## Future demand for education

The future demand for education was estimated by applying a growth factor to the current year estimate of education sessions in 2020/21. The growth factor includes the estimated growth in the number of residential aged care facilities and the number of community care packages through to 2030/31, and the estimated growth in the delivery of education sessions based on the increase in funding for NACAP services.

It should be noted that COVID-19 has had a significant impact on the ability of SDOs to deliver education sessions. Lockdowns and a tightening of visitational rules at residential aged care facilities mean that both residential and community education sessions have been affected. This is reflected in the figures reported below for the COVID-affected year of 2019/20.

### Education sessions in residential aged care facilities

The total number of residential aged care facilities for 2020/21 was 2,695 based on GEN Aged Care data. Consultations with SDOs indicated a soft target set by the SDOs was to visit each facility at least twice per year, and four times per year if possible. A conservative assumption of 2 visits per year results in 5,390 sessions delivered per year across all residential aged care facilities. This compares to the current number of actual education sessions delivered in residential aged care facilities nationally of 951 in 2020/21, 1,112 in 2019/20 and 1,553 in 2018/19. This is 18-29% of the sessions necessary to conduct two sessions per year per facility.

### Education sessions in community care

Education sessions in community care are harder to estimate due to variations in settings of delivery. Sessions in the community were estimated using a similar approach, using the total number of community care recipients. The number of education sessions delivered nationally across all SDOs was 359 in 2020/21, 446 in 2019/20 and 557 in 2018/19 as reflected in OPAN reports. Assuming there are on average 22 attendees per session in community care (based on OPAN unit record data), this is currently reaching 5.3% of community care recipients.

## Supply

The supply analysis was largely qualitative due to data limitations. OPAN, SDOs and other relevant stakeholders were consulted to gain insights into the key challenges affecting the supply for aged care advocacy. The focus was on the factors that affect service delivery. Other factors relating to supply, such as government funding and program requirements (as defined by government), were not explored.

The supply component also involved the development of a program logic. This identifies relevant performance measures to monitor and evaluate the effectiveness and outcomes of the NACAP. The program logic was developed collaboratively with the Department of Health, OPAN and other key stakeholders in the PGG. It drew on information from the expanded NACAP framework, feedback from the stakeholders during the methodology workshop, and the existing program logic framework provided by OPAN.

# Current demand for the NACAP

The purpose of the demand analysis is to develop a detailed understanding of the demand of current users and provide insights into the current unmet demand for the NACAP. The current demand for NACAP services consists of the current met and unmet demand for NACAP in FY-2020/21. Current met demand is the demand for services that were delivered through the NACAP. Current unmet demand is the demand for services that has not been satisfied by the NACAP, due to supply restrictions or unknown demand. Consultations with stakeholders and desktop research revealed the challenges that exist in preventing access to the NACAP, contributing to unmet demand.

## Current met demand

### Overall usage of NACAP services in 2020/21

Based on the OPAN progress report data for 2020/21, 11,849 cases of information, 8,826 cases of advocacy, and 1,310 sessions of education were delivered nationally (see Chart 3.1). A case refers to one instance of service delivered to a user, while a session refers to education being delivered to multiple attendees.[[17]](#footnote-3)

: Information, advocacy, and education over 2018/19 to 2020/21

Source: Data extract based on OPAN Progress reports

Information and advocacy cases steadily increased over time; however, education sessions decreased over the same period. The redirection of education resources to information and advocacy and COVID-19 impacts on access to residential facilities both impacted on the NACAP’s ability to achieve its education targets. These constraints meant that the NACAP reached 66% of its annual delivery target for 2021.[[18]](#endnote-17) Box 3.1 outlines the impact of COVID-19 on aged care delivery across the sector.

Box 3.1: The impact of COVID-19 on aged care advocacy

The COVID-19 pandemic is continuing to significantly affect the aged care sector. Major impacts have included: deaths of older people within residential aged care, family members being prevented from visiting residents, border controls causing pressure on an already strained workforce, and movements to rural areas leading to changes in service delivery models. Department of Health data reveals that, as of 28 January 2022, there were **657 COVID-19 related deaths** in residential aged care facilities since July 2021.†

COVID-19 lead to a spike in complaints to the Aged Care Quality and Safety Commission (ACQSC). There were 9,218 complaints made by aged care recipients in 2020/2021, compared with 7,816 in 2018/19 (the last financial year not affected by COVID-19). This represents an 18% increase in complaints across all care types. Common issues reported in residential aged care include the quality of food provided, treatment of pressure wounds, and the provision of medication. Home care complaints tend to revolve more around fees and charges, and what items they are eligible for in their package. Some of these challenges were exacerbated by the pandemic, especially as closures of facilities meant families were not able to visit residential aged care facilities.

COVID-19 lockdowns have also affected the way NACAP services are delivered. Restrictions on face-to-face meetings resulted in significant decreases in education sessions delivered during lockdowns, but sessions picked up once restrictions were removed. For the period between January and June 2021, OPAN was able to meet 90% of the target residential aged care cohort to deliver education sessions (645 sessions). However, full targets were not met due to some facilities continuing to restrict access to advocates even after state-wide lockdowns were lifted.

The pandemic has and continues to impact service delivery by SDOs. One example of this is the addition of vaccine webinars in January and February 2021. The vaccine webinars reportedly gathered a large and diverse viewer base, with 6,588 attending the first webinar and 2,608 attending the second. The audience consisted of older people, families, and representatives (26%); aged care workers (41%); community visitors (4%); and various other groups (29%).

The pivot towards virtual models of NACAP service delivery will likely be a lasting change, demanding more training and development for more mixed service delivery. Populations in rural and remote areas are likely to benefit from greater adoption of virtual delivery methods. This will be particularly important if the recent trend towards higher population growth in these areas continues.

COVID-19 is expected to have lasting impacts on the aged care sector. These impacts are not all apparent yet, but some are already affecting key aspects of the sector. The pandemic has impacted the way aged care operates from precautionary procedures to limit spread between staff and/or residents to direct impact on staffing availability as staff contract or are exposed to COVID-19. These lasting impacts may have flow-on effects on the demand for the NACAP services.

†Source: Department of Health (2022), COVID-19 outbreaks in Australian residential aged care facilities – national snapshot; Aged Care Quality and Safety Commission (ACQSC) 2021, Sector Performance Data; insights from stakeholder consultation.

Information and advocacy cases also varied by SDO (see Chart 3.2). The distribution of cases across service types was varied. By state, NSW (SRS), Vic (ERA) and Queensland (ADA) delivered the highest number of information cases, making up 60% of the sessions in aggregate. NSW (SRS), SA (ARAS) and Queensland (ADA) delivered the most advocacy cases, making up just over half (55%) of the cases delivered nationally.

In aggregate, over 23,000 information and advocacy cases were delivered to clients in 2020/21, 10.4% of which were related to elder abuse. A further 6,400 cases of advocacy were delivered to individuals who identified with at least one special needs group. Finally, over 2,600 education sessions were delivered, 50% of which included attendees who had experienced elder abuse or were from special needs groups. This well exceeds OPAN’s target of 20% of education sessions including special needs groups.

: Information and advocacy cases in 2020/21 by SDO.

Source: OPAN Progress report 2020/21

Chart 3.2 shows that there was significant variation in the types of services delivered across the country in 2020/21. Across all SDOs, education sessions were heavily affected by COVID-19 due to restrictions on access to residential aged care facilities as well as social distancing limitations on activity within the community.

The differences in information and advocacy usage across states reflect state-based population variations as well as SDO variations in service delivery. Differences in the demographic makeup across states, such as the number of older people from a CALD or an Aboriginal and Torres Strait Islander background can influence the number and type of NACAP services sought. Further, COVID-19 affected states differently, having varying degrees of impact on the service delivery of education sessions.[[19]](#footnote-4) The volume of cases responded to by some SDOs may also have been limited by resourcing constraints. Historical differences in funding across the SDOs has enabled some (e.g., Queensland (ADA)) to service more people than others. Thus, the usage rates do not correspond to the population breakdowns in each of the states, and the demand reflects the capacity of service provision under current resource levels.

#### Current usage of NACAP services across care settings

The OPAN unit record data shows that the provision of advocacy is higher in community care relative to residential aged care (see Chart 3.3).

: Advocacy usage (2020/21) in residential aged care and community care, by age

Source: OPAN unit record data; OPAN Progress Report 2020/21; modelling by Deloitte Access Economics

Across age groups, advocacy usage in community care is higher among those aged between 50-74 than for older age groups, relative to the population within the same age groups.

Those outside of residential aged care and community care received around one-quarter of advocacy services and one-third of information services. Despite the relatively high share of services delivered, the average usage rate for advocacy outside of residential aged care and community care settings is low according to the OPAN unit record data, at 0.1% on average for both males and females, across all age groups. This is because the usage rate captures service users as a proportion of people in the population with a set of characteristics, and the large population base of people not receiving formal aged care drives down the usage rate. Some portion of the users captured in this cohort might be families and representatives of the older people; however, this is unclear from the data.

Consequently, the low usage rate reflects the large population of older people not receiving formal care. Stakeholder consultations suggested that older people and their families, loved ones and representatives tend to discover or reach out to advocacy services during a point of need – often due to an interaction with care providers.

The OPAN unit record data shows that the provision of information across settings is more balanced, relative to advocacy services (see Chart 3.4).[[20]](#footnote-5)

: Information usage in residential aged care and community care, by age

Source: OPAN unit record data; OPAN Progress Report 2020/21; modelling by Deloitte Access Economics

Across age groups, information usage across both settings is highest among those aged 70-79. Females have a higher usage of information services across the younger age groups than males, in residential aged care facilities.

The average usage rate for information outside of residential aged care and community care is low according to the OPAN unit record data, at 0.1% on average for males, and 0.2% on average for females, across all age groups. As in the case for advocacy, the low usage rate is likely due to the large population base outside of aged care and the lower usage of NACAP services by people not in permanent care. Furthermore, across advocacy and information, SDOs are likely to have not characterised the care type (i.e., ‘N/A’) for some users who are not affiliated with residential aged care or community care, reducing the usage rate for this cohort in the NACAP unit record data.

### Issues requiring advocacy

In 2020/21, OPAN and SDOs provided:

* 23,019 occasions of information or advocacy support to older people,
* 2,344 occasions of support to older people at risk or experiencing elder abuse, and
* 2,604 education sessions relating to advocacy and older person abuse prevention across both residential aged care facilities and home care recipients.[[21]](#endnote-18)

Based on the latest NACAP progress report, common issues addressed by OPAN’s advocates include:

* Rights-related: Choice and decision making; choice and dignity, rights, and discrimination
* Quality of care: Issues around safety, care delivery, poor staffing, and poor clinical care
* Financial issues: Issues around bonds, fees, charges, entitlements, and other financial matters
* Insufficient choice and unmet care need: Control over and making choices about care, personal care, and dignity of risk
* Assessment/My Aged Care: Access difficulties, issues with reviews, issues with aged care assessments
* COVID-19: Issues stemming from lockdowns, poor communication, unsupportive alternative visitation options, concerns about care. [[22]](#endnote-19)

Complaints data from the ACQSC may also be indicative of the types of issues that older persons may need assistance with. The ACQSC is the national end-to-end regulator of aged care services focussed on protecting the welfare and rights of consumers. The ACQSC monitors, regulates, assesses, and accredits aged care services subsidised by the Australian Government. The ACQSC helps consumers understand the quality of care and services they can expect to receive, including the ability to lodge a complaint or raise a concern, access advocacy services, and understand the quality standards that apply to your service provider. [[23]](#endnote-20) In 2020/21, the ACQSC made 1,598 referrals to OPAN in comparison to 541 referrals in 2019-20.[[24]](#endnote-21) In 2020/21, 9,220 complaints were received (8% increase from 2019-20[[25]](#endnote-22)) covering 22,084 issues (Chart 3.5). Complaints were raised by representatives or family members (51%), consumers (20%), staff (8%), external agencies (2%) and anonymously (19%).[[26]](#endnote-23) Of the 22,084 issues raised, 77.7% were in residential care, 21.5% were in home care and 0.8% were in flexible care.[[27]](#endnote-24) Table 3.1 summarises the common issues raised in residential and home care.

