OPAN Older Persons Advocacy Network

The National Aged Care Advocacy Program Presenting Issues - Report 3

July 2022 – June 2023

Contents

OPAN receives funding from the Australian Government Department of Health and Aged Care for the delivery of the National Aged Care Advocacy Program.

Version 2 - November 2023

About OPAN

The Older Persons Advocacy Network (OPAN) is a national network comprised of nine state and territory member organisations (members) that have been successfully delivering advocacy, information, and education services to older people across Australia for close to 30 years.

The OPAN members are:

Australian Capital Territory: ACT Disability, Aged and Carer Advocacy Services

New South Wales: Seniors Rights Service

Northern Territory: Darwin Community Legal Service

Northern Territory Central: Catholic Care NT

Queensland: Aged and Disability Advocacy Australia

South Australia: Aged Rights Advocacy Service

Tasmania: Advocacy Tasmania

Victoria: Elder Rights Advocacy

Western Australia: Advocare

OPAN is funded by the Australian Government Department of Health and Aged Care to deliver the National Aged Care Advocacy Program (NACAP). OPAN members support older people and their representatives to address issues related to Australian Government-funded aged care services.

OPAN aims to provide a national voice for individual aged care advocacy, promoting excellence and national consistency in the delivery of advocacy services under the NACAP. OPAN is an independent body, always on the side of the older person. This independence is a key strength both for individual aged care advocacy and for our systemic advocacy.

A message from the CEO

Craig Gear OAM

Over the past two years, OPAN has experienced significant aged care advocacy workforce growth with the expansion of the National Aged Care Advocacy Program (NACAP). This growth has enabled OPAN members and NACAP to support more older people than ever before to understand and exercise their aged care rights.

OPAN members provided 36,904 instances of information and advocacy support to older people, their families and representatives in the 2022-23 financial year representing a 36 per cent increase from the previous year. We have seen the demand for advocacy support increase as reforms such as the introduction of caps for care and package management fees were introduced. We expect that the demand for advocacy will continue to increase as the aged care reform agenda progresses.

This report provides tangible evidence of the many ways in which older people's rights are eroded as they age and need to engage with aged care services.

Every one of the 60 case examples documented in this report reinforces the need for a new rights-based Aged Care Act backed by the legislative and regulatory levers that are necessary to enforce it.

The National Aged Care Advocacy Program is designed to support older people to understand and exercise their aged care rights and raise and address concerns with their aged care providers. As a result, this report shares the experiences of older people who had issues with their aged care service. It is acknowledged that many older people also have positive experiences of aged care.

This year, a number of positive reforms were introduced and are still taking effect. These included the capping of care and package management fees, 24/7 nursing, care minutes, consumer advisory groups, wage increases and star ratings. We hope to see the benefits of these reforms, once embedded, reflected in future NACAP Presenting Issues reports.

"Every one of the 60 case examples documented in this report reinforces the need for a new rights-based Aged Care Act backed by the legislative and regulatory levers that are necessary to enforce it."

In addition, some of the examples shared in this report show the challenges that occur at the interface between systems. Aged care advocates may get involved where interfacing issues impact on an older person and their aged care services. OPAN continues to explore how the scope of the NACAP Framework could be expanded to allow a broader response to the needs and rights of older people.

While a broad range of issues are addressed in this report, two key themes emerged that must be brought to light for change to occur:

- Communication issues consistently presented as issues in advocacy casework for both older people living at home and those living in residential aged care. Older people sought aged care advocacy support because they did not feel heard by their aged care provider and felt their requests to address care concerns were dismissed or ignored.

A message from the CEO

- Choice and decision-making were also identified as top presenting issues across aged care service types. For older people receiving the Commonwealth Home Support Programme or Home Care Packages concerns typically related to service system issues that limit choice and control over who delivers the services, when the services are delivered and the types of goods and services that can be delivered. In residential aged care homes[1] concerns often involved providers making decisions on behalf of an older person or prioritising the decisions of family members or substitute decision-makers over the views and preferences of the older person.

It is critical that issues of communication, choice and control are addressed in the new Age Care Act. Older people must have a voice and be heard when it comes to decisions about their care. Embedding supported decision-making principles into the new Act will facilitate protection of this right.

OPAN looks forward to working with the government and other sector stakeholders on the upcoming Exposure Draft to ensure older people's voices are heard.

Data contained in the 2022-23 Presenting Issues Report demonstrates the depth and breadth of the National Aged Care Advocacy Program – at both an individual and a systemic level. As the aged care sector undergoes a period of fast-moving reform, this program will be essential in informing and supporting older people about their rights. Finally, a heartfelt thank you to all aged care advocates working across Australia in OPAN member organisations. It is your knowledge and tenacity that ensures older people's voices are heard and their rights are upheld.

"As the aged care sector undergoes a period of fast-moving reform, this program will be essential in informing and supporting older people about their rights."

[1] Throughout this report, OPAN refers to residential aged care as residential aged care homes in line with current terminology used by the Department of Health and Aged Care.

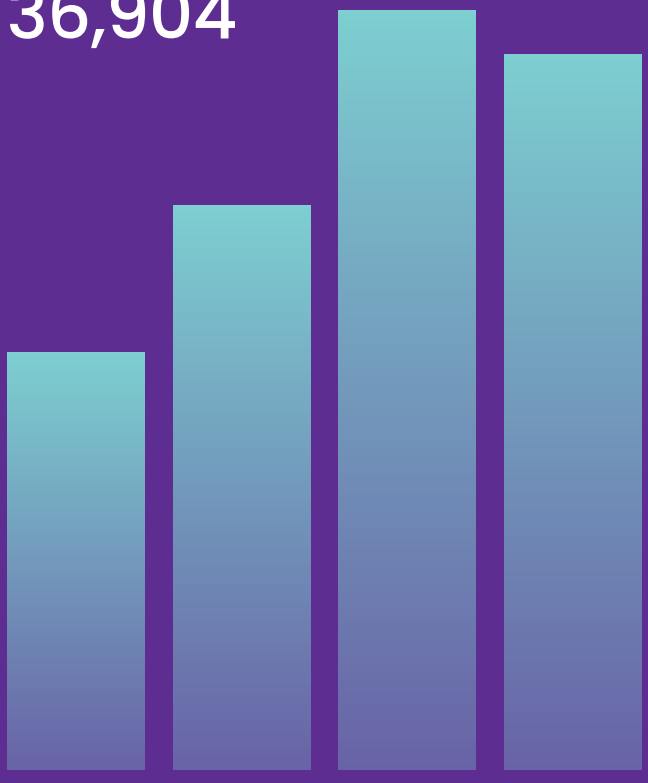
Executive summary

Provided below is a summary of the activity and key issues for older people supported by advocates during 2022-2023.

Information and advocacy

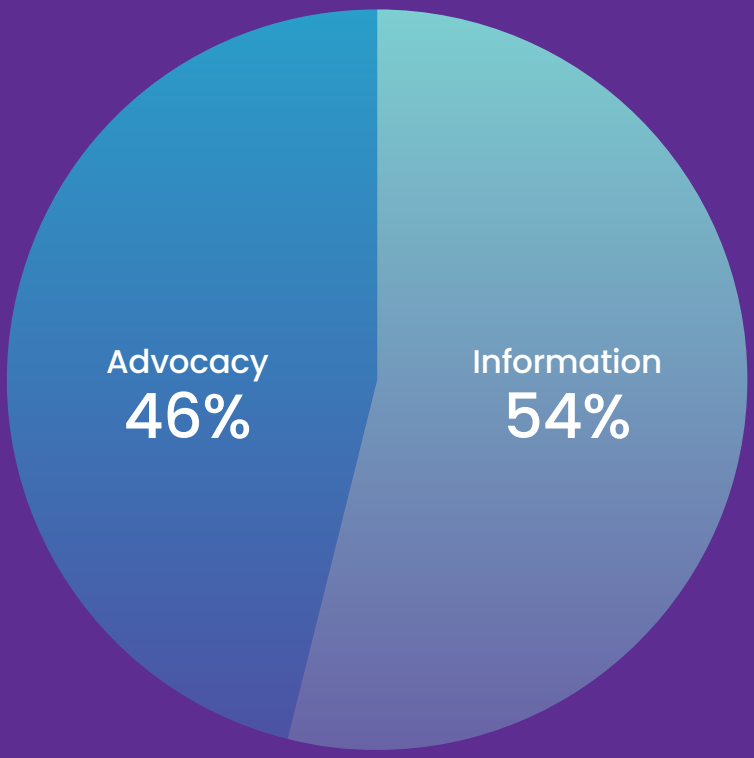
Total number of information provision and advocacy cases in 2022-2023

36,904



Quarter 1	Quarter 2	Quarter 3	Quarter 4
7,645	8,306	10,515	10,438

Percentage of information provision vs advocacy cases



Executive summary

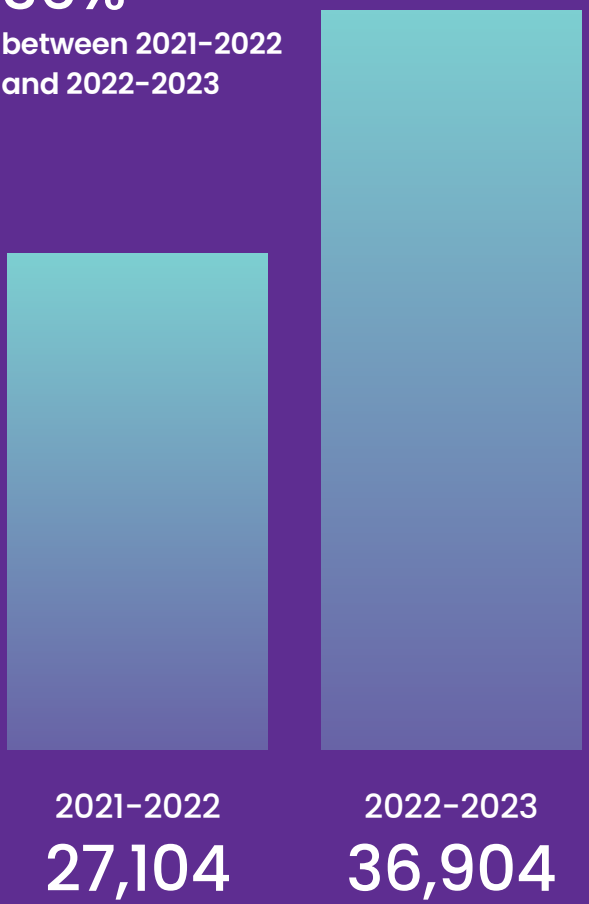
Provided below is a summary of the activity and key issues for older people supported by advocates during 2022-2023.