: ACQSC complaints resolution data across 2019/20 to 2020/21 annual reports

Source: ACQSC Annual Report 2019/20; ACQSC Annual Report 2020/21; modelling by Deloitte Access Economics

Table 3.1: Issues raised in complaints to ACQSC in 2020/21

|  |  |
| --- | --- |
| **Residential Care** | **Home Care** |
| * Personnel number/sufficiency * Medical administration and management * Infectious diseases/infection control * Falls prevention and post-fall management * Personal and oral hygiene * Consultation and communication | * Consultation and communication, including fees and charges * Domestic assistance * Fees and charges, including management of finances and reimbursements * Consistent client care and coordination |

Source: Aged Care Quality and Safety Commission Annual Report 2020/21; Note: The sample for flexible care was too small to report.

### Current usage of NACAP services among vulnerable groups

Vulnerable populations are those who might have reduced access to NACAP and broader aged care services due to individual characteristics (e.g., language barriers, cultural hesitancy to engage with services, health risk factors, elder abuse). It is important to capture demand for vulnerable groups as they face greater barriers to accessing NACAP services but stand to gain large benefits if they can use the services.

The OPAN unit record data captured the following user characteristics for users of information, advocacy, and education:

* Dementia status
* Aboriginal and Torres Strait Islander peoples
* CALD background
* Experience of elder abuse.

As illustrated in Chart 3.6, advocacy usage rate was low among people with dementia and those experiencing elder abuse across residential aged care and community care. The usage of information services was low for people with dementia and those experiencing elder abuse across residential aged care and community care. In contrast, Aboriginal and Torres Strait Islander people have relatively higher usage rates for information and advocacy compared to the average across all cohorts.

: Advocacy and information usage among vulnerable populations, by setting

Source: OPAN unit record data; OPAN Progress Report 2020/21; modelling by Deloitte Access Economics

These results are consistent with insights from stakeholder consultations, which shed light on the barriers faced by these communities. For instance, older people with dementia may rely on carers to comprehend their requirements and find appropriate support on their behalf. This can place a significant strain on the informal carer, who is often experiencing frailty and ageing themselves. Consultations indicated that these vulnerable groups faced significant challenges in accessing the NACAP that are not necessarily captured in the data. We also heard that some SDOs have focused on targeting service delivery for Aboriginal and Torres Islander people which is consistent with a relatively high usage rate for this cohort.

#### Elder abuse

With regard to elder abuse, access to advocacy for those suffering abuse when living in the community can be difficult as the perpetrator is often able to prevent access to advocacy. Family member may be perpetrators of abuse and often exercises substantial control over multiple aspects of their lives, according to stakeholders. This control can lead to social isolation, exacerbating the challenges faced by the individual in accessing help outside of the home. Professional carers can also be perpetrators of abuse within the community - the recently finalised National Elder Abuse Prevalence Study, conducted by the Australian Institute of Family Studies, reported on the prevalence of elder abuse in community settings and found that 3% of perpetrators of abuse were professional carers and a further 5.8% were service providers.[[28]](#endnote-25) This sheds some light on the extent of abuse that may be perpetrated by home care staff. Similar situations in residential care were also raised by stakeholders, for example, where a caregiver may prevent the individual from alerting family and from being aware of supports like advocacy. This suggests that while there is a need for advocacy by older persons experiencing elder abuse, because of the additional hurdles in awareness and access they are also likely to be inadequately captured in current demand.

#### Aboriginal and Torres Strait Islanders

Chart 3.6 also shows that advocacy and information usage by people of Aboriginal and Torres Strait Islander was relatively higher than average. Notwithstanding this, with the exception of advocacy in community care settings, the usage rates are well below the minimum 5% usage target recommended by the Aged Care Royal Commission. One reason for this might be that the services as delivered currently in residential aged care are not culturally appropriate, which stakeholder consultations suggest is important for the services to be taken up by members of these communities. Lasting impacts of institutionalisation means there is a level of trauma associated with residential aged care for many older people within the Aboriginal and Torres Strait Islander communities.

#### Cultural and linguistically diverse communities

Cultural barriers also persist within CALD communities. Australia’s CALD community is incredibly diverse – in ethnicity, beliefs, cultural attitudes, spoken language (including the level of English spoken), and time lived in Australia. The aged care needs of these individuals are equally diverse, with specific language, cultural, and personal care requirements common. This creates service delivery requirements for aged care providers that have, in part, been responded to through the provision of services tailored to specific ethnic groups. As seen in Chart 3.6, the utilisation of advocacy and information services by members of the CALD community is higher than some other vulnerability groups but like for Aboriginal and Torres Strait Islander people, still falling short of the minimum 5% target usage rate recommended by the Aged Care Royal Commission. The exception is that for advocacy usage in community care, usage by CALD older persons is high, at over 6%.

Several stakeholders noted that advocacy in its current form is mostly steered towards English speaking communities. The challenges go beyond language barriers – stakeholders raised that even the word ‘advocacy’ is not directly translatable to all cultures and languages. Older people and their families from CALD backgrounds are more likely to trust people from similar backgrounds, often sharing critical experiences only with members of the same community.

#### Other vulnerable groups

In addition to the characteristics captured in the unit record data, there are a host of challenges faced by other groups that are not captured in the data, but who are equally important to consider as priority populations. These challenges include barriers faced by:

* *Older people with disabilities*: According to stakeholders, the complex health needs and preferences of many people with disability over the age of 65 are not adequately represented across the systems. This was believed to be especially true for older people who are not eligible for NDIS due to the late identification of their disabilities. Many people with disability are informally supported by their families, however, as they age, so too do their family members, thereby reducing these informal advocacy supports. In addition, there are those that experience social isolation due to physical access constraints. Older people with cognitive impairment or communication barriers may face significant barriers to accessing advocacy services and articulating their needs.
* *LGBTIQ+ community*: Consultations revealed that there is a general view that there is a lack of recognition and understanding for the needs of the LGBTIQ+ in the aged care sector, particularly as aged care may be an environment that older persons may consider unsafe to disclose their identities. Older members of the LGBTIQ+ community may lack a safe and accepting environment to disclose their identities and face discrimination from aged care providers. Stakeholder consultations revealed that members of this community reportedly access LGBTIQ+ specific advocacy more than they do aged care advocacy due to a lack of understanding of needs specific to this group within the mainstream system.
* *Veterans, war widows and widowers*: Feedback received from stakeholder consultations reflected that navigating and accessing services is challenging for veterans who have faced sustained physical injury, are incapacitated, or have post-traumatic stress disorder (PTSD) due to conflict. Stakeholders within veteran organisations highlighted the importance of continuing to build partnerships between veteran organisations and aged care organisations, including for advocacy. Veterans’ advocacy services span across aged care and therefore stakeholders have suggested that building partnerships between veterans’ advocacy services and OPAN will assist in meeting the demand for advocacy services. As the system currently stands, veteran advocates face barriers integrating with the aged care system, which restricts their ability to advocate efficiently for their clients.
* *Informal care network*: Stakeholder consultations revealed that people supported by informal care networks often lack awareness of formal advocacy. Better awareness could allow them to access support that is beyond their informal care network. While the need for advocacy is likely to be greater if the older person has no informal carers to advocate for them, the realised demand for advocacy is likely to be lower among those with informal carers if these carers do not reach out for help on behalf of the older person. Older people are often unaware of or face other barriers to seeking advocacy on their own and rely on carers to connect them to advocates. This may result in a disparity between people who can most benefit from advocacy and those who get it.
* *Rural and remote areas*: Stakeholder consultations identified that there is a need to increase presence of advocates in rural and remote areas. Travel times to these areas can be significant, limiting the ability to deliver advocacy services. Stakeholders also suggested that poor internet access, as well as limited digital and health literacy, have been recognised as additional hurdles in raising awareness of advocacy services in these areas.

#### Response to challenges

Notwithstanding the barriers faced by vulnerable groups, more targeted efforts by SDOs are mitigating some of these challenges, already leading to higher utilisation among some states. For example, a key achievement of Senior Rights Service (NSW) was that of the 1000 older people advocated for, over 50% were from vulnerable groups (33.7% regional, 27.1% CALD, 25.6% dementia, 5.4% Aboriginal or Torres Strait Islander, 4.9% financially disadvantaged and 3.3% other).[[29]](#endnote-26) The inclusion of diversity education in the expanded NACAP framework will help aged care providers and staff to understand and meet the unique needs of people from diverse backgrounds. This should progressively improve the engagement of older people from diverse backgrounds with aged care services. SDOs reported that there is also a focus at present on recruiting advocates who are members of CALD communities themselves, with the aim of establishing trust and improving engagement.

## Current unmet demand

According to consultations and desktop research, current unmet demand appears to be driven by low awareness of the availability of NACAP as well as generally increasing demand and growing complexity of issues faced by older persons which presents challenges to service delivery.

Through consultations, it was revealed that **awareness** of what advocacy means, of NACAP and the support it can provide were noted as critical factors in whether, and how, older people engage with the program. Awareness of NACAP in this case refers to both whether an individual knows that it exists and whether they understand what it does. Findings from the consultation process suggest that there are shortcomings with both, which is consistent with previous findings in relation to awareness of the program, such as Review of Commonwealth Aged Care Advocacy Services.[[30]](#endnote-27)

Most stakeholders noted that the awareness of aged care advocacy is extremely low among older people and their representatives. While it is not substantiated by any quantitative evidence, most anecdotal information from the consultations placed awareness in the range of 5-10%.[[31]](#footnote-6) It was also noted by stakeholders that most people who are aware of the program are likely to only become aware in the time of a crisis, such as when they make a complaint to the ACQSC. Those in marginalised cohorts, such as older people with disabilities, CALD people, Aboriginal and Torres Strait Islander peoples, and those in the LGBTIQ+ community faced even greater challenges to awareness and access. This suggests the need for more proactive tailored marketing and advocacy, notwithstanding that there could be capacity limits for this due to current funding and supply constraints according to stakeholders. Some behavioural insight approaches are suggested in Chapter 6 that could increase the take-up of NACAP services.

OPAN also reports that unmet demand for NACAP’s advocacy services is attributable to a rise in **demand** due to the aging population and the increased **complexity** of cases requiring extended support. Specifically,

* The increasing number of persons seeking and entering aged care
* The complexity of a market-based aged care system
* The erosion of person-centred care in the provision of home care packages
* An aged care system that continues to expand and diversify
* The evolution of COVID-19 which has presented unique rights-based concerns and increased advocacy cases
* The ongoing impact of the Increasing Choices Reforms[[32]](#endnote-28)

SDOs have indicated that there is unmet demand for community education sessions targeted to educate older people/family members on navigating the aged care system. Although resources are available through My Aged Care, there appears to be a limited variety of communication resources that offer the support and advice needed.[[33]](#endnote-29) Based on the ACQSC complaints data it may be inferred that there is unmet need in residential care (given the relatively higher volume of complaints). COVID-19 restricted the delivery of in person education sessions in residential care settings, with SDOs noting that Zoom education session were not effective for the older audience due to poor engagement.[[34]](#endnote-30) Given that around half of all complaints are raised by representatives and family members, there is likely to be a need for promotional activities by OPAN to target this group, rather than end consumers.

**Demand management** has become increasingly important to maximise efficiency of advocacy for an equitable approach.[[35]](#endnote-31) In response to the Royal Commission’s recommendation to study unmet demand within NACAP, OPAN established a set of Demand Management Practice Guidelines aimed at improving the consistency of practices in measuring and managing NACAP demand and ensuring a consistent approach to prioritising high risk and high need cases and triaging other low priority cases.[[36]](#endnote-32) To support the implementation of the Demand Management Practice Guidelines, a process for reporting waitlist data was developed.

In the most recent OPAN progress reports, ADA reported wait times for NACAP services could take even 4 to 6 weeks, but this would vary across SDOs. This is expected to reduce with the doubling of the advocacy workforce in the expanded NACAP. 70 additional advocates have already been engaged for 2021/22.