Information and advocacy

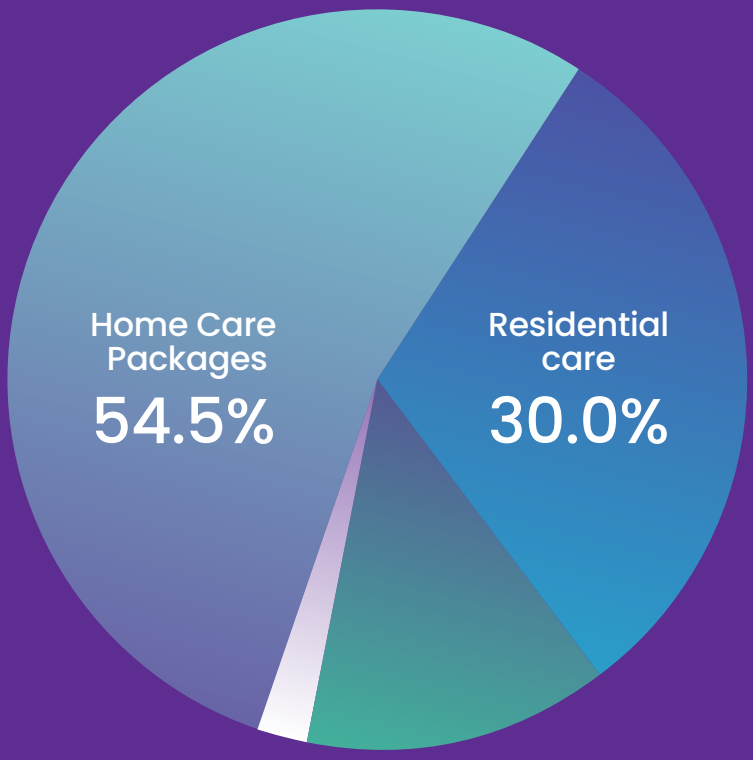
Information and aged care advocacy support increased

36%

between 2021-2022 and 2022-2023



Aged care advocacy cases by aged care type[2]

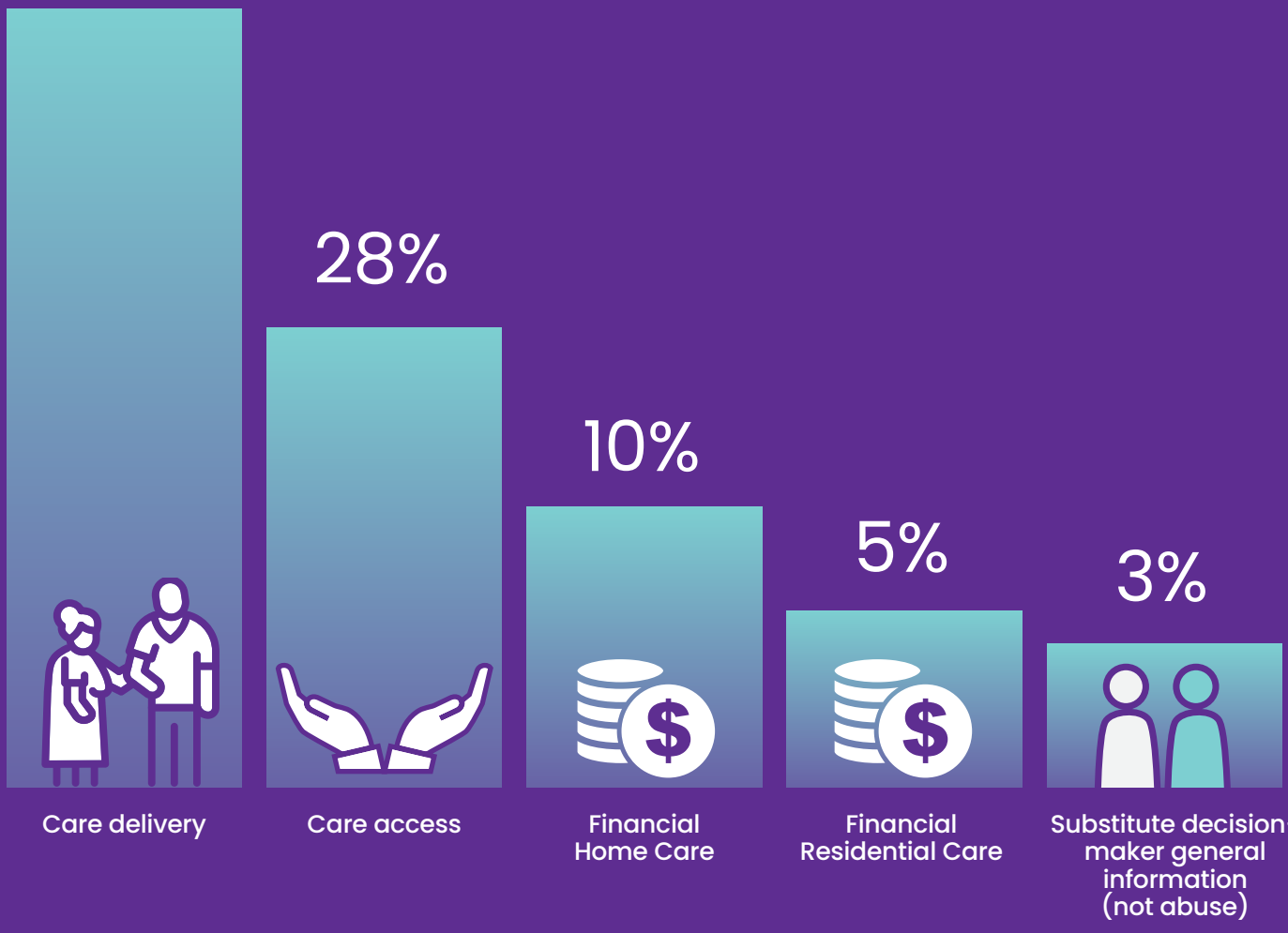


[2] Explanation: the percentage of advocacy cases that involved a presenting issue.
Disclaimer: where an aged care type has not been identified these cases have been removed.
Parameters: closed NACAP Advocacy cases from Quarters 1 – 4 with a value in the issues category column.

Executive summary

Provided below is a summary of the activity and key issues for older people supported by advocates during 2022-2023.

Top issues of aged care advocacy cases across all aged care types[3]



[3] Explanation: the percentage of cases involving an aged care type that had one or more presenting issues.
Disclaimer: where an aged care type has not been identified these cases have been removed.
Parameters: closed NACAP Advocacy cases from Quarters 1 – 4 with a value in the aged care type and issues category column.

Executive summary

Provided below is a summary of the activity and key issues for older people supported by advocates during 2022-2023.

Top Issues by Aged Care Type[4]

Commonwealth Home Support Programme

Care access	65%
Care delivery	27%
Financial – CHSP	4%
Substitute decision-maker general information (not abuse)	1%

Home Care Packages

Care delivery	50%
Care access	26%
Financial – Home care	21%
Substitute decision-maker general information (not abuse)	1%
Abuse of older person	1%

Residential aged care

Care delivery	51%
Financial – Residential care	18%
Care access	12%
Substitute decision-maker general information (not abuse)	7%
Abuse of the older person	5%

[4] Explanation: the percentage of cases involving the specified aged care type that had one or more of presenting issues.
Disclaimer: where an aged care type has not been identified these cases have been removed.
Parameters: closed NACAP Advocacy cases from Quarters 1 – 4 with a value in the aged care type and issues category column.

Executive summary

Top presenting issue in advocacy casework [5]

Care

Accessing aged care

- Understanding and engaging with My Aged Care
- Assessment wait times
- Service availability

Commonwealth Home Support Programme (CHSP)

- Care access
- Communication
- Choice and decision-making

Home Care Packages

- Communication
- Choice and decision-making /care planning
- Financial

Residential care

- Choice and decision-making
- Communication

Diverse and marginalised groups

- Communication/language barriers
- Service access in rural and remote communities
- Culturally appropriate care

Abuse of older persons

- Financial
- Family conflict
- Psychological/emotional
- Misuse of substitute decision-making powers

[5] Top issues in advocacy case work identified through analysis of both quantitative and qualitative data.

Policy recommendations

This report summarises the top presenting issues in aged care advocacy cases in 2022-23, informed by quantitative and qualitative data provided by OPAN members.

The themes presented in this report provide valuable insight into the range of challenges experienced by older people accessing and receiving government-funded aged care services. The following policy recommendations offer solutions to address some of the key issues presented in this report. Many of the recommendations build upon aged care reforms that are currently underway.

Workforce

Recommendation 1:	Continue to invest in growing the aged care workforce by supporting providers to recruit and retain aged care workers.
Recommendation 2:	Invest in skills development and micro-credentialing to address identified knowledge gaps, including dementia support, palliative care, continence care, and medication management.
Recommendation 3:	Enhance older people's access to high-demand services, such as gardening and cleaning through regulatory reforms that support sole traders to become registered aged care providers for delivery of lower-risk services with required adherence to the Statement of Rights and Code of Conduct for Aged Care.
Recommendation 4:	Address workforce shortage in thin markets such as the provision of bilingual and bicultural care, or in regional, rural and remote Australia through innovative regulatory reforms that include enabling older people to employ trusted family or friends to provide care at home.
Recommendation 5:	Continue to invest in, and expand, the rollout of the OPAN Diversity Education model to build the capacity of providers to care for priority population groups.

Policy recommendations

Care access

Recommendation 6:	Continue to invest in information and education services for the general public about My Aged Care and the range of aged care services available.
Recommendation 7:	Review the My Aged Care communication approach in consultation with older people from diverse and marginalised groups and incorporate principles from the United Nations Disability-Inclusive Communications Guidelines and the National Standards for Disability Services.
Recommendation 8:	Develop and produce accessible aged care information in plain English and in a range of other accessible formats.
Recommendation 9:	Continue to invest in face-to-face supports for older people accessing aged care services. Enable a 'no wrong door approach' across the National Aged Care Advocacy Program (NACAP), the care finder program and the Elder Care Support program.
Recommendation 10:	Develop interagency referral protocols between NACAP, the care finder program and the Elder Care Support program.

Policy recommendations

Recommendation 11:	Prioritise the implementation of the single assessment service for aged care that is driven by the diverse needs of older people. Ensure the single assessment service: • Is underpinned by a knowledgeable and skilled workforce • Is appropriately resourced to provide timely face-to-face aged care assessment and referral • Is transparent about aged care assessment wait times and benchmarking data • Uses video communication technology to shorten wait times where appropriate. For example, where an older person provides their consent, has access to a support person, and up-to-date technology with a good internet connection • Uses enhanced client management technology to address service access blocks and resolve communication issues between My Aged Care and the aged care assessment workforce • Improves communication processes between assessors, older people, their families and representatives, and • Provides streamlined access to timely re-assessment that is needs-based.
Recommendation 12:	Adjust key performance indicators for aged care assessment teams to account for the additional time required for aged care assessors to engage with older people with disabilities, from diverse and marginalised groups and those living in rural, regional and remote areas.

Policy recommendations

Service availability and delivery

Recommendation 13:	The Australian Government must ensure appropriate and sustainable funding of the new Support at Home program so that older people have timely access to the services they need and are not forced into residential aged care due to lack of access to appropriate supports and services at home.
Recommendation 14:	The new Support at Home program must be rights-based, in line with the new Act, and retain a consumer-directed care approach to choice and decision-making with flexibility to meet individual needs. The Australian Government must consider flexible funding models that address the unique service access challenges experienced by older people living in rural and remote areas, older people with disability and by some diverse and marginalised groups.
Recommendation 15:	Increase investment in the Transition Care Programme to provide older people with greater choice between returning to care at home or entering a residential aged care home following a hospital admission.
Recommendation 16:	Review the capacity of the residential aged care system in areas where older people are forced to remain in hospital due to a lack of available residential aged care places. Consideration must be given to the difference between operational and available places when conducting this review.
Recommendation 17:	To ensure older people are not displaced from their community, the Australian Government must develop measures to support residential aged care providers that are considering closure, to stay open.
Recommendation 18:	Fast track investment in the National Aged Care Design Principles and Guidelines and fund a pilot of smaller-scale accommodation projects that cultivate a sense of home, provide access to the outdoors and enable connection to the community. Priority should be given to areas experiencing service closures or thin markets.

Policy recommendations

Financial issues

Recommendation 19:	Fast track the Independent Health and Aged Care Pricing Authority's workplan to prioritise benchmarking of cost and activity data within the aged care at home sector.
Recommendation 20:	Improve oversight and regulation of requirements relating to home care package fees and charges to address existing loopholes.
Recommendation 21:	Introduce the ability to waive or shorten the 70-day period to transfer package funds in cases where an existing provider is unable to provide services to meet the care plan.
Recommendation 22:	Hold aged care providers liable for overspending and accumulation of debt if they cannot show evidence of a review and agreement from a client or representative.
Recommendation 23:	Require providers of residential aged care to support older people and their representatives to understand the importance of accurately completing the means-tested fee form to avoid overcharging. This will require residential aged care providers to have a greater understanding of the means-tested fee system.

Policy recommendations

Aged care rights

Recommendation 24:	Implement the new rights-based Aged Care Act to address the breaches of aged care rights outlined in this report including, but not limited to: • equitable access to services and timely access to assessment and reassessment as their physical, psychological and emotional needs change or progress, which is done in a culturally appropriate manner • communication and information in their preferred language or method of communication, with access to interpreters, preferred support person or aged care advocate, and communication aids as required • exercise choice and make decisions that affect their lives and the manner of their death, have access to independent support to make those decisions where necessary, and have those decisions respected and followed, including where they involve personal risk • have their identity, culture, spirituality and diversity valued and upheld when accessing or receiving aged care services • make complaints without fear of reprisal, and have their complaints dealt with effectively, promptly and to their satisfaction • an independent advocate or support person of their choice.
Recommendation 25:	Commence information, education and training on aged care rights and how the Aged Care Act can be implemented for older people and aged care providers from 1 January 2024.
Recommendation 26:	Invest in aged care provider cultural change initiatives through compulsory participation in aged care rights training. Make access to aged care subsidies subject to documented training completion by a set date, similar to child-safe organisation training requirements.
Recommendation 27:	Enforce residential aged care providers to allow advocates to deliver a minimum of one rights-based NACAP education session to aged care participants and staff on an annual basis.

Policy recommendations

Abuse of older persons

Recommendation 28:	Provide funding for the NACAP to deliver a national education program around decision-making for older people, their appointed substitute decision-makers and aged care providers to prevent the abuse of older persons. The education program will include: • the responsibilities and limitations of substitute decision-making roles • the decisions must reflect the will and preferences of the older person • the requirement for the older person to be included in all decisions to the greatest extent possible • the importance of using supported decision-making • the right to an independent aged care advocate.
Recommendation 29:	Provide additional funding to NACAP to deliver specialist aged care advocacy services that will contribute knowledge and expertise to support good practice in guardianship and administration matters and the development of supported decision-making practice models within aged care.

Aged care advocacy

Recommendation 30:	Promote and refer to the NACAP throughout the aged care journey as an independent source of information and support to help improve older people's experience of aged care and address aged care concerns. This will include building the capacity of aged care providers to resolve issues such as communication.
Recommendation 31:	Educate staff working in My Aged Care, the care finder program, Elder Care Support program, aged care providers and aged care assessors on the role advocates have in enabling older people to have a voice and choice in addressing and resolving issues with their current provider or in choosing to move to a new provider.
Recommendation 32:	Provide further funding for the rollout of the OPAN Self-advocacy toolkit to support older people and their representatives address initial concerns themselves, particularly around communication and care planning.

Accessing aged care

In 2022–23, 26 per cent of all requests for information and aged care advocacy support related to issues with accessing aged care services. These issues have been outlined by OPAN in the last two National Aged Care Advocacy Program (NACAP) Presenting Issues reports. Older people continue to find the aged care system confusing and difficult to navigate. They still experience issues engaging with My Aged Care and continue to face long wait times for aged care assessments.

OPAN recognises the Australian Government has recently invested in a variety of initiatives to assist older people to navigate the aged care system, including the care finder program which commenced in January 2023 and the Elder Care Support program (for Aboriginal and Torres Strait Islander communities) which is currently being rolled out across Australia. These programs have specific eligibility criteria to ensure that targeted cohorts who are facing significant barriers to access are supported to connect with the aged care system.

OPAN members have and will continue to refer older people to these programs where appropriate. However, older people and their families and representatives will naturally continue to seek support to access aged care via the NACAP. Some may be ineligible for the care finder program or Elder Care Support program, while others may be eligible but want to speak to an aged care advocate they already know and trust. All three services must work collaboratively to ensure a "no wrong door approach" is applied and older people receive timely and appropriate support in accessing the care they need.

My Aged Care

Understanding the aged care system continues to be problematic for many older people and their families or representatives. A large proportion of older people assisted by aged care advocates to access aged care throughout 2022–23 said they had no prior knowledge of My Aged Care, the Commonwealth Home Support Programme (CHSP) or the Home Care Packages Program (refer to case example 1). OPAN members report that many people accessing aged care for the first time experience high levels of confusion when trying to understand the range of available aged care options, the process for accessing the various types of aged care services and the associated fees and charges.

Accessing aged care

Many of the older people assisted suggested there is not enough information, education or promotion of My Aged Care to the general public. Aged care advocates have observed that a lack of accessible information on the role of My Aged Care and the type of aged care services makes it increasingly difficult for some older people to begin the journey of accessing aged care. OPAN members have noted that it is particularly important for information to be made available to older people who do not have internet access or who are unable to effectively use online services.

OPAN members report that the complexity of the aged care system often prevents or delays older people's access to aged care services. There are numerous steps required to gain approval for aged care services and then further steps to begin receiving aged care. Communication about these steps is not always clear or easily discerned and this often leads to stress and frustration for service users (refer to case example 2). It has been suggested by OPAN members that communication from My Aged Care should be less official, less repetitive and made easier to read for older people and their families. Communication processes must be improved for older people without support, internet connection and those living with disability, including hearing, vision, and memory loss.

Advocates have observed that older people living with vision or hearing impairment often find it more difficult to access aged care information. Advocates have been involved in cases where people who are legally blind have been sent detailed letters about their assessment outcomes and the next steps for accessing care that they could not read. Advocates have also been involved in cases where people living with hearing loss are unable to communicate with My Aged Care over the phone and have sought the support of an advocate to progress their access to care.

Over this reporting period, both advocates and older people have experienced a range of challenges communicating with My Aged Care over the phone. There have been periods where the wait time to get through to a My Aged Care contact centre staff member has been up to, and in some instances, above 30 minutes (refer to case example 3). There were many cases where older people and their family members simply could not wait that long due to health conditions or caring responsibilities. There were some occasions when advocates and older people persisted with the wait time, but the phone call was cut off when they eventually reached the contact centre.

Accessing aged care

OPAN has established active feedback mechanisms for ensuring these types of concerns are raised with the Department of Health and Aged Care in a timely manner. This year, the Department of Health and Aged Care supported OPAN members to be set up in the My Aged Care service and support portal as agents. As agents, advocates can better support older people to engage with My Aged Care, access information about the status of their care and progress their aged care journey. The agent functionality meant that on some occasions, advocates were able to bypass delays with the My Aged Care contact centre and access client information online via the portal.

Case example 1

A family member of a potential aged care recipient contacted an OPAN member for the support of an aged care advocate. The family member and older person live in a rural community and had heard about aged care advocacy through word of mouth. The older person had a recent stay in hospital and the family member was unaware of any assistance available after discharge. Neither the older person nor their family member had heard of My Aged Care. The advocate was able to ascertain that the older person was registered with My Aged Care, although they had no idea how that happened. The advocate found that the older person had referral codes available for domestic assistance and garden maintenance.

The advocate organised for the older person and family member to meet with two aged care providers in the area, and with the support of the advocate they were able to have services put in place quite quickly. The older person has since contacted the advocate on a few occasions for clarity around available services, fees, charges and invoicing as well as general information about My Aged Care.

Accessing aged care

Case example 2

An older person living independently was starting to find some tasks around the home and garden more difficult. They called My Aged Care and were advised they had been approved for services under the Commonwealth Home Support Programme and would soon receive a letter with codes that could be used to engage an aged care provider. The older person contacted an OPAN member and requested support from an aged care advocate to communicate with potential providers and sign up for services. They noted that they had received a letter from My Aged Care but did not understand what the next steps were or how to contact a provider. The older person was able to get an aged care provider list from My Aged Care and selected their preferred provider.

The advocate supported the client to contact the provider who advised that they did not have any service availability. Another five providers were contacted and none had service availability.
The older person and the advocate contacted My Aged Care and arranged an assessment for a Home Care Package. The client was subsequently approved for a Level 2 package. This process took several months.

Case example 3

An older person was referred to an aged care advocate for support to access cleaning and gardening. The older person described a decline in their physical health and some concerns with memory. Initially, the older person attempted to contact My Aged Care several times by phone but became frustrated with having to wait on hold for lengthy periods, over an hour in one instance.

The advocate offered support to the older person to engage with My Aged Care. After a lengthy wait of 45 minutes, the older person was finally able to talk with a My Aged Care representative about their support needs and a referral was made to the Regional Assessment Service. The advocate supported the older person to make an appointment for the assessment and the older person requested the advocate attend the assessment. The assessment went well, and recommendations were forwarded for domestic assistance and transport via the CHSP.

Accessing aged care

Assessments

Wait times for both Regional Assessment Services (RAS) and Aged Care Assessment Teams (ACAT) continue to be a concern. In some areas, older people are waiting up to three months just to receive an initial contact from a RAS or ACAT assessor let alone an assessment. Concernedly, one OPAN member reported a six-month wait for an ACAT assessment for some locations. These wait times are adversely impacting older people urgently in need of care. Sadly, while OPAN is not linking causality, some older people have died while waiting for an assessment.

Time frames vary across the nation, with regional, rural and remote areas appearing to experience more noticeable delays. One OPAN member has observed that the delays in accessing an assessment in regional, rural and remote areas often align with the availability of services in these areas. It has been suggested that assessments are not being prioritised in these areas because there are simply no aged care providers with capacity to support an older person's identified needs after the assessment.

Advocates have provided support throughout 2022-23 to ensure older people receive timely access to the appropriate level of assessment. Advocates have noted that older people receiving CHSP are often automatically referred by My Aged Care to RAS for reassessment even when the older person identifies a significant increase in need and specifically requests an ACAT assessment. This can lead to further delays for the older person, as the RAS often makes an internal referral to ACAT and the older person commences a new waiting period. These wait times coupled with time spent in a national queue and waiting for a service to be available means that older people are left without necessary care and support for significant periods of time.

Advocates note that delays can also be experienced when an older person misses a call from an assessor calling to book a visit. This often occurs because the older person is suspicious about answering unknown phone numbers, or the assessor does not leave a message with return contact details (refer to case example 4). Case example 5 demonstrates the impacts of missed communications between assessors and older people. Improved communication processes between assessors and older people must be prioritised with the introduction of the single assessment system for aged care from 1 July 2024.

OPAN members continue to raise concerns over the continuation of assessments over the phone in some areas. Assessments over the phone often make it difficult for older people to communicate their care needs and consequently, many are not approved for the appropriate levels of care. Advocates regularly provide support to older people at assessments to ensure they understand the process and are supported in communicating all their care needs. Advocates have reported that in some cases assessors do not appear to be appropriately skilled in adequately assessing an individual's needs and taking into consideration important factors such as chronic health conditions, carer stress and trauma histories. OPAN members have stressed the importance of a skilled assessment workforce ready for commencement of the new single assessment system for aged care.