SDOs have found that there has also been an increased number of urgent cases requiring a more immediate response. [[37]](#endnote-33) These cases typically treat clients with significant distress from issues regarding access to services or threat of withdrawal. For urgent cases, advocates typically respond within a few days to a week depending on the issue.[[38]](#endnote-34)

Many of the challenges to accessing the NACAP uncovered through the consultation process are also reflected in the OPAN’s *Raising the voice of people accessing aged care* report released in December 2021.The report provided insights based on a thematic analysis of OPAN’s quarterly progress reports. Of note, the report highlighted that current unmet demand is affected by the new challenges resulting from COVID-19 for advocates and support services in aged care especially in supporting older people’s rights in residential aged care facilities, quality of care and availability of services, and the specific challenges that diverse and marginalised groups face.

# Future demand

This chapter presents the results of the future demand analysis. The future demand analysis combines quantitative and qualitative techniques to develop a detailed view of the NACAP over the coming years. The quantitative component involved the estimation of the met and unmet demand for aged care advocacy each year between now and 2031/32. The qualitative aspect draws on insights from the consultation process to complement the quantitative findings.

A detailed discussion of the approach to estimating future demand is provided in Section 2.3.

## Trends influencing total demand

Consultations across the aged care sector revealed that generational changes, government policy, demographic trends, increasing dementia, increase in aged care service use and growing complexity will be key drivers of demand for aged care advocacy.

### Demographic trends including life expectancy

Demographic trends will also shape advocacy needs. An improvement in health and life expectancy means that more people are living longer and staying at home longer. Both the proportion of people aged 65 years and above and the proportion of the Aboriginal and Torres Strait Islander population aged 50 years and above are on an upward trend. The former has increased from 12.4% to 16.3% in the 20 years leading up to 2020 (ABS population trends). The Intergenerational Report 2021 projects the number of people aged 65 years and older will double over the next three decades.[[39]](#endnote-35) This suggests that the need for aged care services and advocacy will rise over the foreseeable future.

### Increasing dementia

The prevalence of dementia among those aged 65+ is expected to grow by 35% between 2021 and 2030.[[40]](#endnote-36) This means that aged care services will need to increase to support a growing cohort of people with dementia. Those living with dementia often have the strongest need for advocacy as they lack the competency and understanding to self-advocate when needed. This means that the growing number of people living with dementia is likely to be accompanied by a corresponding increase in the demand for aged care advocacy.

### Increase in aged care service utilisation

The utilisation of aged care services will rise as the number of older Australians – particularly those living to very advanced ages – grows. The number of people using home care tripled (from 47,684 to 142,436) in the decade to 2020. The number of people using residential aged care and respite care increased by more than 13% and 50% respectively over the same time.[[41]](#endnote-37) The Australian Government will increase the supply of home care packages by 80,000 by 2023, increasing the total number of home care packages to 275,000. This will translate into increased demand for aged care advocacy, especially as older people seek to remain within their own homes.

### Growing complexity

The movement towards personalised care will introduce greater complexity to the delivery of aged care support. There is a growing diversity of care needs among older people and an increasing focus on delivering services that are sensitive and appropriate to these needs. This includes the specific care needs relating to cultural backgrounds, sexuality and gender diversity, mental illness, and other groups such as care leavers and veterans. Failing to deliver appropriately designed services to these cohorts will only serve to increase complexity in the long-term.

Models of care focused on choice and control rely on consumer involvement and understanding. This increases complexity, and a complex system carries the risk of disengaging consumers without appropriate supports. An example of this is the recent changes to home care payment arrangements which are reported to have increased confusion among recipients. While thoughtful policy and implementation will help to alleviate this complexity, it is likely that many recipients will face challenges (at least in the short-term). This may increase the demand for aged care advocacy – particularly specialist advocacy – as a key support for navigating the system and responding to issues.

### Government policy and reform

The next tranche of government reforms will further the move towards consumer choice and control, and this may increase the demand for advocacy. Increasing consumer choice is a positive outcome but presents challenges as older people may find it difficult to navigate the service options and corresponding fee schedules. Past reforms have demonstrated that complaints and concerns are likely to rise as new policies are introduced.

Some stakeholders indicated that home care providers are poor at communicating aged care rights with their consumers. Policy directed at service providers embracing a rights-based approach to residential aged care may also influence the demand for aged care advocacy. This may occur if older people are made to feel more confident in raising concerns about a service.

It is also noted that the availability of information regarding aged care services is likely to improve significantly with the current reform agenda. Service Australia, Care Finders, and Indigenous Care Finders will help to improve touch points for current and future aged care consumers. While the exact impact of this on demand levels for the NACAP is difficult to predict, improved availability of information will at the very least change the nature of NACAP requests.

### Generational changes

Many stakeholders indicated that the changing characteristics and attitudes of the older population are expected to increase the demand for advocacy in the future. While speculative, stakeholders hypothesised that a generational shift is soon to occur. This shift would involve the current generation who are accepting of services as provided being gradually replaced by a new generation of aged care consumers who are cognisant of their rights and needs. The extent that this will shift the power balance and expectations of consumers and potentially increase the scrutiny of service quality will also depend on structural changes to support or empower consumer voice. Some stakeholders noted that the upcoming generation will also be more likely to self-advocate given higher digital literacy, decreasing the demand for formal advocacy. The net effect of these opposing factors remains unclear.

## Future total demand

Drawing from the insights from consultations outlined in Section 4.1, our model for total demand growth is driven by several factors, including population growth, demographic changes, and reforms to the aged care system. Each of these factors is accounted for in the projections of the target population that underpins the subsequent analysis of service usage.

The future total demand was estimated by establishing the size of the NACAP **target population** in each year between now and 2031/32 and multiplying by the relevant maximum total demand rate.

### Future demand for information and advocacy cases

As shown in Chart 4.1, most users of the NACAP are recipients of community aged care. A similar number of users are recipients of residential aged care or fall in the ‘other’ category – this includes recipients of respite care, those who are pre-entry to aged care, and those not engaging with the aged care system. This distribution of users is assumed to continue over the forecast period. This means that any change in the distribution of users across service types i.e., information or advocacy is only driven by changes in the composition of the target population.

: Projected NACAP users from 2020/21 to 2031/32, by care type

The number of users are expected to increase constantly in the future for all care types.

Source: Deloitte Access Economics analysis based on OPAN and AIHW data.

Chart 4.2 presents these same data, disaggregated by service type instead of care type. A minor shift from information towards advocacy is projected to occur. This is based on the composition of the aged care population and the current usage patterns of the NACAP. That is, advocacy usage rates are higher in community care and most growth in the aged care population will occur in community care.

: Projected NACAP users from 2020/21 to 2031/32, by service type

Future demand for OPAN services is expected to increase constantly for all care types.

Source: Deloitte Access Economics analysis based on OPAN and AIHW data.

### Future demand for education

Chart 4.3 shows that the demand for education will gradually grow over the next decade. Growth will be slightly faster in community aged care, reflecting the significant expansion in home care places. The analysis suggests that a much greater emphasis on education with the community will be required, as this is where system growth and complexity are expected to be concentrated.

: Demand for education sessions from 2020/21 to 2031/32, by care type

Future demand for OPAN education sessions is expected to increase constantly for all care types.

Note: \*2020/21 figure is assumed to be the same as the number of sessions delivered in 2018/19 to filter out impacts of COVID-19 on service delivery. The actual education sessions delivered in 2020/21 were 951 for residential aged care and 359 for community care.

Results in Chart 4.4 show that the gap that currently exists between the sessions delivered today with the funding available and the target of 2 sessions per residential aged care facility will widen going forward without either additional funding for education services or a reallocation in existing funding from advocacy and information to education. Delivering the sessions to a larger audience can also lead to wider education delivery without a need for more sessions.

: Projection of education sessions delivered in residential aged care from 2020/21 to 2031/32, estimated actual delivery and targeted delivery

Education sessions are projected to grow incrementally into the future.

Note: \*2020/21 figure is assumed to be the same as the number of sessions delivered in 2018/19 to filter out impacts of COVID-19 on service delivery. The actual education sessions delivered in residential aged care facilities in 2020/21 were 951.

## Future met and unmet demand

Chart 4.5 presents the estimates of met and unmet demand for aged care **advocacy and information services** from the current year until 2031/32. Met demand is observed to grow rapidly in the short-term as new funding is provided. While this funding is shown to lift the usage rates for advocacy and information services from 1.8% and 1.9% respectively in 2020/21, they will not reach the target of minimum 5% usage recommended by the Aged Care Royal Commission.

This means that significant unmet demand will remain. The usage rates for advocacy and information services peaking at 4.3% and 4.7% respectively in 2022/23. The unmet demand will grow in the years following this peak as growth in the target population and the cost of delivering services is projected to outpace growth in funding. This analysis shows that more funding is required to meet the Aged Care Royal Commission recommended target of minimum 5% coverage across aged care recipients.

: Usage rates across both residential and community aged care, 2020/21 to 2031/32

Usage rates of advocacy and information services for both care types, are predicted to level out and lower over time. However, unmet demand will remain and grow.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

Chart 4.6 presents the analysis for **advocacy** services only, disaggregated by care type. It is assumed that the current distribution of demand remains constant over the coming years. The projections show that usage of advocacy services in the community care setting will exceed the Aged Care Royal Commission’s recommended minimum of 5% usage. In contrast, usage in residential care will peak at only 2.9%, suggesting that more will need to be done over the coming years to address unmet demand for advocacy services – particularly for residential aged care recipients.

: Advocacy usage rates, 2020/21 to 2031/32

Usage rates for advocacy services only for both care types, are predicted to remain constant in coming years.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

Chart 4.7 presents the same analysis as Chart 4.6, but this time for **information** services. Again, it is assumed that the current distribution of demand remains constant over the coming years. Both usage rates will approach the Aged Care Royal Commission’s recommended minimum target of 5% and will be more evenly distributed across the care types. This suggests that the way information services are currently distributed across care types is more appropriate and could be maintained as funding is increased.

: Information usage rates, 2020/21 to 2031/32

Usage rates for information services only for both care types, is assumed to remain constant in coming years.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

## Scenario modelling

The modelling presented in Sections 4.1.6 and 4.3 is based on a total demand rate of 5%. As discussed in Box 2.1, this was based on the recommendations of the Aged Care Royal Commission. This 5% is based on the recommendations of the Aged Care Royal Commission, which suggested an “immediate funding increase to enable a minimum of 5% of older people to access advocacy services”. Desktop research, qualitative research, and comparison of aged care advocacy in other jurisdictions did not reveal the ideal proportion of people should be accessing advocacy services. Given the challenges in determining quantitative factors influencing demand, two scenarios were modelled, 1) based on a minimum coverage target of 7% and 2) based on differentiated total demand rates across vulnerability groups. As these scenarios use the same funding schedule as the results presented in Section 4.3, the met demand profile remains unchanged while unmet demand is higher.

### Scenario 1: 7% total demand rate for all recipients

Scenario 1 considers a situation in which the total demand rate is 7% for all recipients of aged care. While the charts presented in Section 4.3 showed that the planned funding increase is insufficient to meet a 5% usage rate, this scenario illustrates how much higher unmet demand may be if a higher usage rate (7%) was used in the modelling.

Chart 4.8 shows that unmet demand is much larger for both advocacy and information services over the whole forecast horizon. Where unmet demand in 2020/21 for advocacy was around 13,400 under the main modelling using a 5% demand rate assumption, this rises to nearly 21,800 under this scenario with a 7% demand rate. Similarly, the unmet demand for information in 2020/21 rises from around 12,800 to 21,200. The way this unmet demand is distributed remains the same as before, as it has been assumed that the total demand rate is the same for both service and care types.

: Usage rates across both residential and community aged care, 2020/21 to 2031/32

Unmet demand is shown to be much larger for both advocacy and information services in forecasts.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

: Advocacy usage rates, 2020/21 to 2031/32

Advocacy services only for both care types show a downturn in usage growth as met and unmet demand remains constant.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

: Information usage rates, 2020/21 to 2031/32

Information services only for both care types show a downturn in usage growth as met and unmet demand remains constant.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

### Scenario 2: Higher demand among vulnerability groups

Scenario 2 considers a situation in which each vulnerability group has a different total demand rate. This scenario was modelled to demonstrate how much unmet demand may exist if some of the vulnerable groups have a greater need for service that mainstream cohorts. It is based on insights from the stakeholder consultation process which suggested that vulnerability groups have higher need for advocacy and simultaneously have scope for higher usage.