Accessing aged care

Case example 4

Advocacy support was requested for an older person who is blind and from a culturally, ethnically and linguistically diverse background and requires higher level support to remain living independently at home. An advocate supported the older person with a referral to My Aged Care. A high priority was placed on their case and a referral was made to the ACAT for a comprehensive assessment. When the ACAT assessor phoned to schedule an appointment, the older person missed the call. The ACAT assessor did not leave a return telephone number or telephone ID and the older person was unable to recall their phone number to call back. Subsequently, ACAT cancelled the referral, stating that they attempted to contact the client on three occasions.

The advocate contacted the ACAT team leader and requested that the referral be reinstated. The client was granted an assessment by the RAS which resulted in a high priority referral to ACAT. In the interim, the RAS assessor reissued the client referral codes under the Commonwealth Home Support Programme for assistance with meal preparation, domestic assistance, and transport. However, no domestic assistance services were available in their area.

Case example 5

An older person had an aged care assessment scheduled but missed it due to a hospital admission. On discharge, they attempted to reschedule the assessment, but their calls were not returned by the assessment team. The older person wanted assistance to arrange aged care services at home as their partner and carer had recently died and they were struggling with daily tasks without the support of their carer. The older person said they were desperate for assistance and felt like they were being sent around in circles and not getting any assistance. An advocate attempted to call the assessment team and the mobile number provided for the assigned assessor, but there was no answer or callbacks for either number. The advocate continued to make calls over several days, eventually speaking with a Regional Assessment Service assessor who said the older person had not been at home for the assessment and did not answer any of their calls. The advocate informed the assessor that the older person had been in hospital and was now in a desperate situation. The advocate queried the referral to the Regional Assessment Service when there were limited CHSP services available. The assessor acknowledged the older person would have difficulties finding a CHSP provider but also noted that it would be at least a three month wait for an ACAT assessment. The assessor said the team were working from the older person's last assessment conducted in 2017. The advocate informed the assessor that the older person's health had deteriorated over the past five years, they no longer had a carer, and they urgently needed a higher level of home support. The assessor advised they would assess the client the following day as a matter of urgency.

Accessing aged care

Service availability

Service availability continues to be one of the most significant issues impacting older people. Service availability concerns span the CHSP, Home Care Packages Program and residential aged care. Older people are finding it increasingly difficult to find the care they need, when they need it. Lengthy wait times for both assessments and service access mean that many older people are becoming anxious about a future where their care needs are not met. OPAN members report that service availability issues are most critical in rural and remote locations and have noted that in some areas there are no aged care providers available at all.

Service availability concerns are most apparent in the CHSP. Older people are frustrated by the lengthy process they must endure to receive CHSP approvals, only to find there are no services available for them to access. Some CHSP providers (mainly local government) are withdrawing their services prior to the commencement of the new Support at Home program, creating significant voids in the CHSP service landscape. (Refer to page 28 for more detail on CHSP service availability)

Advocates report that people are also having trouble finding suitable Home Care Package providers. The wait times for a Home Care Package can be substantial. This becomes a particular concern in areas where CHSP availability is low and older people do not have access to interim CHSP support while they wait for a Home Care Package. Service availability issues leave some people feeling pressured to act fast and sign agreements with providers without giving the agreement adequate consideration. One OPAN member reported on a case where an older person declined to sign a service agreement following an initial meeting with a provider, as they wished to consider their options. The following day they decided they would like to accept a Home Care Package with the provider, only to be told their package had been taken by another person and the service would not be accepting any new clients.

OPAN members have also raised concerns about the availability of both respite care and permanent places in residential aged care homes. Older people and their families are finding it increasingly difficult to access residential respite care in a timely manner following COVID-19 lockdowns that occurred in the first half of this year. There is a perception among advocates that there are fewer respite places available and a general reluctance among residential aged care providers to accept people for respite stays. This is contributing to carer burnout and is also impacting the ability of carers to undergo treatment or hospitalisation for their own health needs.

Accessing aged care

OPAN members report that there are many older people who are stuck in the hospital system with no available options for long-term care. One of OPAN's members has reported that there is a severe shortage of available residential aged care places in remote areas of Australia. As a result, older people are forced to stay in hospital until residential aged care places become available. Some older people are waiting in hospital for over a year. An inadequate supply of residential aged care in remote communities often results in older people having to move away from their communities into regional centres to receive long-term care, placing additional pressure on an already overloaded system.

OPAN members in multiple states and territories have commented on the growing number of residential aged care closures. One OPAN member noted that the process of relocating large numbers of aged care residents is placing a significant strain on an already pressured aged care system. OPAN members have expressed concern about the immeasurable impact that closures have on residents and their families. Uncertainty about future care and accommodation causes enormous stress for all parties. In many circumstances, residents have limited choices when it comes to their relocation options. Advocates have been involved in some cases where residents have had to move to a new location that is a substantial distance (1 to 3 hours) away from their hometown, family and friends. One OPAN member shared the story of a resident who was forced to move three times following residential aged care closures.

OPAN members have also observed that some residential aged care providers appear to be unwilling to permanently accept older people with high level care needs or challenging behaviours (refer to case examples 6 and 7). Workforce shortages may be a contributing factor in these decisions. One OPAN member has also identified an emerging trend of residential aged care providers insisting that potential residents have the agreement of their general practitioner to attend the residential aged care home before they will offer a permanent place (refer to case example 8). There has been an influx of older people wanting to enter residential aged care homes, but their regular general practitioners are not willing to commit to providing services in that environment. This issue is more common in rural areas where general practitioners are at or over capacity. Telehealth appointments could be a potential solution for addressing shortages of general practitioners delivering services in residential aged care.

Accessing aged care

Case example 6

An older person with a disability had lived independently their entire adult life but after a recent fall had been discharged from hospital into residential respite care after it had been determined that it was unsafe for them to return to their own home. The older person has cerebral palsy and requires assistance transferring between bed to wheelchair and with showering and toileting. Their respite care period was due to expire in the coming week and the provider would not offer them a permanent placement.

A My Aged Care website search yielded five potential placements but each provider, upon requesting further details about the older person's circumstances, stated they were unable to meet their needs. The older person eventually found a permanent placement at a residential aged care home that had originally advised they had no suitable places available, but after meeting with the older person, agreed to accommodate them.

Case example 7

An older person had been in hospital for over 1,000 days and required assistance from an advocate to transfer into a residential aged care home. The older person has high bariatric care needs, and this has contributed to mental health issues such as anxiety and depression. All of the residential aged care providers that were approached declined the older person due to a lack of required staffing and equipment.

With the support of state/territory health services, a residential aged care provider was assisted in preparing a room with ceiling hoists and bariatric equipment required to support the older person. The state/territory health service committed to financially support the provider with extra nursing staff for a period of one year until the provider has a plan in place to support the resident on an ongoing basis.

Accessing aged care

Case example 8

A family member of an older person experiencing a significant decline in health, sought advocacy support to find a residential aged care provider that would accept the older person without an attending general practitioner. The family member shared that they were unable to leave the older person alone, which made it increasingly difficult for them to work. The family member was feeling very stressed, and this was not helping their care relationship.

The advocate made numerous phone calls to residential aged care providers and general practitioners, before finally convincing the older person's existing general practitioner to attend to the older person in the residential aged care home of their choice.

Commonwealth Home Support Programme

Throughout 2022-23, 64 per cent of advocacy cases with the Commonwealth Home Support Programme (CHSP) involved issues relating to care access.

OPAN members provided older people with information and support to understand and gain approval for CHSP services but found that CHSP service availability continued to prevent or delay many older people from accessing the services they needed. Care delivery was the second highest issue category recorded for CHSP. Communication (30 per cent) and choice and decision-making (20 per cent) accounted for 50 per cent of CHSP care delivery concerns. Workforce and service supply issues were identified as key factors contributing to concerns in these areas.

Service access and navigation

OPAN members have noted that the demand for CHSP services continues to exceed supply. This is largely attributed to a combination of workforce supply and funding issues. Concerns about availability of domestic assistance, gardening and home maintenance services were the most common concerns raised. One OPAN member suggested that some service providers were prioritising access to these service types to people on Home Care Packages.

Many people assessed as eligible for CHSP are experiencing significant delays in accessing services. OPAN members report older people are often frustrated that despite completing the assessment process and receiving approval for CHSP services there are limited services available.

Commonwealth Home Support Programme

OPAN members observed some providers indicate they have service availability on the My Aged Care "Find a Provider" webpage, but they are not available when an older person enquires about the service. Some of these services may have the funding to deliver the services but not the workforce.

Some providers are informing potential clients that their books are closed for new referrals, and they are not keeping wait lists. Where wait lists do exist, the wait time can range from 9 weeks to 18 months. In extreme circumstances, advocates have reported older people waiting up to three years to receive CHSP services after being placed on a wait list (refer to case example 9). Aged care advocates note the wait times appear to be significantly longer in regional, rural and remote areas.

OPAN is concerned that the current system, of approving older people for services they are unable to access, means that many older people are falling through the cracks and left without the care they need to remain living independently at home. A system needs to be introduced for monitoring unused CHSP approval codes to ensure older people are not left without essential services for extended periods of time.

Case example 9

An older person received a referral code from the Regional Assessment Service in June 2020 for domestic assistance. The RAS provided them with a list of aged care providers and encouraged them to search for a provider themselves. They found a provider who was prepared to place their name on a waitlist for domestic assistance, but there has been no communication from the provider about their status on the waitlist.

The older person noted that since being placed on the wait list over two years ago, their needs have increased and while they were now receiving a range of other services, they had still not been able to access domestic assistance. The older person was seeking aged care advocacy support because there were no navigator services in their area.

Commonwealth Home Support Programme

Communication

Throughout the year, older people reported that they often felt they were not listened to by their service provider. Advocates were involved in numerous cases where an older person had concerns and made multiple attempts to address these concerns with their provider with no success. This lack of engagement often continued until an advocate intervened.

OPAN members have noted poor communication typically occurs during changes in an older person's care services. This includes continual changes in the older person's support workers and service dates and times (refer to case example 10). It can also include unexpected service cancellations, which are never rescheduled. There have been many instances of older people being unable to reach their providers via phone. Older people report they leave a message, but these are often not acknowledged or returned.

OPAN members observed an increase in cases of this nature following the July 2022 changes to the Social, Community, Home Care and Disability Services (SCHADS) Industry Award 2020. The introduction of 2-hour minimum shift times for workers meant providers had to change staff rosters to meet the new requirements. Unfortunately, business needs did not always align with the needs of their clients and shift changes often occurred with no communication from the provider.

Staff shortages are impacting the capacity of providers to provide timely communication. OPAN members have reported some providers have said they are struggling to retain the administrative and rostering staff who would typically communicate changes with the older person. Advocates have played an important role in supporting older people to address communication concerns and in doing so addressing underlying concerns relating to the quality of their CHSP care and services.

Case example 10

An older person requested advocacy support because they were experiencing frequent changes in staff, and regular service cancellations and their CHSP provider had not provided timely communication about these changes.

An advocate supported the older person to raise these issues at a meeting with their provider. The provider acknowledged there had been a decline in the quality of services due to a lack of staffing and provided reassurance that they were putting strategies in place for the onboarding of new staff members. When the advocate followed up with the older person a few weeks later, they reported a marked improvement in communication from the provider.

Commonwealth Home Support Programme

Choice and decision-making

Many CHSP cases relating to choice and decision-making involved an older person being unhappy with their CHSP provider, but feeling they had no alternative options available. This lack of choice was most apparent in rural and remote locations, and in circumstances where the older person was receiving services in high demand including domestic assistance and home maintenance. In many of these cases, the older person had tried to discuss their quality-of-care concerns with the provider but did not have their concerns acknowledged or responded to (refer to case example 11).

Choice and decision-making concerns were also commonly raised by older people who felt they had little control over when they received their services and who delivered their services. Many older people expressed a desire to have a consistent team of support workers coming into their homes. With consistent workers, trust can be built, and workers become familiar with an older person's care needs and preferences. OPAN members report that staff shortages are affecting the reliability of regular service provision, and older people are becoming increasingly frustrated by inconsistent workers and service times.

OPAN members also observed that several choice and decision-making issues were raised in response to changes introduced to the SCHADS Industry Award 2020. Advocates were involved in several cases where CHSP providers insisted that the older person must accept a 2-hour block of care. In many of these circumstances, the older person did not require a 2-hour block of care, and the block would result in other care needs not being met. Changes to the SCHADS Industry Award 2020 also saw providers introducing increased fees for CHSP services. Some older people felt they had little option but to accept the increase in fees.

One OPAN member reported a provider was advising their clients that if they were not happy with the fee increases, then they could find another provider. With scarce CHSP service availability, many older people did not have the option to choose another provider and felt forced to accept changes in both service times and fees.

Throughout the reporting period, advocates also supported numerous older people to make informed choices about their care. Several older people receiving CHSP services sought advocacy support because they felt pressured by either their provider or My Aged Care to transition to a Home Care Package. In these circumstances, advocates provided information to support the older person in understanding the differences between the two programs and to weigh up how the change may impact their care needs (refer to case example 12). OPAN members' Financial Advocacy Officers were also active in providing information on the differences in fees and charges across the two programs.

Commonwealth Home Support Programme

Case example 11

An older person living in a remote location was unhappy with their CHSP provider. The provider did not offer a sufficient range of services; the quality of the services was poor, service times were always changing, and the provider regularly charged fees for services that were not delivered. The older person submitted a written complaint to the provider after their telephone messages were ignored. This eventually resulted in a face-to-face meeting between the older person and the provider. Verbal apologies were issued, and the older person was told that the provider would get to the bottom of the quality and timing issues and provide them with answers. The provider never got back to the older person.

The older person decided to terminate services due to the provider's failure to provide quality service and to address complaints raised. With no alternative providers available in this remote community, the older person has sought support privately and had to purchase their own mobility equipment.

Case example 12

An older person sought support to understand their rights in choosing an aged care service type. The older person received CHSP services across multiple providers. Their services included meals, transport, personal care, physiotherapy and podiatry. The older person had been approved for a Home Care Package but had declined the package. The Home Care Package approval was reactivated late in 2022 but the older person was not aware reactivation had occurred until they received a letter advising that the Home Care Package approval must be actioned by a certain date. The letter advised the older person that they would be better supported by a Home Care Package, but the older person felt unsure about what to do.

An advocate discussed the current needs of the older person and fees and charges associated with a Home Care Package. The older person said that they were very happy with the workers and services provided through CHSP and decided to decline the Home Care Package. The advocate supported the older person to contact My Aged Care and confirm their preference for continued services through CHSP and that they would reactivate the Home Care Package approval in future if needed.

Home Care Packages

In 2022–23, 55 per cent of all aged care advocacy cases related to Home Care Package issues. Concerns relating to care delivery accounted for half of all Home Care Package cases. Communication, care planning, choice and decision-making were the most common care delivery concerns raised.

Aged care advocacy support was also sought to address financial issues in 21 per cent of all Home Care Package cases.

A significant proportion (26 per cent) of Home Care Package cases involved an issue with care access. Most of these cases (51 per cent) included requests for support to find, change or engage with Home Care Package providers. Support to change providers was very commonly requested by older people who were frustrated by unresolved issues relating to their care delivery and Home Care Package costs.

Communication

Communication was the top presenting advocacy issue for Home Care Packages in 2022–23. Communication presented in 29 per cent of Home Care Package care delivery cases. The Aged Care Quality and Safety Commission's most recent Sector Performance Report (January–March 2023) revealed similar results, with lack of consultation or communication identified as the most common Home Care Package complaint.

OPAN members reported that communication issues typically involved a breakdown of communication between the Home Care Package provider and the older person (refer to case example 13). This breakdown often presents as the provider not:

- returning the older person's phone calls
- contacting the older person when there has been a change to their service time or scheduled worker
- listening or responding to the older person's expressed needs
- following through on actions they had agreed to with the older person
- communicating or consulting the older person on changes to their care plan, home care agreements and fees and charges in a clear and transparent manner.

Home Care Packages

Aged care advocates also reported on a couple of cases where communication issues were associated with providers utilising care coordinators based overseas. In these circumstances, older people reported challenges communicating across different time zones and expressed concerns about the lack of face-to-face communication (especially for care planning purposes). One OPAN member reported similar concerns about providers of self-managed Home Care Packages, noting that these providers are often located interstate and have limited involvement or face-to-face engagement with their clients, particularly when the client lives in a rural or remote location.

OPAN members reported that a breakdown in communication from providers can often cause distress for the older person involved (refer to case example 14). Advocates have observed that older people have been particularly distressed when they have not been able to communicate with their providers about unmet care needs, increased fees and charges or unexpected Home Care Package debts. OPAN members are concerned that, in many cases, providers appear to ignore communication attempts from their clients until the older person engages an advocate or the Aged Care Quality and Safety Commission.

Workforce shortages and high rates of staff turnover are contributing to communication issues with providers. OPAN has observed that some advocacy cases relating to communication involve changes in care coordinators and an absence of adequate handover between the new and outgoing care coordinators.

Case example 13

An older person on a Level 3 Home Care Package sought aged care advocacy support to address concerns with their provider. The older person reported that their services were erratic, with scheduled services cancelled or changed on a regular basis. The older person had tried to call the provider about their concerns several times, however, the calls mostly went unanswered. The provider rarely responded to messages requesting they return the older person's calls. When the provider did engage, the older person felt that their concerns were not listened to or taken seriously. On one occasion, the older person organised and paid for private cleaners because their cleaning service was cancelled without notification. They had also engaged a private gardener because they were advised there was a ten week wait for gardening services. The older person was also concerned that they were being charged a care management fee, despite the lack of service provision and lack of communication with the care coordinator. The advocate contacted the care coordinator and discussed the older person's concerns. Subsequently, the older person received a call and was advised a cleaner would attend on a regular basis and gardening services would commence shortly. The care coordinator also apologised for the lack of communication. The older person was happy with the outcome but expressed concern the provider may revert to 'their old ways' and if that happened, they would consider changing providers.

Home Care Packages

Case example 14

An older person on a Level 2 Home Care Package sought aged care advocacy support as they had been unhappy with their service provider for a long time. The older person noted that communication with their provider was difficult, and they never returned their calls. The older person only received domestic assistance and when they signed up for the Home Care Package the provider agreed to have their home cleaned fortnightly by female cleaners only. Over the next few weeks, the provider continued to send male workers to do the cleaning.

Despite efforts to communicate with the provider and stress the importance of female cleaners, the provider continued to send male cleaners forcing the older person to turn them away. The older person reported the stress of trying to communicate with the provider caused increased anxiety and resulted in many weeks of sleeplessness.

Choice, decision-making and care planning

Choice, decision-making and care planning were top care delivery issues raised in relation to Home Care Packages. While these issues can present in casework as separate issues, commentary from OPAN members suggests that these issues are frequently closely aligned.

Choice and decision-making issues accounted for 22 per cent of Home Care Package care delivery cases. Some of the issues raised around choice and decision-making were related to a lack of choice when accessing services or changing providers. This type of issue appeared to be more prevalent in regional, rural and remote locations where thin markets exist. Many older people were seeking to change providers because they were unhappy with the quality of the care or service they received but felt trapped because there were no alternative options available.

OPAN members also reported the impact of aged care workforce shortages on choice. In some cases, this meant requests for preferred aged care workers could no longer be met. In other cases, individuals have not been able to request preferred service times and have instead been offered blocks of time when their service may start, for example between 10.00 AM and 2.00 PM. These large service blocks make it difficult for older people to plan their day.

Care planning issues were present in 20 per cent of cases relating to Home Care Package care delivery. OPAN members report that some providers do not actively involve older people in the development of their care plans. There are many instances where care plans are developed without any consultation or discussion with the older person or their representatives. In some circumstances, older people are asked to review and sign a care plan

Home Care Packages

without being provided adequate time to read and absorb the content of the plan. This process can be particularly challenging when an older person is asked to review the care plan on an iPad or tablet.

OPAN members have also observed that appropriate care planning is sometimes restricted by a provider's business model. Several providers conduct care plan reviews remotely with limited engagement with the older person and their environment. Advocates report there are often no allowances in care plans or Home Care Package budgets for regular ongoing assessment and planning. OPAN members have shared that some providers state that they only need to update a care plan annually. This approach does not take into consideration the change in needs many older people can experience over the course of a year.

Cases where choice, decision-making and care planning issues were closely aligned, typically related to the inclusion or exclusion of specific items or services within care plans. This issue has been ongoing for several years.

In January 2023, a revised Home Care Packages Program Operational Manual was released. The manual introduced changes to goods and services included and excluded from a Home Care Package. These changes caused anger, confusion and frustration for many older people and some expressed concern about losing their right to choice and consumer-directed care. There were many instances where changes to the manual resulted in changes to an older person's care provision. Many had been receiving excluded items through their Home Care Package for years. Some had recently been approved for an item and were bewildered when they were advised they were no longer allowed to receive it.

These care plan changes often occurred without appropriate communication or consultation with the older person. OPAN members observed that some providers appeared to be reluctant to engage in meaningful dialogue about the changes and would often just say, 'the government rules have changed.' This prevented consideration of the older person's individual needs and circumstances and discussion of alternative ways of meeting these needs.

Since the introduction of the manual, OPAN members report that some providers have been reluctant to approve requests for goods or services that are not expressly included within the manual and have not been utilising its decision-making framework to consider requests that are not expressly excluded.

Home Care Packages

The manual was designed to give providers 'information and tools to use when working with care recipients to develop a care plan that optimises health and wellbeing in accordance with their assessed ageing-related care needs, care goals and preferences.' However, OPAN members have been involved in many cases where older people have made requests for items that are supported with a letter from their general practitioner or other health professionals outlining how the item would enhance their health and wellbeing and providers would still not consider its provision. In some circumstances, the provider has been so focused on following the inclusions and exclusions guidance they have overlooked the clinical needs of the older person (refer to case example 15).

One OPAN member made the comment that the manual did not recognise the impact of ageing in relation to existing conditions as demonstrated by case example 16. Another OPAN member said the prescriptive nature of the manual and the inclusion and exclusion framework has created unintended consequences. They provided an example where an older person's Home Care Package funds were depleted unnecessarily, and it appeared that the limitations of the manual had led to inefficient use of Commonwealth funds (refer to case example 17).

Case example 15

The carer of an older person with a disability sought aged care advocacy support to secure approval for the purchase of a queen size electrical adjustable bed with their Home Care Package funds. The matter had been pending for more than 1 year despite an occupational therapist (OT) report that provided clinical justification for the purchase. The Home Care Package provider had only been willing to offer a king single bed stating that a queen size is unnecessary and would 'bring benefit to other parties'. The carer stated that they had tried to reach out to the provider multiple times but had not received a response.

The advocate connected with the provider and highlighted the importance of relying on the clinical recommendations of the OT report and if necessary, seeking an updated report or reassessment. During the advocate's conversation with the provider, they continued to bring the focus back to clinical approval of the queen size bed and pointed out that the dimensions of this proposed equipment were clearly linked to the care requirements of the older person and there was no benefit to other parties. The provider stated that the advocate had introduced 'new clinical information' which they were willing to investigate further. The advocate felt they had simply restated what was in the OT report. A renewed focus by the provider on these clinical matters led them to approve the purchase of the queen size bed. The older person was relieved and pleased with this outcome after four weeks of persistent advocacy.