Table 4.1 shows the specific total demand rates modelled for each vulnerability group and the resulting overall total demand rate. The total demand rates for each group were assumed to be the same for both advocacy and information. They were also assumed to be the same for both types of care, except for those with dementia, who were modelled to have a higher rate of demand in community care due to the greater complexity of services. Other vulnerability groups had their maximum demand rates set based currently observed higher rates of usage (e.g., matching the usage rate of culturally and linguistically diverse individuals in residential care with the observed usage rate in community care).

: Total demand rates modelled in Scenario 2, by vulnerability group

|  |  |  |
| --- | --- | --- |
| **Group** | **Residential care** | **Community care** |
| No identified vulnerability | 5.0% | 5.0% |
| Aboriginal and Torres Strait Islanders | 7.0% | 7.0% |
| Culturally and linguistically diverse | 12.0% | 12.0% |
| Dementia | 7.0% | 9.0% |
| Elder abuse | 10.0% | 10.0% |
| **Total** | **7.8%** | **7.0%** |

Source: Deloitte Access Economics.

Like Scenario 1, the following charts show that unmet demand is much larger across both advocacy and information services than in the modelling of the interim measure. Unmet demand is also observed to be greater than in Scenario 1, primarily due to the higher total demand rate in residential aged care. In this scenario, the unmet demand for advocacy services is 23,200 in 2020/21, rising to 26,900 by 2031/32. There is also an unmet demand of 22,600 recipients of aged care for information services, increasing to just over 25,000 by 2031/32.

: Usage rates across both residential and community aged care, 2020/21 to 2031/32

Unmet demand is shown to grown constantly over time, but usage rates to lower for both advocacy and information services. 

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

: Advocacy usage rates, 2020/21 to 2031/32

Advocacy services for both types of care would remain constant in usage, however unmet demand is predicted to grow.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

: Information usage rates, 2020/21 to 2031/32

Information services for both types of care would remain constant in usage, however unmet demand is predicted to grow.

Source: Deloitte Access Economics analysis of OPAN and AIHW data.

# Supply of the NACAP

## OPAN’s capacity to meet the projected demand

The ability of OPAN to meet the projected demand will depend on the supply of advocates and their capacity and capability to meet the advocacy needs of the aged care population. Section 4.1.6 showed that the demand for the NACAP is expected to grow over the next decade as the population ages and the aged care system expands. All else being equal, this means that a significantly higher number of advocates will be required.

Funding to OPAN is increasing to help meet this anticipated demand. This funding boost will enable more advocates to be recruited and for investment in capacity building. Chart 5.1 shows the number of full-time equivalent (FTE) advocates operating across the network, both prior to and following the impending expansion of the NACAP. The total number of advocates nationally prior to expansion was 56, and this will increase to 145 following expansion.

: Supply of advocates prior to expansion and post expansion, by state

Expansion of OPAN has increased the supply of advocates across all Australian states and territories, more than doubling in NSW, VIC and Queensland.

Source: Deloitte Access Economics based on OPAN data.

The demand analysis suggests that these increases in FTE advocates will be insufficient. As shown in Section 4.3, demand gaps will remain for both advocacy and information services when aggregated across care types. A significant demand gap will exist for advocacy services in residential care, while smaller demand gaps will remain for information services in both residential and community care. Analysis of the FTEs required to meet the projected demand would require data regarding the total FTE hours per instance of service to establish an average time spent per advocacy and information case. While advocacy hours were available in the unit record data provided by OPAN, this measure did not represent FTE hours. As such, this FTE analysis was not possible.

The NMDS being implemented by OPAN may be suitable for more detailed supply analysis in the future. The NMDS will include a variable for staff time spent, measured as the amount of time an advocate or other staff member spends working on information provision, an advocacy case, or an education session. The NMDS Data Dictionary has marked this as being an optional data item for all case types. For future analysis, it is important that this variable is consistently recorded, and the hours represent FTEs – that is, inclusive of all time spent on the case, both directly and indirectly.

The consultation process with OPAN SDOs and a wide range of other stakeholders operating in, or interacting with, aged care advocacy revealed several current challenges relating to supply of advocacy. Some of these challenges are common across each SDO, while others arise due to unique operating conditions in specific parts of the network.

Stakeholder consultations revealed key supply factors affecting the usage of NACAP services are:

* Recruitment and Retention of advocates
* Cultural, language, behavioural, and personal care needs
* Providing services to regional and remote areas

### Recruitment and retention of advocates

As highlighted in the 2018 Aged Care Workforce Strategy Taskforce, the aged care sector faced challenges in recruiting and retaining workers in general.[[42]](#endnote-38) From our consultations, key stakeholders highlighted the recruitment and retention of advocates can be challenging for SDOs. This reflects the challenging nature of the job and the challenges of adequately preparing an advocate for the many complicated scenarios that arise in the role. Lack of organised professional development and opportunity for career progression frequently results in high turnover of advocates, which poses a barrier to service delivery as trust, rapport, and understanding of local nuances are crucial, especially with special needs populations. While some of these issues may endure, the expansion of NACAP will help with the doubling of the advocacy workforce.

### Cultural, language, behavioural, and personal care needs

The cultural, language, behavioural, and personal care needs of some special needs’ groups can pose challenges for service delivery. Advocates who can communicate in languages other than English are in high demand in locations where a large percentage of the population speaks language other than English as their primary language. This includes culturally appropriate advocacy for CALDs and Aboriginal and Torres Strait Islander peoples, as well as person-centred advocacy for care leavers, veterans, and people with mental illnesses. As the NACAP grows, it may become necessary to accommodate the recruitment of advocates who can guarantee that various groups have fair access to safe, rights-based care.

### Regional and remote areas

With current resource and funding restrictions, reaching out to regional and remote locations to provide services has proven difficult. Travel times to reach these communities can be long, putting a significant burden on already limited resources for outreach and service delivery. Several SDOs stated that their presence in these areas is critical, but that their present financing only allows for two visits per year.

The relative paucity of other services (e.g., health, aged care, disability) in these areas also has implications for the role of an advocate. In many circumstances, the advocate's duty might expand to include broader case management, in which the advocate is in charge of accessing the various services that the elderly person requires. Consumer choice is also limited due to a lack of available services. In some cases, this will lead to a higher number of complaints as there are no alternatives to seek out. However, other consumers may be more hesitant to complain as they risk retribution from the community’s only service provider.

The challenges with recruitment and addressing special needs are further magnified in regional and remote areas. Recruitment and retention of advocates can also be challenging in regional and remote areas. Many SDOs highlighted the isolation that can be felt when operating as an advocate in remote communities. This lack of support, combined with the fact that they often have to shoulder greater responsibility, adds significant pressure to the role of the advocate that may not be experienced in better-connected areas.

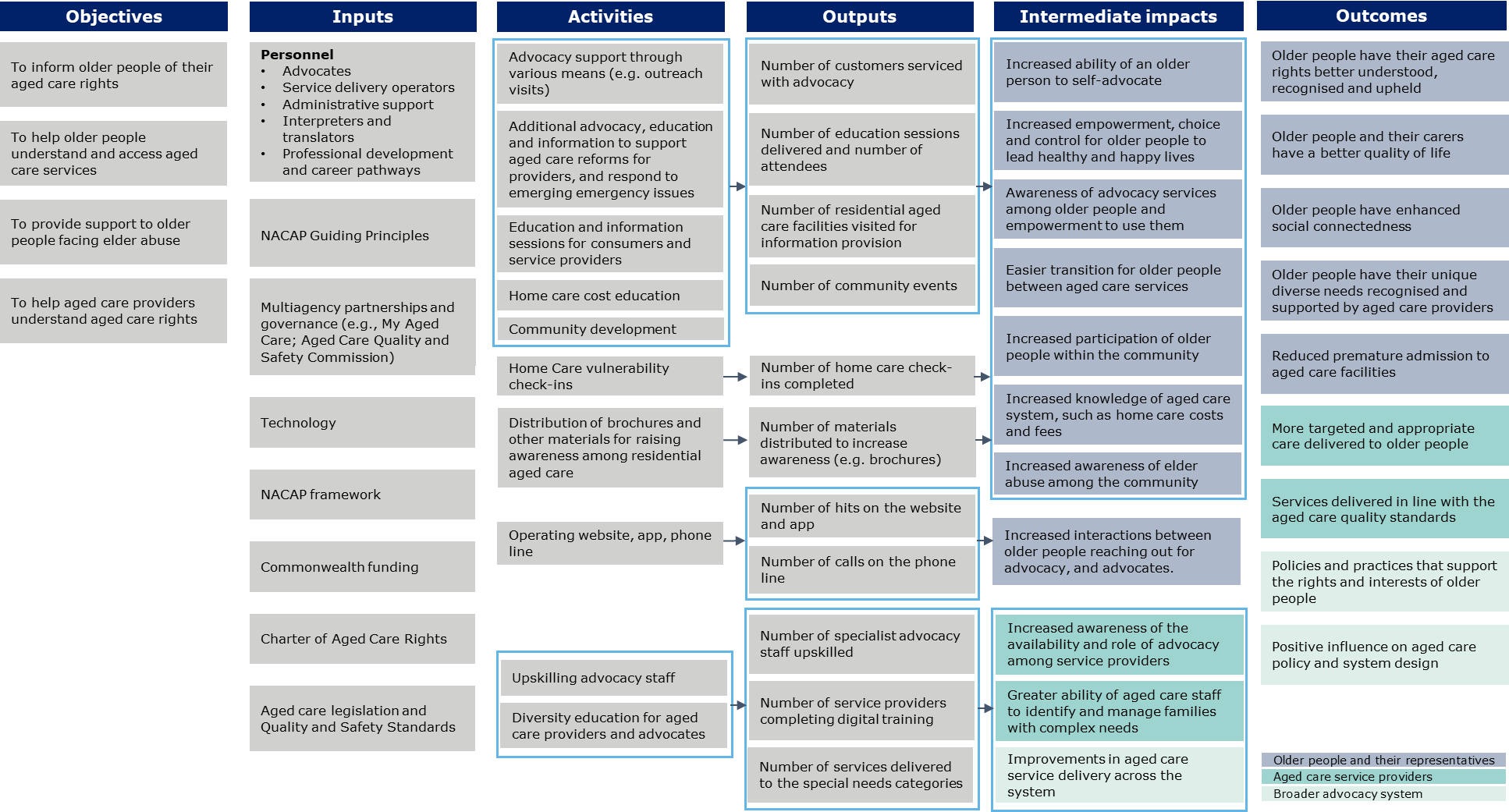
## Service design, monitoring and evaluation

As NACAP expands it is also important to evolve service design to better meet the access and advocacy needs of its target population. Stakeholders in consultations noted a number of constraints in the current program design. For example, stakeholders highlighted the need for greater levels of proactive advocacy, however, noted that this was likely limited within the existing NACAP due to capacity constraints of the SDOs. Some SDOs and stakeholders also identified that capacity limitations impacted their ability to build local connections with regional, rural and remote communities, with advocates only travelling to communities twice per year which impacted the ability to build trust. Lastly a small number of stakeholders highlighted that SDOs predominantly focussed on providing information and advocacy to individuals, rather than advocating at a group level (i.e., residential aged care facility level), potentially only solving point issues. It was noted that some group advocacy was being undertaken during COVID-19 lockdowns, highlighting an ongoing potential area of demand.

Ongoing and strengthened monitoring and evaluation will be key to ensuring that NACAP continues to meet the needs of target populations through its activities. The NACAP program logic (see Figure 5.1) outlines how OPAN can monitor and evaluate the NACAP as it expands in the coming years and provides a foundational understanding of the program from objectives to key inputs and activities, to the measurable outputs / indicators and long-term outcomes.

The NACAP program logic includes the additional activities under the expanded NACAP and reflects the current understanding of the services, its aims and target outcomes. The program logic was developed collaboratively with the Department of Health, OPAN and other key stakeholders, using information from the expanded NACAP framework, feedback from the stakeholders during the methodology workshop, and the existing program logic framework provided by OPAN.

: Program logic model for NACAP advocacy services



Source: Deloitte Access Economics, with feedback from Department of Health, NACAP demand modelling Project Governance Group and OPAN

# Learnings from other advocacy programs and jurisdictions

This section provides an overview of advocacy programs in other sectors and jurisdictions as well as comparing them to NACAP. A review of other advocacy programs can provide comparisons that might be helpful for informing the design and implementation of NACAP.

In this section, NACAP was compared to the National Disability Advocacy Program (NDAP), mental health advocacy organisations, veteran advocacy organisations and several international jurisdictions, namely United Kingdom, New Zealand and Canada.

The sector comparisons found that there is an overlap in target population between the NACAP, NDAP, mental health, and veteran advocacy organisations, which could provide an opportunity to improve advocacy awareness through cross-sectoral linkages of advocates between each sector.

The jurisdictional comparison found that the diverse nature of advocacy services across these jurisdictions, suggest at this stage that is challenging to determine suitable comparators to be used for the NACAP program.

## Disability advocacy in Australia

The National Disability Advocacy Program (NDAP) provides people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation. There are six broad models of disability advocacy:

* Citizen advocacy: matches people with disability with volunteers.
* Family advocacy: helps parents and family members advocate on behalf of the person with disability for a particular issue.
* Individual advocacy: upholds the rights of individual people with disability by working on discrimination, abuse and neglect.
* Legal advocacy: upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.
* Self-advocacy: supports people with disability to advocate for themselves, or as a group.
* Systemic advocacy: seeks to remove barriers and address discrimination to ensure the rights of people with disability.

Advocacy agencies are funded to provide disability advocacy support in specific geographic areas. There are generalist and specialist advocacy agencies across Australia.

The target group for advocacy support provided by NDAP, as per section 8 of the Disability Services Act 1986, include those people with disability that:

1. Is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of such impairments
2. Is permanently or likely to be permanent; and
3. Results in:
   1. A substantially reduced capacity of the person for communication, learning or mobility; and
   2. The need for ongoing support.

In 2016/17, 58 advocacy agencies in locations across Australia were funded $17.7 million to deliver advocacy services to approximately 12,000 people with disability as well as a broader group benefiting from information, referrals and support to progress systemic matters on their behalf. This is equivalent to approximately 0.04% of people with disability receiving advocacy services each year.[[43]](#endnote-39)

In addition to the NDAP, State Governments also fund disability advocacy services.

Recent reviews have highlighted the increasing demand for advocacy services and growing waitlists as a result of the introduction of the NDIS with limited increases in NDAP funding.

* **2015 Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings[[44]](#endnote-40)**
  + Recommendation 16 outlined the need to provide significant investment to NDAP to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS.
* **Review of the National Disability Advocacy Framework (NDAF)[[45]](#endnote-41)**
  + Key themes identified during the Review of the NDAF (2016) identified the need for independent advocacy, the provision of advocacy for all people with disability regardless of NDIS eligibility, the need for increased advocacy funding, the need for improved data collection, and the important for systemic advocacy.
* **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (ongoing)[[46]](#endnote-42)**
  + The current Royal Commission released its interim report in 2020 and noted the importance for advocacy in preventing and addressing violence, abuse, neglect and exploitation. In addition, the Royal Commission noted the lack of advocacy services including for First Nations people with disability and people with complex needs and that existing advocacy services are under-funded.

**Implications for NACAP**

In disability advocacy in Australia there are significant constraints in advocacy services within disability, with only a small number of people (0.04%) able to receive advocacy services due to limited awareness and program capacity.

There is an opportunity to however, draw on the localised nature of disability advocates and the connection to community they are able to create. Consultations suggested there is an opportunity to create greater connection across these services, including the potential to improve the leverage of resources in regional, rural, and remote locations.

Stakeholders within the disability sector also highlighted the importance of cross-sector linkages between the disability and aged care sectors. In particular, the linkage between the National Disability Advocacy Program (NDAP) and NACAP is deemed insufficient, creating a disjointed system for older people with disabilities. Cross-sectoral linkages will impact advocacy awareness, due to the expanded customer base organisations can deliver information to.

## Mental health advocacy in Australia

Mental health advocacy organisations at the national and state levels across Australia represent and promote the interests of the sector, focusing on advocating for policies, programs, and interventions to facilitate better mental health outcomes for all Australians. They play an important role in gaining recognition of the perspectives and experiences of people with living experience of mental illness, or psychological distress.

Analogous to the disability sector, mental health advocacy can be categorised into four areas that inform one another:

1. Individual advocacy: aids individuals in exercising their rights through accessing information, voicing feedback and resolving issues.
2. Systemic advocacy: promotes community and system-wide change to deal with structural inequalities and inadequacies. Advocacy organisations can draw on individual experiences to inform systemic advocacy and related reform ideas.
3. Legal advocacy: provides legal information, advice, and assistance about all areas of mental health law
4. Non-legal advocacy: represents or supports individual consumers in self-advocacy. Advocates listen to and communicate a person’s preferences and wishes as expressed by them, regardless of whether or not the advocate considers that to be in their ‘best interest’.

Recent funding in the 2021/2022 national budget has been allocated to the National Mental Health and Suicide Prevention Plan, which will mean more Australians will be able to receive legal and non-legal advocacy support. Funding of $2.0 billion over four years from 2021/22[[47]](#endnote-43) includes support such as:

* $77.1 million in the National Legal Assistance Partnership to support the early resolution of legal problems for those experiencing mental illness
* $278.6 million over four years from 2021/22 to expand and enhance headspace youth mental health services, including in conjunction with the states and territories
* $54.2 million over four years from 2021/22 to work with the states and territories to establish child mental health and wellbeing hubs to provide multidisciplinary care and preventive services
* $16.9 million over four years from 2021/22 to provide mental health services and support to Australians from culturally and linguistically diverse communities, including for survivors of torture and trauma

In addition to national funding, significant state-based funding is also provided to advocacy services. The recent Royal Commission into Victoria’s Mental Health System has also resulted in uplifts in funding to support advocacy programs in Victoria.[[48]](#endnote-44) A key recommendation was to provide an opt out non-legal advocacy service for consumers who are subject to or at risk of compulsory treatment.[[49]](#endnote-45)

Data on demand for access to mental health advocacy services include:

* Independent Mental Health Advocacy (IMHA) in Victoria cites since 2015, 41,513 advocacy and coaching for self-advocacy services have been delivered along with 79,701 occasions of giving information and referrals[[50]](#endnote-46)
* Legal Aid NSW provided 67,653 civil law services in 2019/20, including duty services at the Mental Health Review Tribunal[[51]](#endnote-47)
* Queensland Alliance for Mental Health (QAMH) reached over 40,100 people in 2020/21 through online member forums that contribute to advocacy work[[52]](#endnote-48)
* Mental Health Advocacy Service (MHAS) in WA cites 3,605 people’s voices were better heard and represented through their access to an MHAS advocate in 2020/21 and 7,581 complaints, spending $3.1 million in 2020/21[[53]](#endnote-49)

However, constraints on advocacy efforts in resourcing and access requirements limit the impact of the important role these organisations play.[[54]](#endnote-50) There are complicated and fragmented pathways between mental health services and other services and systems required to support and treat mental illness, such as legal and non-legal advocacy services. Additionally, there is limited publicly available information or data on access rates for advocacy services. A historical lack of funding and funding uncertainty due to competing demands between individual and systemic advocacy has also detracted from broader systemic advocacy projects and ambitious reform agendas.

**Implications for NACAP**

A significant amount of funding has been recently dedicated to improving access to a diverse range of mental health advocacy programs. The range of advocacy services provided across the system is broader than that provided by NACAP, including the provision of legal advocacy and supporting carers and families. In addition, the recent Royal Commission in Victoria’s recommendation for an opt out model for non-legal advocacy for those subject to or at risk of compulsory treatment, provides for greater outreach and increased awareness of the value of advocacy.

## Advocacy for veterans in Australia

Veterans’ advocacy and aid in Australia is offered from a variety of ex-service organisations (ESO’s) around Australia at both a national and state level. Supported by the Department of Veterans’ Affairs (DVA), ESO’s represent and promote veterans and their related network through a variety of services.[[55]](#endnote-51) Advocates at ESO’s assist veterans, their families and their network in accessing the support, services and information required to enhance financial and physical wellbeing, self-sufficiency and recognition of service and sacrifice.[[56]](#endnote-52) There are eighteen ESOs currently listed on the DVA’s registry.[[57]](#endnote-53) Advocates are generally volunteers from the veteran community or partners of veterans. In 2021/22 budget, the Australian Government allocated $4.7 million over 4 years to provides financial support to ESOs that assist veterans and family members with advice about and assistance with claims, entitlements and services.[[58]](#endnote-54) Advocate services help veterans prepare and lodge DVA claims and review/appeal decisions through the Veteran Review Board (VRB) or the Administrative Appeals Tribunal (AAT). Veteran advocacy services provided through ESOs provide access to information and service referrals for:

* Health and treatment
* Rehabilitations
* Housing
* Transport
* Support for transitioning to civilian life
* Medical, financial, legal and police matters
* Funeral arrangements and bereavement assistance

Services provided by advocates accredited under the Advocate Training and Development Program (ATDP) are free, however a small cost may be incurred for incidental costs.[[59]](#endnote-55)

Some ESOs are unable to satisfy demand and not all veterans and their families receive prompt assistance. Over 40% of veterans and their families had to wait more than a month for an advocate with less than 10% waiting longer than three months, according to ESOs. ESOs frequently referred persons in need of emergency assistance to another ESO or agency.[[60]](#endnote-56) Demand for veteran advocacy from ESOs is currently estimated using DVA/VRB data about compensation services provided and the information surveyed from ESOs. Using the DVA Annual Report 2019/20, it is estimated that 20,161 primary compensation claims (20% of claims) and 3,500 VRB applications (4% of applications) were supported by an advocate. No data is available for wellbeing support services from ESOs.[[61]](#endnote-57) The veteran population as supported by the DVA as of March 2020 was 244,725. With an estimated 23,661 veterans receiving advocacy for claims and applications, approximately 9.67% of veterans are advocated for, excluding advocacy for wellbeing support services.[[62]](#endnote-58) With an increasing veteran population and a declining veteran advocacy workforce, there is a need for advocacy services to meet unmet demand.[[63]](#endnote-59)

The Veterans’ Advocacy and Support Services Scoping study found that veterans’ advocacy service is not meeting veterans’ needs for competent representation at the Administrative Appeals Tribunal. Additionally, the study found that the veterans’ advocacy system as presently structured is not adequate and will fail to provide veterans and their families with a professional advocacy service into the future.[[64]](#endnote-60)

ESO’s work with the DVA and other ESO’s to,

* Establish and improve community services
* Improve referral services for quality care
* Public opinion regarding veteran matters, and
* Preserve the memory of those who served and sacrificed themselves for Australia.[[65]](#endnote-61)

Individual veteran advocates support veterans and families through face-to-face consults, calls, emails, forums, community event, publications, and programs. These supports have a strong focus on health, housing, aged care, disability services and DVA applications, aiming to reduce the stress and anxiety and improve successful outcomes for the veterans and their network.[[66]](#endnote-62) Veteran services are strongly aligned with aged care services due to the strong representation in residential facilities.[[67]](#endnote-63)

In July 2021, a Royal Commission into Defence and Veteran Suicide was established to examine the systemic issues within the Defence Force involving mental health risks to veterans and the availability of support services.[[68]](#endnote-64) With the high suicide rates in the military community, crisis support is a strong focus within veteran advocacy services, referring veterans to services like, Open Arms, Life Line Australia, Beyond Blue, Defence Member and Family Helpline and Defence All-Hours Support Line.[[69]](#endnote-65) Advocacy in this area has become increasingly important to improve referral networks and supports to veterans facing mental health vulnerabilities.

**Implications for NACAP**

Veteran advocacy in Australia has a strong link to both mental health and disability services due to the physical and mental challenges experienced by veterans. Consequently, veteran advocacy has numerous constraints involving the diversity of needs for support in the veteran community. In addition, the existing advocacy model faced severe supply issue, where 84% of the advocates were born before 1965.[[70]](#endnote-66) Over the next five years, data indicates that the current veteran advocacy workforce will decline by 30%.[[71]](#endnote-67) In contrast to the NACAP, there is no national body to coordinate the advocacy services. While individual ESOs and advocates are supporting veterans, the service each advocate can provide is limited to their own circle of operation, and the existing dispersed network of advocates are unable to resolve complex systemic issue. In addition, veteran advocacy is delivered by volunteers, whereas NACAP program is delivered by paid employees. In considering the anticipated volunteer workforce loss, ESOs must direct attention to the recruitment, training and mentoring of new advocates to ensure sustainability to meet demand.