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Case example 16

An older person with post-polio syndrome, sought aged care advocacy support after their request to purchase medical-grade footwear through their Home Care Package was rejected by their provider. The provider declined the request on the basis that the boots were not required due to age-related decline.

An advocate contacted the provider and noted that the older person's decline had been significant in the past couple of years because of ageing. The advocate contacted Polio Australia, various podiatrists and footwear technicians to gather sufficient evidence that polio is impacted by ageing and ageing accelerates and compounds the effects of polio symptoms. The advocate supported the older person to seek a podiatry assessment to support their request. After many months the provider advised they had reviewed the decision and they would fund the boots.

Case example 17

An older person required transport to attend a social support activity as set out in their care plan. Initially, their Home Care Package funded fuel to enable the older person to drive to the activity. This approach supported the older person to maintain their independence. Following the release of the revised Home Care Package Program Operational Manual, their provider advised the older person that fuel was excluded under the Home Care Package Program.

With the support of an advocate the older person referred to the factsheet titled Home Care Packages Program Inclusions and Exclusions – FAQs for Providers, which implied that they could access a fuel card because they lived in a rural region. However, the provider advised that they could not issue a fuel card as the factsheet also stated that a fuel card can only be considered where there is no access to taxis. As a result, $780 of the older person's Home Care Package funds were used to pay for a return trip in a taxi. The same trip would cost approximately $100 in fuel.

Home Care Packages

Financial

OPAN members provided advocacy support for 995 cases relating to Home Care Package financial issues in 2022-23. This equates to 21 per cent of all Home Care Package cases.

In the first half of the reporting period, OPAN members continued to see issues associated with the July 2022 changes to the Social, Community, Home Care and Disability Services (SCHADS) Industry Award 2020. As the reporting period progressed the focus shifted to issues relating to the aged care reforms that commenced in January 2023. These reforms introduced capped prices on care management and package management fees and removed providers' ability to charge brokerage and exit fees.

In the previous NACAP Presenting Issues Report (January 2022 to June 2022) case management fees were identified as an area of concern with many older people questioning why their fees were so high when the case management services received were so limited. Over the years, OPAN members have witnessed case management fees as high as up to 50 per cent of an individual's Home Care Package budget. OPAN therefore welcomed reforms capping care and package management fees at 20 per cent and 15 per cent of the total Home Care Package budget.

Despite the apparent benefits associated with this reform, OPAN members were involved in several advocacy cases where providers that had previously had care and package management fees well below the new caps, increased their fees significantly to meet the capped amounts, appearing to treat the upper limit as a target. One OPAN member reported a provider almost tripled their fees in response to the reform. This provider had advised their Home Care Package recipients that their fees were increasing to 'align with the government recommended caps.' OPAN members were also involved in cases where providers had removed the brokerage fees previously charged but increased their care management, package management and direct care fees. This has led to major variations in the fees older people are charged for home care services. For example, one provider may charge $45 per hour for assisted shopping, whilst another charges $95 per hour. OPAN members have also observed that even after the caps were put in place, some providers were charging the maximum capped amounts and then adding extra service fees on top of the caps. These extra service fees were typically charged when the provider had outlined a set number of hours for care and package management and delivered services beyond this set time. In some instances, the older person required additional care management time to address unresolved complaints. OPAN members suggest more needs to be done to regulate home care packaging pricing.

Home Care Packages

OPAN members observed that many older people experienced increased care costs associated with the combined impacts of changes to the SCHADS Industry Award 2020 and the introduction of care and package management fee caps. As a result, OPAN members have been involved in an increasing number of cases where older people with high needs are running out of Home Care Package funds to cover their basic care and support needs. There have been many instances where older people have had to pay out of pocket to maintain the level of services they require. OPAN members have observed how rising costs of service provision have impacted the mental health of some older people. Some older people have shared with advocates that they are having to offset rising Home Care Package costs by forgoing required medications, doctors' visits and food items. Many are anxious about their ability to remain living independently in their own home.

Concerns associated with Home Care Package invoices and statements continued to be an area of concern in this reporting period. Issues with invoices and statements were present in 21 per cent of cases relating to Home Care Package finances. Issues raised in this area were typically related to budgets and statements not being clear and accurate. OPAN members have heard from older people that they want simplified, easy to read and well categorised statements. They also want timely access to statements. OPAN members have been involved in cases where some older people have not received a financial statement for up to two years and are unaware of the amount of funds that are available to them.

Errors and overcharges were present in 17 per cent of all Home Care Package financial cases. Most cases involving financial errors and overcharging involved invoicing and accounting errors, fees and charges for services that were not received, fees that did not reflect amounts outlined in a Home Care Package service agreement and invoices where parts of the budget were unaccounted for including income from supplements (refer to case examples 18 and 19). OPAN Financial Advocacy Officers (FAOs) reported there were many instances where providers were simply not managing budgets effectively and had allowed Home Care Package budgets to run at a deficit for significant periods of time. Several older people expressed disappointment that their provider had allowed overspending to occur and had not brought it to their attention sooner.

Home Care Packages

There were many instances where providers suggested that the older person was responsible for repaying accumulated debts despite the poor management of funds by the provider. This caused distress for older people and their families. Some older people felt forced to cease services until the debts were paid off. In many cases, older people said that they no longer trusted their providers and sought advocacy support to change provider.

In some cases, debts were associated with income-tested fees. These cases typically involved the older person not being supported to understand and submit income assessments, Services Australia losing the paperwork that had been submitted, or providers not actioning updates sent by Services Australia in relation to the application of income-tested fees. All scenarios resulted in the older person being charged the default income-tested fee amount.

OPAN members have reported that the removal of exit fees has made it easier and more cost-effective for older people to change providers. However, the 70-day quarantine period for the transfer of unspent funds between providers has been creating some challenges. FAOs report that this legislative requirement, introduced as part of improved payment arrangements, means that older people are having to wait too long to access their Home Care Package funds when changing providers. Many older people are disadvantaged by this process as their services are either disrupted or suspended during the 70-day transition period. Advocates are concerned that there are no exceptions to this rule even when providers agree about the need for an earlier transfer of funds. OPAN members suggest some level of lenience is required, especially in circumstances where the older person is seeking a new provider because their original provider does not have enough staff to service their needs.

OPAN members have reported that staffing shortages are impacting older people's ability to change providers and are also restricting older people from making the most of their Home Care Package. For some older people, particularly those living in rural and remote locations, there are simply not enough staff available to deliver the care they need. In these circumstances, advocates have observed that some older people are receiving limited services and accumulating significant amounts of unspent funds. Advocates have said the accumulation of excess funds can make it difficult for an older person with changing needs to access an assessment for a higher-level Home Care Package. Aged Care Assessment Teams are often reluctant to grant approval for higher-level Home Care Packages when it appears that the older person is not adequately using the funds available to them on their current Home Care Package level (refer to case example 20).

Home Care Packages

FAOs also report that the accumulation of unspent funds is being influenced by the payment of providers in arrears. OPAN members have observed some older people accumulate unspent funds for their future needs because their providers do not have sufficient cash flow to support the purchase of high-cost equipment and assistive technology items prior to payment by Services Australia. Cash flow issues associated with payments in arrears are also starting to impact the ability of older people to exercise choice and obtain value for money when accessing services. Several cases have been recorded where an allied health professional or tradesperson has refused to deliver services to an older person via their Home Care Package. Many allied health professionals and tradespersons have reported that providers will not pay their invoices until the end of the month. In some circumstances, payments have taken several months and required significant follow-up with the provider.

Case example 18

Aged care advocacy support was provided to an older person who had raised concerns about their Home Care Package being in a deficit of $7,000.

An FAO supported the older person in reviewing statements and email correspondence spanning a one year period. During this process, the FAO identified some concerns relating to the management of Home Care Package funds including invoices for services that had never been delivered.

The FAO supported the older person in writing a letter to the manager of the service outlining their findings and requesting that the debt be reversed. The provider agreed to absorb the $7,000 by waiving care management and Home Care Package management fees over an eight-month period. The older person was very pleased with this outcome.

Home Care Packages

Case example 19

A carer of an older person receiving a Home Care Package sought support to self-advocate. The carer expressed concern that the package had a debt that was growing each month. They had made numerous unsuccessful attempts to call the Home Care Package provider and address the growing debt.

An FAO arranged a home visit with the carer and supported them in reviewing the older person's Home Care Package budget and statements and providing information to assist them in their conversations with the provider. The carer identified that the older person was eligible for a dementia supplement which had not been captured on the statements for the past four months and questioned the provider about this. The provider responded by advising that an error had occurred with the funding and the older person's Home Care Package would be credited.

The carer was happy to see $5,500 refunded in the next statement. The carer stated they would monitor the statements more closely from now on.

Case example 20

An older person lived alone in a remote town 1.5 hours away from a regional centre. They could no longer walk and relied on the 2 to 3 hours a week of assistance with personal care and cleaning provided by their Level 2 Home Care Package. Over the Christmas and New Year period they were left without any services for almost a month which resulted in the accumulation of unspent Home Care Package funds. They were seeking a higher level of Home Care Package however their local Aged Care Assessment Team would not assess them for a higher level of Home Care Package due to their unspent funds. The older person explained that they had asked for more services many times but their Home Care Package provider keeps reporting they are short staffed. They have tried to find another provider who can deliver in their region but have not been successful.

An advocate supported the older person in writing a letter to their provider asking for improvements in communication and service delivery, which resulted in some small improvements. The advocate also provided support to talk to another provider about delivering the Home Care Package in the older person's region. However, this provider's staff were predominantly located in a regional centre meaning the older person's budget would be exhausted by staff travel costs rather than direct service delivery. The advocate supported the older person to request an Occupational Therapist assessment regarding home modifications that could support their care needs and effectively utilise their unspent funds. The advocate was advised that there is usually a six month wait time for OT assessments. The older person expressed frustration with the aged care system and commented that they could not believe that the system had been designed to support the elderly.

Residential aged care

In 2022–23, 30 per cent of all aged care advocacy cases related to residential aged care. Most of these cases involved issues with care delivery (51 per cent) or financial issues (18 per cent).

Issues relating to choice and decision-making and communication were the top two care delivery concerns recorded. Quality of care was recorded as the third-highest care delivery concern.

While not a top issue in the quantitative data, OPAN identified several issues in the qualitative data in relation to unsafe and inadequate quality of care. These included issues with excessive wait times for call bell responses, residents being left in soiled continence aids for hours, poor food quality, undetected dehydration, malnutrition and weight loss, a lack of clinical oversight or support for personal hygiene, issues with medication and pain management and lack of access to allied health professional care (refer to case examples 21 to 24). Quality of care concerns present in a range of care delivery categories including communication, care planning, and choice and decision-making. Workforce supply issues were regularly cited as an underlying factor influencing the quality of care.

Qualitative data from OPAN members suggests that residents and their family members are often hesitant about raising their concerns and are fearful of retribution.

Case example 21

An older person living in residential aged care reported staff had ignored call bells and told them to 'shut up' when they called out for assistance. They stated staff had been rough when assisting them to undress and called them inappropriate names.

The aged care advocate supported the older person to self-advocate at a meeting with management. The older person communicated their concerns regarding treatment by staff and raised a range of care quality issues. The older person was successful in having their concerns addressed with reassurances made and strategies put in place by management. The older person was very happy with how the meeting went and with suggestions made. The older person told the advocate they appreciated how management checked in with them regularly through the meeting and listened to their concerns.