As the Royal Commission currently investigates mental health rates of veterans and the availability of services, there is a strong opportunity to improve the connection between mental health and veteran advocates. Additionally, services alike can improve service delivery through collaboration due to the overlap between veteran, disability, and mental health services.

In veteran advocacy, there is strong inclusion of veteran families and their network to aid in support. NACAP has the opportunity to improve the scope of its’ advocacy and service delivery with expanding resources and information to the support network.

## International aged care advocacy experiences

### Aged care advocacy in New Zealand (NZ)

In 2021, the older population, aged 65 and over, represented 16.75% of New Zealand’s population with 816,738 individuals. This number is expected to continually rise to almost 25% by 2041 with 1,344,441 people aged over 65.[[72]](#endnote-68)[[73]](#endnote-69) Today, 69,713 New Zealanders are living with dementia with an expected rise to 99,245 by 2030.[[74]](#endnote-70) The rise in population age and subsequently, people living with dementia, increases the demand for aged care services with increased level of support.[[75]](#endnote-71)

Aged care in New Zealand involves a variety of support services and residential aged care. Support services for older people include personal care, household support, carer support and equipment for in-home and community care.[[76]](#endnote-72) Residential aged care provides long-term care which offers rest home care, continuing care (hospital), dementia care and specialised hospital care. These services are provided by variety of retirement villages, care homes, hospitals and health services working under their specific District Health Board (DHB).[[77]](#endnote-73) There are 20 DHBs across New Zealand with 663 certified bodies.[[78]](#endnote-74) In 2020 approximately 44,970 adults utilised residential aged care, representing 5.69% of the population over 65 at the time.[[79]](#endnote-75),[[80]](#endnote-76)

Similar to the ACQSC in Australia, the Health Quality and Safety Commission (HQSC) New Zealand inspects regulated aged care to ensure quality improvement in aged care. Through partnership with the aged care sector and future Aged Care Commissioner, HQSC aims to develop and implement a quality improvement program.[[81]](#endnote-77) Additionally, ARC services are regulated under a national contract between DHBs and ARC providers, ensuring a national standard of services provided to residents in long-term residential care under The Health and Disability Services (Safety) Act 2001.[[82]](#endnote-78)

In New Zealand, there are a range of advocacy services available to older people operating at an individual and national level. The need for aged care advocacy is growing in New Zealand, like the rest of the world, due to the ageing population requiring high quality care.[[83]](#endnote-79) National groups such as the New Zealand Aged Care Association (NZACA) and Age Concern NZ are New Zealand’s largest advocacy bodies in the aged care sector representing the population over 65.[[84]](#endnote-80) Both advocacy groups are dedicated to promoting the wellbeing and welfare of the older population and are strongly involved in increasing the availability and quality of services. They are independent of the government however work as a second voice to resolve issues at an individual level and lobby for policy change at a national level. [[85]](#endnote-81)[[86]](#endnote-82)

Age Concern NZ is one of New Zealand’s largest advocacy service dedicated to people over 65. It is a national membership charity made up of 34 local Age Concerns across New Zealand promoting the rights, wellbeing, respect, and dignity of old people through individual level advocacy. Age Concern NZ is composed of local Age Concern members which pay a membership fee to the national office and operate under membership standards. Local Age Concerns provide volunteer, elder abuse, health promotion and policy/advocacy services to New Zealander’s older population. Age Concern NZ supports older New Zealanders with programs and advocacy around aged care provision with a focus on social connections, health promotion, elder abuse and neglect prevention, individual advocacy, policy submissions, research and communications. Individual advocacy is delivered through local Age Concern visitations and call communications to help the older population exercise and understand their rights, as well as address issues endured within aged care. In the last year, members of local Age Concerns visited 70,420 lonely and isolated older people and received 2,452 referrals where elder abuse was suspected.[[87]](#endnote-83)

Age Concern NZ also provides national advocacy to issues affecting older people, as well as equips local Age Concerns to deliver crucial services to the local communities. The national office provides resources on a variety of topical issues, policy submissions, network supports and coordinates both the Accredited Visiting Service and the Elder Abuse and Neglect Prevention Services. Age Concern works closely in the aged care sector where self-advocacy is not universal and is required to improve the quality of care and residential services for the older population.[[88]](#endnote-84) Age Concern NZ provides a range of educational programs to improve independence as well as key services involving:

* Elder Abuse and Neglect Prevention
* Social Connection programs
* Health Promotion
* Accredited Visiting Service
* Referrals

Age Concern NZ is primarily funded through government contracts for services including the Accredited Volunteer Service, Elder Abuse Services, Health Promotion Programs and Policy/Advocacy work. Most contractual income is passed onto local Age Concerns to run these programs whilst retaining national coordination and management fee. The rest of Age Concern NZ’s income is from corporate partnerships and sponsors, grants, estates, and donations.[[89]](#endnote-85) The latest available report in 2019 showed $2.2 million (NZD) was spent on business operations, primarily focussed on advocacy services.[[90]](#endnote-86)

The New Zealand Aged Care Association (NZACA) is New Zealand’s largest and most influential association representing all parts of New Zealand’s aged residential care (ARC) sector, and also provides national advocacy. The NZACA is a not-for-profit, national membership organisation affiliated with 93% of New Zealand’s ARC sector. The NZACA aims to ensure the sector receives the support and recognition required for the provision of high-quality care to the older population. The NZACA provides national-level advocacy to shape policy and provide leadership on issues impacting the aged care sector.[[91]](#endnote-87) There are two types of national advocacy conducted by NZACA:

* Systemic advocacy: A process that takes on generic issues that affect individuals and groups. The focus is usually on structural or political issues with advocates acting as spokesperson.
* Empowerment advocacy: A process emphasising sharing information and resources and teaching individual skills to facilitate self-empowerment towards self-advocacy.[[92]](#endnote-88)

Member care facilities providing aged care to older New Zealanders receive support, representation, and educational resources from NZACA and must abide by the following rules and codes of conduct including the Code of Residents Rights’ and Responsibilities, which provides a set of consumer rights and responsibilities to be respected by NZACA members and the Code of Health and Disability Services Consumer’s Rights which are legally enforceable.[[93]](#endnote-89)

### Aged care advocacy in the United Kingdom (UK)

In 2021, approximately 13 million people in the UK population were aged over 65 representing 19% of the population.[[94]](#endnote-90) With continued growth expected, by 2039 the estimated representation of this cohort will reach 23.9%.[[95]](#endnote-91) The need for care is likely to be substantial. Associated with growing old is the onset of long term and chronic conditions which require adequate care and management. 75% of the UK population over the age of 75 have more than one long term condition which rises to 82% in the over 85 cohort.[[96]](#endnote-92) Age UK found that in 2017, 1 in 7 people in the UK over the age of 65 were estimated to be struggling to carry out at least one essential activity of daily living and require support.[[97]](#endnote-93)

In 2020, 6.45% of the older population received aged care in the UK. With 838,530 older adults receiving aged care, 58.5% received residential care and 41.5% received in home social care.[[98]](#endnote-94)[[99]](#endnote-95) Research shows that 97% of people in the UK would choose to stay in their own homes to be cared for if they could.[[100]](#endnote-96) This decision has increased the availability of in-home care to meet consumer preference. In the UK, residential care entails nursing homes (care homes with nursing) and residential homes (care homes). There are 17,500 care homes across the UK with 490,326 living in residential care facilities. The uptake of aged care service and facilities in the UK for adults over 65 is 3.77% for 2020.[[101]](#endnote-97) Over recent years the occupancy rates of care homes in the UK remained relatively high and stable between 87 and 89 percent. After COVID-19 impact on mortality, care home occupancy reduced to 79% in mid-2020. All providers of regulated care are inspected by the Care Quality Commission to ensure high quality and safety of care in hospitals, dentists, ambulances, and care homes, and the care given in people’s own homes.[[102]](#endnote-98)

In the United Kingdom, the Older People’s Advocacy Alliance (OPAAL) is a funded charity that promotes and develops independent advocacy services for advocacy providers.[[103]](#endnote-99) OPAAL does not provide advocacy services directly but provides a framework of operations for new and existing advocacy providers. There are a significant number of aged care advocacy organisations within the UK that provide help and advocacy on a range of issues including financial matters, health and wellbeing, care and support for housing and other matters, and employment and further education. Many of these providers operate around the UK and form the membership base of OPAAL. OPAAL provides an advocacy checklist for member organisations to publicly demonstrate the commitment towards older people care. With an OPAAL membership, members will receive training on advocacy, access to resources and accreditation, and lastly be advertised as an advocacy member.[[104]](#endnote-100)

The primary categories of advocacy covered by OPAAL’s member organisations include:

* **Non-instructed advocacy** – decision making for an older person who is unable to convey their needs due to barriers such as cognitive impairment, substance misuse, temporary unconsciousness and other factors.[[105]](#endnote-101),[[106]](#endnote-102)
* **Peer (Group) self-advocacy** – facilitating advocacy in a group setting through people who have undergone similar experiences.[[107]](#endnote-103)
* **One-to-one citizen advocacy** – advocacy programs delivered by citizens with the skills to support people who are disadvantaged and not in a position to exercise their rights. The citizen volunteer builds a one-to-one relationship with the older person they are supporting and is independent of any service providers.[[108]](#endnote-104)
* **Individual casework advocacy** – individual casework management provided for issues that might need legal attention
* **Independent Mental Capacity Advocate (IMCA)** – an advocate appointed to act on behalf of someone who is unable to make decisions or communicate their needs due to mental health constraints.[[109]](#endnote-105)
* **Deprivation of Liberty Safeguards (DoLS)** – advocacy for a person who is unable to consent to their care arrangements in a care home or a hospital due a deprivation of their liberties.[[110]](#endnote-106)
* **Independent Mental Health Advocate (IMHA)** – advocacy for people facing challenges surrounding their mental health care and treatment, and information about the rights of people under their rights under UK’s Mental Health Act.[[111]](#endnote-107)
* **Independent Complaints Advocacy Service (ICAS)** – support for people who want to make a complaint about the National Health Service (NHS) through the NHS Complaints Procedure.[[112]](#endnote-108)

Individual casework advocacy is the most available form of advocacy across OPAAL membership locations followed by non-instructed and one-to-one citizen advocacy. OPAAL is committed to campaigning for more advocacy provision through developing its’ membership basis.[[113]](#endnote-109)

One of OPAAL’s largest membership organisations spanned across the UK is Age UK. Age UK is the country’s leading charity and advocacy network dedicated to helping everyone make the most of later life through companionship, advice, support and advocacy for older people who need it most. The network includes Age Scotland, Age Cymru (Wales), Age NI and more than 130 Age UKs throughout England. Age UK, governed under charity, trust and company law, advocates for the health and financial well-being, education, equality and rights of older people. Age UK’s advocacy and support networks for the older population are in line with the advocacy and support framework envisioned by OPAAL working towards an older future.[[114]](#endnote-110)

Age UK advocacy services support older people (aged 50+) to make decisions and to be heard when decisions are being made about their lives. This can include listening to their views and concerns, assisting with exploring options, informing older persons of their rights, providing information to help them make informed decisions and helping older persons contact relevant people or contact them on their behalf (referral and signposting). This advocacy work has been applied for decisions relating to care planning, medical appointments and admissions, financial planning and administration, debt management and housing.