Residential aged care

Case example 22

An older person living in residential aged care experienced multiple pressure injuries, weight loss, bruising and had an open wound on their hand. The older person's representative had attempted self-advocacy to ensure the older person's care and urgent health needs were addressed. Following an external general practitioner appointment, the older person was admitted to hospital with severe (grade 3) pressure injuries.

The representative accepted aged care advocacy support to submit a complaint to the Aged Care Quality and Safety Commission. The older person was transferred to alternative accommodation following discharge from hospital.

Case example 23

Aged care advocacy support was sought for an older person living in a residential aged care home with advanced dementia. The residential aged care home contacted the older person's family to take them to hospital for a small cut requiring stitches. On examination, the treating doctor at the hospital informed the family that it was a deep cut to the bone and that it was estimated to be at least five days old. The family spoke with the site manager and said there was some confusion as to how the injury occurred with no internal incident reports made and no reports made to the Serious Incident Response Scheme.

An aged care advocate supported the family to raise safety concerns and requested information on how the injury occurred. The advocate informed the family about how to escalate concerns and the family decided to proceed with a complaint to the Aged Care Quality and Safety Commission.

Residential aged care

Exercising choice and control allows older people the opportunity to live the life they choose.

Case example 24

An older person living in a residential aged care home sought advocacy support to address quality of care concerns. They said they had never seen a staff member clean the communal commode chair, and on one occasion it was returned to their room with another person's faeces on it. On raising this concern with staff, they wiped it off with a cloth. No gloves or cleaning products were used. They also informed the aged care advocate that they waited for hours for assistance with toileting and remained sitting in saturated continence aids during this time. The older person also said that food quality had declined stating the previous evening's dinner consisted of a hot dog.

The aged care advocate supported the older person to raise these issues with management. Management said they would ensure staff cleaned the commode chair properly between each use. In response to food and wait time concerns management encouraged the older person to raise these issues as they occurred, otherwise staff would not be aware of the need to address them. The advocate encouraged the older person to also discuss food issues during resident meetings, as other residents may have similar concerns.

Choice and decision-making

Choice and decision-making concerns presented in 22 per cent of all care delivery cases for residential aged care. OPAN members reported that these cases often involved the providers making decisions on behalf of an older person or prioritising the decisions of family members over the views and preferences of the older person. In many cases, older people were simply not consulted or included in decisions relating to their care. OPAN members noted this approach applied regardless of whether an older person was experiencing decision-making ability issues. It is important that residential aged care providers understand that exercising choice and control allows older people the opportunity to live the life they choose.

Cases relating to choice and decision-making were often closely aligned with dignity of risk issues. In these cases, the older person's right to exercise choice was often denied due to the perceived risk associated with a decision. OPAN members report that an older person's right to take risks was often perceived as conflicting with the provider's responsibility to maintain a duty of care. Many of the cases in this area have involved an older person wishing to leave residential aged care and visit their community for social outings or to shop (refer to case example 25). Some older people expressed that being able to leave their residential aged care home helped them feel a sense of independence and allowed them to reclaim a part of the life they had before entering residential aged care. OPAN notes that, as with all adults, older people have the right to make decisions about the care and services they receive and the risks they are willing to take. Aged care advocates are often successful in supporting older people to discuss their right to take risks with their providers and explore strategies that support the older person to do this while also addressing the provider's duty of care concerns.

Residential aged care

Case example 25

An older person was admitted into residential aged care three years ago after a series of falls. They sought the support of an advocate because they felt every aspect of their life was being controlled by the residential aged care provider, and they wanted to make some choices of their own. They said they would like to be able to get a taxi to the local shopping centre and to walk in the garden alone when they wanted to. They explained that they recently received a diagnosis of very early stages of dementia and since then the provider had not allowed them to leave the residential aged care home at all. The older person's family member was their appointed substitute decision-maker and wanted to support them to make their own choices and exercise freedom safely.

The advocate provided information to the older person and their family member about the right to dignity of risk and supported them to self-advocate. The older person and their family member met with the chief executive officer (CEO) and manager of the residential aged care home to discuss their views and wishes. At the meeting, the older person was advised by the CEO and manager that their decision about the older person leaving the residential aged care home would not change. Further to this, a representative of the residential aged care home wrote to the family member and advised they were going to apply to the Civil and Administrative Tribunal to have her removed as a substitute decision-maker.

The older person and their family member sought aged care advocacy support to meet with the CEO and manager of the residential aged care again. At the meeting, the advocate referred to the Charter of Aged Care Rights and the older person's right to make choices that involved personal risk. The advocate also discussed the ethics of threatening to remove the family member as a substitute decision-maker and the need to educate the staff at the residential aged care home about dementia. Following the meeting the CEO apologised to the older person and their family member and a plan was developed to support the older person to safely leave the residential aged care home both for walks in the garden and to visit the shopping centre. The older person was very happy with the outcome and expressed that they felt they would not have achieved the same outcome without an advocate.

Residential aged care

Communication

Communication issues presented in 21 per cent of residential aged care cases relating to care delivery. One of the most common concerns observed by advocates has been older people and their families or representatives communicating a care need and not having this heard or actioned. As demonstrated in case examples 26 and 27 some older people feel no one is listening to them. In some cases, requests have been heard and incorporated into care plans but have not been communicated with frontline staff.

OPAN members have reported that poor communication can cause frustration and anger for the older person and their family or representatives and can lead to a breakdown of the relationship with the provider. This can impact the older person's care, and their ability to feel safe and cared for in their residential aged care home.

OPAN members have suggested that staffing and workforce issues are having a significant impact on the quality of communication between residential aged care providers, older people and their representatives. Both residents and residential aged care staff have stated that insufficient staffing levels and ongoing staff turnover are impacting the levels of care and service provided.

OPAN members have observed that staff shortages have led to the increased use of agency staff. Poor communication between providers and agency staff can contribute to quality-of-care concerns. Residents in one residential aged care home informed an advocate that agency care staff are simply not aware of their care and support requirements. Similarly, poor communication between staff on different shifts or across different areas of the service is also impacting on the quality and consistency of care received by the older person (refer to case example 28).

Residential aged care

OPAN members have also been involved in several cases where older people have faced specific barriers in communicating with staff and other residents. There have been some cases where older people have expressed difficulties in communicating with staff who do not have English as their first language. In some instances, they have raised concerns that the staff do not understand their requests. In other instances, older people have noted feeling uncomfortable when staff communicated with each other in another language while providing support to them (refer to case example 29). There were numerous cases where family members or representatives raised concerns about an older person not being able to communicate because their hearing aids had gone missing or had not received the required maintenance (refer to case example 30). In these instances, family members noted how isolating it was for the older person to not be able to hear and engage in conversation.

There have been some instances where communication has been poor following an incident such as a fall or hospital admission. These types of cases typically involved the provider not communicating important details with families or representatives in a timely manner. In some cases, providers have not provided hospital staff with the medical information required to treat the older person (refer to case example 31).

There were also some circumstances where providers were not appropriately equipped to identify factors contributing to changed behaviours and engage with the older person and their family or representatives to explore options for addressing concerns. One OPAN member shared an example where an older person was admitted to the hospital for changed behaviours and was found to have a serious health condition. It was later revealed that psychotropic medicines administered by the provider had prevented the older person from being able to communicate about the pain they were experiencing. Case example 32 is of a provider seeking hospital admission for an older person and refusing to accept them back due to changed behaviours. The provider had not communicated their concerns with the older person about their changed behaviours nor did they provide any notice regarding termination of tenure.

Residential aged care

Case example 26

An older person sought aged care advocacy support because they were frustrated and upset about the poor communication they experienced at their residential aged care home. The older person explained that they had moved into the residential aged care home three months ago and felt that no one was listening to them. They described frequent changes in staff and that they were now unsure who the manager was. They had not been invited to participate in their care planning and when they had communicated care needs and preferences with staff members, nothing was followed through.

They had requested to be assisted to shower between 7:00 AM and 9:00 AM so that they could participate in the morning exercise class. Although they had asked several staff members, they never received assistance and they felt their entire morning was wasted waiting to be showered. The older person said they felt they were having to 'conform' to the routine or function of their residential aged care home instead of being able to live their life the way they wished.

The advocate explained the Charter of Aged Care Rights and provided information about their rights in relation to the concerns they had raised. The advocate also provided the older person with some options for addressing the communication concerns. The advocate empowered the older person to self-advocate, and they arranged a meeting with the Care Manager to discuss their concerns. At this meeting, the older person expressed their concerns and was able to articulate their rights under the Charter of Aged Care Rights. They requested to be involved in future care planning processes and asked for their specific requests to be documented in their care plan. As a result, their preference for an earlier shower was accommodated and they are now able to participate in the exercise classes.

Residential aged care

Case example 27

An older person sought aged care advocacy support to address communication issues with staff at their residential aged care home. They requested assistance from staff members who frequently did not speak in a manner they understood. They felt as though each time they raised concerns they were minimised or 'swept under the rug' and this made them become extremely anxious.

They noted there were many people living with dementia in their residential aged care home and felt that staff had a 'one size fits all' approach to communicating with residents. They treated every resident as if they had dementia rather than treating each person individually. An advocate supported the older person to discuss concerns about the communication breakdown in a meeting with management at their residential aged care home.

The meeting resulted in changes to the way the staff engaged with the older person. A weekly meeting was also scheduled, so the older person had an opportunity to ask questions about their care and recovery after their weekly doctor's appointment. In the weeks following the meeting with management, the older person reported that communication had improved, and care staff had been much more respectful. They were provided with updates on their care and felt more involved and at ease with the care they were receiving.

Residential aged care

Case example 28

Aged care advocacy support was requested for an older person living in a residential aged care home, with early-stage dementia. For several months the residential aged care home had not:

- *provided the correct meals as prescribed by the dietician*
- *provided walking aids resulting in the older person having a bad fall and sustaining moderate injuries*
- *communicated changes in the older persons' care needs with staff.*

The residential aged care home had suggested on multiple occasions that the issues could be related to agency staff not following handover procedures. However, the older person's family had observed incidents spanned across several shifts and included both staff employed by the residential aged care home and agency staff. Family members had maintained records of each incident including dates and times and asked the manager to investigate the incidents.

This investigation highlighted several concerns. Both staff employed by the residential aged care home and agency staff were not following handover procedures or policies and procedures for documenting the care being delivered. As a result, no one knew if a particular service had been provided and it was regularly assumed that staff on the last shift must have delivered the service to the older person.

The investigation also revealed that the residential aged care home did not have systems in place to ensure that staff had access to information on the care needs of residents across various wings of the facility. Staff, who were assigned shifts in wings they were not familiar with, had no way of identifying the care needs of people in that wing other than word of mouth from their colleagues. Once identified management at the residential aged care home put several measures in place to address communication and handover issues.

Residential aged care

Case example 29

An older person sought aged care advocacy support after asking care staff on multiple occasions not to dry their body so roughly with a towel after a shower, as it was painful. The older person stated that the staff often do not seem to understand their requests, ignored them, and then spoke among themselves in their own language.

The advocate provided information on options for addressing their concern and the older person requested that the advocate speak with the manager but 'not make a big fuss' because they liked living there and by and large the care was very good. When the advocate raised the concerns with the manager, they agreed to address the older person's feedback on the pain they experience when being towel dried. They also stated that staff had been asked not to speak in their own language when caring for a resident, and they would address this again in an upcoming education session for staff.

Case example 30

The family of an older person living in a residential aged care home sought advocacy support after noticing that the older person was not wearing their cochlear implant hearing devices when they visited them. The older person's audiologist reported that the use of the devices had dropped significantly, and it appeared that they were worn less than eight hours per day.