Age UK’s advocacy services can be delivered at an individual level using the networks free, confidential advice line or a local Age UK service which offer spokespeople the opportunity to educate and advocate homecare and retirement issues.[[115]](#endnote-111)

To provide services to the older population, Age UK received 52% of funding through charitable contributions (donations, legacies, grants, and lotteries and raffles), and 44% through trading activities (charity shops and services alike). In 2020, Age UK had £58,210,000 available in net resources for charitable activities and spent £63.6 million, with £14.1 million (22.2%) going to campaigning and research. Age UK’s three-year objective is to make the most difference for disadvantaged older people through effective campaigning and influencing, underpinned by policy work and research advocacy.[[116]](#endnote-112)

In 2019/20, Age UK handled 711,000 enquiries and responded to 233,332 enquiries on the national Advice Line.[[117]](#endnote-113)

### Aged care advocacy in Canada

Unlike Australia, oversight of Canada’s aged care varies across provincial and territorial government departments and agencies. In 2021, the population of Canadians over the age of 65 was 7,081,792 representing 19% of the population. There is high demand for aged care resources, with 40,000 people waiting to be admitted into an aged care facility[[118]](#endnote-114) and 430,000 people have unmet home care needs.[[119]](#endnote-115) In 2019, 7.9% of Canadians aged 65 and over lived in residential care facilities such as residences for seniors or health care and related facilities.[[120]](#endnote-116) In comparison to Australia, New Zealand and the UK, utilisation of aged residential care in the older population of Canada is greater, however the Canadian Institute for Health Information (CIHI) found that 1 in 5 seniors in residential care have similar needs to individuals supported in the community.[[121]](#endnote-117) With the baby boomer population entering aged care, the demand for aged care is set to double by 2031. Along with the ageing population growth is dementia. Following recent trends, the dementia rate of Canadians is expected to rise 66% over the next 15 years with onset risk doubling every five years after the age of 65.[[122]](#endnote-118)

As the population ages, government policies are progressively encouraging older people over the age of 65 requiring support to seek home care. Although this progressive model relieves stress on hospitals and aged care facilities, it places pressure on caregivers and patients who are not equipped for home care.[[123]](#endnote-119)

The provision of long-term care (LTC) homes, the equivalent of residential care homes, has been identified as a major issue within Canadian aged care and is currently under reform across all jurisdictions. Residents of LTC homes are assessed and deemed eligible by social service agencies at a provincial level and can generally take months from application. Provinces including British Columbia, Alberta and Ontario fully fund medical support and services in LTC homes.[[124]](#endnote-120)

Canada’s aged care is regulated at a national level and governed at a provincial level. The Canada Health Act (1985) regulates reasonable, continued access to quality health care to all Canadians at a national level by establishing criteria and conditions for insured health services and extended health care services, including aged care.[[125]](#endnote-121) Aged care across Canada is governed by provincial/territorial legislation. Different provinces have governing bodies and commissions to control aged care administration and ensure quality of care is provided. Recognised in British Columbia, Alberta and Ontario is the Commission on Accreditation of Rehabilitation Facilities (CARF) involved in a variety of Canadian services including aged care. CARF controls the standards in aged care to ensure provision of high quality of care.[[126]](#endnote-122)

Individual level advocacy is delivered at a provincial and territorial level. Due to the variation in aged care provision and governance, there is no national body delivering individual advocacy across all of Canada. However, recently, as a result of the COVID-19 pandemic, CanAge was established in 2020 as a national agency that advocates for policy change at both, national and provincial levels to improve the lives of older Canadians.[[127]](#endnote-123) In partnership with federal and provincial governments, CanAge supports health and well-being, financial matters, housing aids and lobbies for policy change in support of its’ members - older people, their loved ones and advocates. CanAge’s advocacy primarily involves government engagements and has successfully lobbied 141 policy implementations and written 62 submissions (12 federal).

Below we consider individual advocacy in the three largest provinces of Ontario, Quebec, and British Columbia.

Ontario

One of the largest individual aged care advocacy groups within Ontario is Concerned Friends. Concerned Friends is a registered charity that is funded solely by memberships and donations to address the lack of care in Long-Term Care Homes. The mission of Concerned Friends is to advance the health and well-being and enrich the experiences of Ontario citizens living in LTC homes.[[128]](#endnote-124) Concerned Friends operates with volunteer advocates providing advice and assistance to residents in LTC homes and their family and friends. Volunteer advocates advocate through a toll-free service line or email as well as provide resources on determining the right LTC home. Concerned Friends also ensures that LTC homes follow the Long-Term Care Homes Act, Ontario’s legislation designed to help ensure residents of LTC receive safe, consistent, high-quality and resident-centred care.[[129]](#endnote-125) Through LTC home inspections, Concerned Friends inspected a total of 627 homes in 2020 and found 1000 critical incidents, 659 complaints and 170 follow-up cases. Concerned Friends inspected 774 fewer LTC homes in 2020 in comparison to 2019.[[130]](#endnote-126)

Quebec

In Quebec, the Conseil pour la protection des malades (CPM), translated to “Advice for the protection of the sick”, protects the well-being of health and social service users across the province. CPM advocates for Quebec’s sick, elderly, disabled and psychiatric population ensuring they have high-quality care and respected in their dignity.[[131]](#endnote-127) CPM is an independent not-for-profit organisation established to defend and promote the rights to receive dignified and adequate healthcare. CPM provides an individual level consulting service for advocacy, development tools and resources, a mediation and conflict resolution service and a referral service to multiple resource departments and health network authorities. Additionally, CPM provides individual legal assistance and has initiated class actions to defend the collective rights of residents.[[132]](#endnote-128)

British Columbia

In British Columbia, the Office of the Seniors Advocate (OSA) was established to monitor and analyse senior services and issues in BC, making recommendations for improvement to government. The OSA is an independent office of the B.C. provincial government acting in the interest of seniors and their caregivers. The OSA provides information and referrals for individuals who are navigating services and tracks concerns. Their duties are mandated under the *Seniors Advocate Act*. In 2020/21, the total budget for the program was $2.5 million (Canadian Dollars).[[133]](#endnote-129) The number of phone calls made to the OSA was 12,794, and website traffic increased significantly during the pandemic.[[134]](#endnote-130)

Issues identified by the OSA included underinvestment in LTC and shortage in both home support and support for low-income seniors. These systemic issues recognised by the OSA have been raised to the Government of British Columbia to be addressed. Individual contacts with the OSA identified community care issues of decreased support and assistance from caregivers and families in long-term care, closures of leisure centres resulting in feelings of social isolation and assistance to access Better at Home programs in rural areas.[[135]](#endnote-131)

### Summary of international comparisons and implications for NACAP

A summary of the aged care advocacy in each jurisdiction is described in Table 6.1. In comparison to Australia and New Zealand, the United Kingdom and Canada both have a larger proportion of people aged 65 and up. The United Kingdom has the lowest rate of residential aged care uptake among its over 65 population, followed by Australia.

Advocacy programs in New Zealand and the United Kingdom provide advocacy at individual and national level. Noting that historically, Canada aged care advocacy was largely led by community coalitions, based in each province or territory reflective of the aged care systems in which they operate. However, a united national advocacy agency, CanAge, was only recently form in 2020 to advocates for the rights and well-being of aging Canadians during the COVID-19 pandemic.

This study finds that the diverse nature of advocacy services across these jurisdictions, suggest at this stage, it is challenging to determine suitable comparators that could be used for the NACAP. A comparison of advocacy usage rates across jurisdictions is determined to be inappropriate as usage data reported by aged care advocacy in each jurisdiction differs by counting method and nature of services delivered.

: Summary of aged care advocacy in Australia, New Zealand, Canada, and UK

| **Characteristic** | **Australia** | **New Zealand (NZ)** | **Canada** | **United Kingdom (UK)** |
| --- | --- | --- | --- | --- |
| **Population over 65** | 4,248,800 (2020)[[136]](#endnote-132) | 816,738 (2021)[[137]](#endnote-133) | 7,081,792 (2021)[[138]](#endnote-134) | ~13,000,000 (2021)[[139]](#endnote-135) |
| **Population % over 65** | 16.4% | 16.75% | 19% | 19% |
| **Uptake of residential aged care as % of populations over 65** | 5.6% (2020)[[140]](#endnote-136) | 5.69% (2020) | 7.9% (2019) | 3.77% (2020) |
| **Eligibility and criteria** | Indigenous Australians aged 50+ and non-Indigenous Australians aged 65+. Interaction with aged care system either at present or being assessed for services | NZ citizen or eligible for publicly funded health or disability services/assessed by NASC | Canadian citizen or permanent resident – criteria differs between province | UK citizens or residents who demonstrate physical or mental impairment or illness on means |
| **Central advocacy body** | OPAN | Age Concern NZ | CanAge | OPAAL |
| **Role / services** | OPAN is a national network comprising nine state and territory member organisations that offer free, independent and confidential support and information to older people seeking or using government funded aged care. Via an advocacy hotline, OPAN helps people understand and exercise their aged care rights, seek appropriate services, and find solutions to issues faced with their aged care provider. Additionally, OPAN delivers the National Aged Care Advocacy Program (NACAP). | Age Concern NZ promotes the rights, wellbeing, respect and dignity through individual and national level advocacy for the older population. Working closely with aged care providers, Age Concern NZ supports the older population through programs and advocacy with special focus on social connections, health promotion, elder abuse and neglect prevention, public policy and research and communications. Age concern NZ delivers individual advocacy across 34 local Age Concerns through local visitations, calls and emails to address a variety of concerns. | CanAge works to improve the lives of older Canadians through advocacy, policy and community engagement. Individual level advocacy is performed at a provincial level. The Office of the Seniors Advocate (OSA) in British Columbia offers a 24-7 information and referral line for individuals navigating the system. The OSA collaborates and makes recommendations for service providers, government, and health authorities to improve efficiency, effectiveness, and outcomes | OPAAL is a funded charity that promotes and develops independent advocacy services for advocacy providers. OPAAL does not provide advocacy services directly but provides a framework of operations for new and existing advocacy providers. Many of advocacy providers operate around the UK and form the membership base of OPAAL. OPAAL provides an advocacy checklist for member organisations to publicly demonstrate the commitment towards older people care. With an OPAAL membership, members will receive training on advocacy, access to resources and accreditation, and lastly be advertised as an advocacy member. |
| **Funding i.e., government or otherwise** | Australian Government | NZ Membership Base/public support | Canadian Membership Base | Charity |

Source: Deloitte Access Economics.

# Future considerations

Through investigating the demand and supply of the NACAP using data analysis and consultation techniques in this project, a number of future considerations were also uncovered. Several challenges relating to data availability and extraction were identified throughout this process, and learnings that should be considered in future data collection and similar data analysis are outlined below. As the NACAP grows it will be important to better understand the services delivered and the user base through stronger data collection, monitoring, and evaluation. The stakeholder consultations also identified several challenges that have affected uptake of the NACAP. The most significant factor affecting usage of NACAP is low awareness. Recommendations to improve awareness and take-up based on stakeholder suggestions and using behavioural insights are detailed in this chapter.

## Data limitations and assumptions

Consideration needs to be given to learnings relating to data limitation for future expansion of this analysis. The OPAN unit record data was critical in estimating the current met and unmet demand for NACAP services. However, significant gaps in the current data illustrated the need for streamlined data collection and accessibility. Table 7.1 presents a summary of the key limitations from the unit record data, their implications for understanding the state of demand, a set of opportunity for future NACAP data collection that should underpin the development and approach of the NMDS.

: Key data limitations from OPAN unit record data

| **Area** | **Limitations** | **Implication** | **Opportunities for future NACAP data collection** |
| --- | --- | --- | --- |
| **Comprehensiveness**  *Data gaps across states* | Data gaps for user characteristics across states prevented an accurate analysis of how NACAP was reaching vulnerable populations across States | Without these data it is difficult to understand whether NACAP is addressing special needs. | Encourage the recording of key features of a user such as whether they are experiencing elder abuse or have dementia. Doing so will enable a better allocation of funding for NACAP services across user needs. |
| **Consistency**  *Inconsistent data capture* | Inconsistent data capture across states for optional fields (e.g., CALD status) meant that usage rates for certain populations might have been under- or overestimated, depending on the operations within the State | Inability to capture breakdowns for given characteristics and SDOs, reducing an understanding of NACAP demand among vulnerable populations. | Adopt consistent data capture to ensure consistent capture of characteristics across SDOs. It is understood that the minimum dataset project will address this. |
| **Quality**  *Instances of inaccurate data* | Instances of inaccurate data, with some records showing extreme values, impeded an understanding of the true user characteristics | Impeded understanding of characteristics of users accessing the services. | Provide advocates with training on data definitions and data requirements and conduct periodic data checks at SDO level to better support prioritisation of needs. |
| **Clarity**  *Unclear whether the data captures the characteristics of the user or caller accessing the service* | Lack of clarity around whether the unit record data captured the characteristics of older people or those calling on behalf of the older people reduced data accuracy | Compromised accuracy in the characteristics of those requiring NACAP services and missed potential for additional information on users accessing services on behalf of an older person. | Provide an opportunity to capture information on the caller (in addition to the older person). Specifically, whether they are the older person seeking help or a family member, loved one or a representative. |

Source: Deloitte Access Economics.

The data limitations affecting the analysis did not only relate to the unit record data. There are also similar limitations to the publicly available data that are used to establish the size of the NACAP target population. For example, there are insufficient publicly available data regarding the prevalence of different vulnerability groups in aged care to disaggregate estimates at the state level. So, while the recipients of residential and community aged care are available for each state, it is not possible to produce estimates with sufficient granularity (e.g. the number of recipients of residential aged care in Victoria who have dementia). Combined with the limitations of the unit record data, this means that any projections produced at the state level would be imprecise and unreliable.

## National Minimum Dataset project

Since June 2021, OPAN has been working on setting up the NMDS by implementing enhanced data and reporting capabilities across SDOs to enhance the level of detailed data and statistical analysis ability for aggregated de-identified client and activity data across SDOs in future. This includes the development of clear definitions, counting rules and relevant data items related to the service activities, client information, presenting issues and service outcomes. This will provide quantifiable data to guide ongoing understanding of the older person's experience, assisting in the identification and resolving systemic challenges. Ensuring that the above unit record data limitations are addressed through the NMDS project will assist OPAN and the government in resolving systemic challenges and enable a better understanding demand and supply of NACAP services and support monitoring and evaluation as outlined in Section 5.2.

## Using behavioural insights to increase uptake of the NACAP

As low awareness of NACAP is a key contributor to the low take-up of services, effort to increase take-up of NACAP has largely centred on activities such as education sessions (in both residential aged care and general community settings), and online outreach from the website and social media. However, consideration of behavioural insights may also help increase the effectiveness of current awareness activities or directly increase take-up of NACAP. Behavioural insights help policy makers and service delivery organisations better understand the behaviour of consumers in order to encourage consumers to make choices that result in better outcomes for the consumer. Often behavioural insights driven interventions can be low-cost approaches to improving social outcomes.

Some helpful principles for encouraging specific behaviours are to consider how to make it easy, attractive, sociable, and timely.[[141]](#endnote-137) Below we consider how they might be applied to increase NACAP take-up.

To make it **easier** to access NACAP, one option would be to shift the largely reactive program to increasingly proactive elements. One example might be that as the older persons cohorts becomes increasingly tech savvy, a regular email or text messages that asks the question “Do you need an advocate? Respond ‘Yes’.” This could be a scalable way to make it easier for consumers to access NACAP.

Personalised materials are known to **attract** more attention. Although materials are already being distributed to consumers as they enter care, perhaps to increase the attention given to those materials, a nominated person from the older persons’ network (i.e., those who are likely to reach out for the NACAP service on behalf of the older person) could also be sent a personalised letter from OPAN introducing the service.

Consultations suggested that there are **social** norms and general beliefs that may be barriers to accessing NACAP. These relate to the fear of retribution by consumers and societal views that normalise the incidence of depression in aged care. Consumers may have concerns about the negative impacts on their aged care services if they make a complaint, and that they may not be able to receive the care they need. Interventions to target these views could support greater usage of NACAP services. Peer comparisons are an effective way to changing behaviour to increase positive behaviour.[[142]](#endnote-138) Giving consumers confidence through case studies and narratives so that they can see that others who are in the same position have accessed and benefited from NACAP can help tackle the beliefs and culture around fear of retribution and in turn increase engagement with the service. Similarly, informing consumers about the (common) incidence of mental health challenges through communications and campaigns can help reduce stigma associated with mental health issues and promote health seeking behaviour.

Providing **timely** information can further support greater awareness and take up of NACAP services and receiving information at different times can have significant impacts on behaviour.[[143]](#endnote-139) Consumers are more receptive of new things and information when it is more significant to them. Consultation seemed to suggest that information is already being provided at some key points such as moving into an aged care home, transitioning between homes or receiving new aged care services. To build on this, further consideration should be given to how to better identify points where there could be issues. Given that we know that consumers only think about NACAP when there is an issue, there is a need to target information provision at critical points where consumers are most receptive. Similarly, consideration should be given to how the representatives of older persons, who may reach out for NACAP on behalf of the older person could be targeted by communications. A better understanding of the demographics of representatives and the consumer journey to accessing NACAP could help improve timelier information provision.

### Project insights to increase take-up of NACAP

Through the consultations, stakeholders also suggested a number of other ways to increase take-up including:

* **Engaging informal carers –** representatives of older people play an important role in accessing assistance on behalf of older people. This is apparent in ACQSC complaints data which indicated that around half of complaints are raised by representatives and family members of older persons.[[144]](#endnote-140)
* **Delivering services on country** - to increase engagement with the services, so that the people can maintain connection to land, family and kinship, especially in light of Australia’s legacy of forced removal from land and dispossession.
* **Cultural training** - training existing advocates and employing new advocates who are from Aboriginal and Torres Strait Islander populations or from CALD backgrounds to increase serviceability in other languages and with due consideration to the cultural contexts of communities.

# Endnotes

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# Appendix A - Detailed consultation approach

OPAN, SDOs and other relevant stakeholders were consulted to gain insights into the key factors driving the demand for aged care advocacy, broad trends in the aged care system affecting this demand and the challenges faced by service delivery organisations in delivering these services to the intended recipients. Full details of the findings can be found in the *Early Findings Report – November 2021*.

An extensive consultation process was conducted with aged care advocacy stakeholders, including aged care peak bodies, aged care consumer and carer advocacy groups, organisations representing care issues for older Australians (e.g., mental health, disability etc.), relevant Commonwealth and jurisdictional government bodies, and subject matter experts. In addition to these stakeholder groups, the 9 service delivery organisations representing OPAN were also consulted. Table A.1 provides a summary of the stakeholders consulted, the format of the consultation and the status of the consultation.

Consultations were conducted as virtual sessions over Microsoft Teams as focus groups or individual organisation interviews. Each consultation was guided by semi-structured interview scripts containing the questions for discussion, which were shared with stakeholders ahead of time to maximise input and contribution. Although best efforts were made, some stakeholders were identified as relevant but were not able to be consulted for this project

: Summary of stakeholders, consultation status and format

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Craig Gear[[145]](#footnote-7), OPAN | Individual interview |

OPAN SDO

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Aged and Disability Advocacy (ADA) Australia | Individual interview |
| Advocacy Tasmania | Individual interview |
| Aged Rights Advocacy Service | Individual interview |
| Senior Rights Service | Individual interview |
| Elder Rights Advocacy | Individual interview |
| Aged Care Advocate | Individual interview |
| Advocare | Individual interview |
| Darwin Community Legal Service | Individual interview |
| ACT Disability, Aged and Carer Advocacy Service (ADACAS) | Individual interview |

Representatives for priority populations

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| The National Aboriginal Community Controlled Health Organisation (NACCHO) | Individual interview |
| Co.As.It | Focus group |
| Federation of Ethnic Communities Councils of Australia (FECCA) | Focus group |
| Centre for Cultural Diversity in Ageing | Focus group |
| Partners in Culturally Appropriate Care (PICAC) | Focus group |
| LGBTIQ+ Health Australia | Individual interview |

Aged care consumer and carer organisations

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Dementia Australia | Individual interview |
| National Seniors Australia | Individual interview |
| Returned Services League Australia (RSL) | Individual interview |
| Elder Abuse Action Australia (EAAA) | Individual interview |
| Association of Independent Retirees | Individual interview |
| War Widows | Individual interview |
| Council of the Ageing (COTA) | Individual interview |
| Totally and Permanently Incapacitated Veterans (TPI) | Individual interview |

Aged care and health peak bodies

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Mental Health Australia | Focus group |
| Australia Federation for Disability Organisations (AFDO) | Focus group |
| Aged and Community Services Australia | Focus group |
| Anglicare Australia | Focus group |
| Leading Age Services Australia (LASA) | Focus group |

Government and Jurisdictional bodies

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Brisbane North Primary Health Network | Individual interview |
| Department of Health Victoria | Individual interview |
| Commissioner for Senior Victorians | Individual interview |
| WA Primary Health Alliance | Responses provided as comments on a pdf of the stakeholder questions |
| WA Country Health Service | Individual interview |
| Department of Veteran Affairs (DVA) | Individual interview |

Service providers and other bodies

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| CRANAplus – Rural and Remote training | Individual interview |
| Remote Accord | Individual interview |

**Subject matter experts (SMEs)**

|  |  |
| --- | --- |
| **Stakeholder** | **Format** |
| Dr Catherine Barret (Celebrate Ageing) | Individual interview |
| Dr Joseph Ibrahim | Individual interview |
| Kathy Eager (Director of AHSRI) | Individual interview |
| Dr Barbara Blundell | Individual interview |

**Stakeholders not attended or declined to participate**

National Advisory Group for Aboriginal and Torres Strait Islander Aged Care (NAGATSIAC)

Disability Services Australia

Uniting Care Australia

Baptist Care Australia

End of Life Direction for Aged Care (ELDAC)

Services Australia

Rural and Remote consumers

* + 1. Stakeholder consultation questions

**Trends and awareness of advocacy**

* What trends have you observed in the last 5 years, in aged care advocacy services, and what is driving these? E.g. trends in the demand for and / or referral to advocacy services, funding, policy, consumer trends, issues faced by clients etc.
* Roughly what proportion of the eligible population do you think is aware of NACAP advocacy services, and what is driving or preventing wider awareness?

Use of NACAP services

* Would you have a sense of the current demand (number of users, their demographics etc) for NACAP services? If not, please move to Question 7.
* Could you describe the users who are likely to be seeking NACAP services, such as their demographic characteristics, or common experiences?
* How does the need for and access to NACAP services vary across settings, such as in residential care facilities, in home care, before entering aged care?
* Could you describe the population cohorts who would benefit the most from the use of NACAP services? How do these vary by service type (advocacy, information, education)?
* Roughly how many people who might benefit from these services are currently not using them, and why? E.g. as a proportion of residential aged care population, proportion of existing aged care service providers, etc.
* Could you describe the population cohorts who are most likely missing out on the services, and what the barriers are? E.g. age, health status, geography, language and culture, long wait times.
* How do you think NACAP advocacy services are meeting current needs and future requirements?
* What would be the key drivers of the change in demand for NACAP services?

Future outlook

* The demands of Australia’s older population are likely to grow in complexity, with many consumers requiring multiple supports. What complexity trends have you noticed, that may affect how NACAP services are delivered going forward?
* What key reforms do you expect will affect the demand for NACAP services now, and over the next 5-10 years? How can key reform activities be leveraged to support better outcomes in the future?
* What are the transition paths to or from NACAP and other services, if any?
* More generally, what are your projections for the future demand for aged care (by settings, such as residential and in-home care)?

Data

* Do you have any suggestions for data sources relevant for estimating current and future demand for NACAP services, including any you might be able to share?

Delivery of NACAP services (OPAN stakeholders only)

* How do you identify and prioritise the population cohorts to deliver NACAP services to?
* How can the delivery of NACAP services be strengthened? E.g. Capacity building and training requirements, increasing complexity among elderly people, lack of awareness and understanding of abuse, understanding changes in the sector.

# Appendix B - Program Expenditure

: NACAP Program Expenditure ($ millions)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Year** | **2020/21** | **2021/22** | **2022/23** | **2023/24** | **2024/25** | **Total** |
| Total NACAP budget | 14.80 | 30.45 | 39.25 | 40.15 | 41.10 | 165.75 |
| Emergency & Additional Reform Advocacy | 3.10 | 1.15 | 3.02 | 1.78 | 1.55 | 10.60 |
| Diversity Education Project | 0.00 | 1.12 | 1.36 | 1.66 | 2.02 | 6.16 |
| **Total funding excluding Emergency & Additional Reform Advocacy and Diversity Education Project** | | | | | | **148.99** |

Source: Department of Health

Limitation of our work

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