The advocate provided support to raise and address this matter with management at the residential aged care home and improvements did occur. However, over time there were staff changes and use of the hearing devices declined again. The devices were not being charged correctly and as a result, the older person was reportedly experiencing a rapid decline in their health. The family was concerned as without the hearing devices the older person was extremely isolated. On one occasion when the family approached staff about the devices not being worn, they were told that the older person had lost them. When the family walked with staff to the older person's room the devices were on their bedside table in plain sight.

The advocate worked with the residential aged care home to educate staff on the importance of wearing cochlear implants and provided laminated information to staff with instructions on charging and use of the hearing devices. The case was monitored over a two month period and improvements were made with the older person's hearing device use resulting in an increase in their overall wellbeing.

Residential aged care

Case example 31

Aged care advocacy support was sought by the representative of an older person who had fallen out of a hoist while being transferred. Their representative noted that access to medical care had been delayed for over 12 hours and communication from the residential aged care home had been poor. When the older person was eventually admitted to hospital the residential aged care home failed to supply the hospital with timely access to the older person's health records.

An advocate supported the representative in setting up a meeting with the residential aged care home manager to express their care concerns and discuss processes and strategies to improve communication between all parties. At the meeting, the manager agreed to undertake an internal investigation into the barriers preventing medical information from being shared with the hospital.

Case example 32

An older person was admitted to hospital by their residential aged care home. The residential aged care home advised the older person and the hospital social worker that due to their behaviour the residential aged care home would not allow the older person to return to their residential aged care home when discharged from hospital. The older person had been ready for discharge for three weeks. An advocate was engaged to support the older person. The advocate identified that the residential aged care home had not communicated with the older person effectively and had not provided them with a letter outlining their concerns or provided any formal notice regarding their tenure at the home. The advocate contacted the residential aged care home and advised them of their security of tenure responsibilities. That afternoon the residential aged care home formally provided the older person with the required notice and outlined their reasons for providing notice to leave. The client was discharged back to the residential aged care home the next day.

The advocate supported the older person to lodge a formal complaint to the Aged Care Quality and Safety Commission. The Aged Care Quality and Safety Commission contacted the residential aged care home about the complaint and the residential aged care home began assisting the client to look for a suitable care alternative. Subsequent meetings were also held with the residential aged care home so that the older person had an opportunity to have their side of the story heard. The older person was later supported to transfer to a new residential aged care home.

Residential aged care

Residential aged care fees and charges

Older people living in residential aged care homes sought advocacy to address a range of financial issues, including transparency of fees and charges, invoicing errors, unexplained debts and increases in fees and charges. There were also several cases relating to extra service fees.

Cases relating to extra service fees often involved an older person not realising they were paying an extra service fee or not knowing what benefits they should be receiving as part of this fee. Financial Advocacy Officers (FAOs) have supported several people to try to renegotiate their extra service fees. Many were simply not using the extra services they were paying for (refer to case example 33). Advocates were involved in several cases where an older person was unable to pay for their necessities because the high care and accommodation fees for residential aged care had left them with limited funds to pay for living costs such as medical expenses. In these circumstances, aged care advocacy support was provided to apply for financial hardship.

One of the biggest residential aged care financial challenges identified by OPAN members was that older people and their representatives often found the fee structures for residential aged care complex and confusing. OPAN members observed that residential aged care providers often failed to communicate with older people about the different fees and charges associated with moving into residential aged care including basic daily care fees, means-tested care fees and their options to pay for accommodation fees. This lack of communication was most apparent in cases involving means-tested fees.

Forms for financial means assessment are lengthy and many people have difficulty understanding and completing them without support. FAOs have been involved in numerous cases where older people have not received an appropriate level of information about the assessment process for means-tested fees when they moved into residential aged care. As a result, there have been many instances where means-tested fee forms have been completed incorrectly or not completed at all. In these circumstances, Services Australia charges the default means-tested fee which is set at the maximum rate. This has resulted in many older people receiving invoices indicating accumulation of significant debts.

Residential aged care

FAOs have provided specialist information and support to many older people experiencing financial distress associated with debts for means-tested fees (refer to case example 34). In many cases, the older person has sought support from their residential aged care provider to understand and rectify the issue, but the provider just referred them to Services Australia. FAOs have observed that Services Australia was often unable to provide older people with timely responses to their questions in a way that they could understand causing further confusion and anxiety.

With the support of FAOs, issues with means-tested debts could often be rectified but the process was lengthy and distressing for the older person. OPAN recommends preventative measures be put in place to ensure these types of situations do not occur in the first place. More onus needs to be placed on providers to support older people to understand the importance of completing the means-tested fee form without errors to avoid financial implications. This will require providers to have a greater understanding of the means-tested fee system.

Case example 33

An older person sought aged care advocacy support as they were being charged $25 a day for extra services. With the support of an FAO, it was identified that the older person had never signed an agreement for extra services. A refund was negotiated for the 209 days they had been charged the extra services fee without agreement.

The FAO was also able to support the older person in renegotiating the extra service fee down to $9.23 per day, as they were not using most of the services offered within the fee.

Case example 34

An older person living in a residential aged care home had accrued a debt of over $80,000 due to their aged care provider not submitting their means assessment form to Services Australia when they moved in. The older person was subsequently charged the highest rate for the means-tested fee and despite the aged care advocate's intervention the client had to wait several months for Services Australia to review the case and balance the debt.

During this time, the client was paying the maximum required amount and experienced distress every month upon receiving their statement.

The advocate discussed the issue with the residential aged care provider and highlighted the need for a more proactive oversight process to prevent similar situations occurring in the future.

Flexible care

Flexible care is offered through Multi-Purpose Services (MPS), the Transition Care Programme, the Short-Term Restorative Care Programme (STRC), the Innovative Care Programme, and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFAC). Flexible care services represent a very small proportion (2 per cent) of the aged care service system and OPAN members have been involved in a very small number (0.6 per cent) of cases relating to flexible care.

Flexible care aged care advocacy cases have typically involved STRC and the Transition Care Programme. Only a handful of cases have involved MPS or the NASTIFAC Program. Qualitative reports from OPAN members have revealed some insights into the experiences of older people accessing and receiving services under STRC and the Transition Care Programme. However, the quantitative data is not strong enough to draw any sound conclusions about the top presenting issues in flexible care aged care advocacy casework.

Short-Term Restorative Care Programme

OPAN members supported older people with a range of issues relating to the Short-Term Restorative Care Programme (STRC) in 2022-23. There were several cases where older people sought support to understand and access STRC. Aged care advocates observed that some people experienced significant delays between being assessed and approved for STRC and the approval being accepted and actioned by a STRC provider (refer to case example 35). Aged care advocates supported some older people to access additional periods of STRC where their goals had not been met in the initial round of care (refer to case example 36). As with other aged care service types, communication issues featured in some of the STRC cases and impacted the timely resolution of care and service provision issues.

Flexible care

One older person expressed disappointment that they were not permitted to self-manage their STRC, in the same way they could manage a Home Care Package. Another person shared that out of the $11,991 in funds allocated to their 8-week STRC services, their provider would take a total of $3,717 in care and management fees. They suggested these fees were excessive and unreasonable considering the short time frame of the services and the lack of support provided to the older person during this time. This scenario raised questions about the need for caps on care and management fees for the STRC Programme.

There were a few cases where older people expressed confusion about the goods and services they could receive as part of the STRC Programme, indicating that guidance in this area was not very clear. Many of these cases related to the purchase of equipment. OPAN members observed that STRC providers appeared to be reluctant to approve the purchase of equipment, especially in circumstances where the older person would be transitioning from the STRC Programme to a Home Care Package. Case example 37 provides an example of how errors with invoicing almost prevented the purchase of equipment. These insights are worth further consideration as the STRC Programme prepares to transition to the new Support at Home program in 2025.

Case example 35

An older person had been assessed 2 months prior for services under STRC but had not received any communication from the assessor or an STRC provider about potential commencement dates.

Their aged care advocate contacted My Aged Care and the relevant Aged Care Assessment Team for further information. It was determined that STRC had been approved but the approval had not been picked up by a provider. With the support of the advocate, a provider was engaged and a case manager was scheduled to visit the older person in the coming weeks, to discuss the development of a care plan.

Flexible care

Case example 36

An older person sought aged care advocacy support because several of the goals they had identified at the commencement of their STRC services had not been achieved. At the direction of the older person, the aged care advocate communicated with the STRC provider about these concerns. The provider initially agreed to make a referral for a second period of STRC, but later advised that there were not enough goals to justify another referral.

The older person with the support of the advocate mapped out a full list of care goals, provided this information to the provider and queried their decision. The provider finally agreed there were enough identified goals and submitted the referral, which was approved by an Aged Care Assessment Team assessor immediately without issue. With advocacy support the older person transferred to another provider and was very satisfied with the service provided.

Case example 37

An older person contacted an OPAN member and shared that they felt that their STRC provider was not communicating with them effectively. There were occasions where calls to the provider were not going through at all, were ignored or were not returned in a timely manner. The older person advised that they wanted to connect with their provider and discuss if they could purchase some equipment utilising their STRC funds. The older person noted that if the purchases were approved, they would like all items to be ordered prior to the completion of their STRC services.

The aged care advocate liaised with the provider, who improved their communication by prompt and regular contact with the client via phone and email. A dispute around the availability of funds was also settled after a statement was sent to the older person and errors relating to fees and charges were resolved. This freed up additional funding and all items that the older person wanted to purchase were approved and ordered prior to the completion of their STRC services. The client advised the advocate that their input had helped them tremendously.

Flexible care

Transition Care Programme

Information and aged care advocacy support for the Transition Care Programme has continued to be primarily focused on supporting older people to understand and access the program and to address quality of care concerns.

The Transition Care Programme is designed to support older people to recover their function after a hospital stay. People are often presented with the option to access the program while still in hospital and in a vulnerable state. In some instances, people feel pressured to make a decision about accessing the Transition Care Programme without fully understanding how the program works. This pressure often comes from hospital staff, who are under pressure to relieve bed shortages.

Aged care advocates have supported older people and their families or representatives to understand the scope of the Transition Care Programme and how it interfaces with other aged care programs, including the Home Care Packages Program (refer to case example 38). Advocates have been involved in some cases where people have become fearful that accessing the Transition Care Programme in the residential aged care setting could lead to a permanent placement. Advocates have provided information to help alleviate these concerns. Case example 39 provides an example of a case where a person accepted care under the Transition Care Programme in a residential aged care home, but later decided they would prefer to receive the supports available through the program in their own home. An advocate supported the older person to action this preference after their Transition Care Programme provider flagged decision-making ability concerns and suggested the older person may not be able to return to their home.

Advocates have also provided support in cases where people have been unhappy with the level and quality of support they have received through the Transition Care Programme. It has been observed that quality of care concerns appear to be most prevalent in residential aged care settings. Quality of care concerns often relate to access to allied health professionals to support rehabilitation and restore functional independence. While restoration of function and independence is a key focus of the Transition Care Programme, it is not commonly embraced in residential aged care settings. As with other aged care service types, lack of communication between Transition Care Programme providers, older people and their families or representatives can exacerbate care and service provision issues.

Flexible care

Case example 38

A family member sought aged care advocacy support on behalf of their parent who was hospitalised after a fall and then discharged to the Transition Care Programme. The family member had also been trying to organise a Home Care Package provider for their parent, but potential providers declined these requests because the parent was receiving services under the Transition Care Programme.

An advocate explained the differences between Home Care Packages and the Transition Care Programme to the older person and their family member. The advocate also provided links to further information on the My Aged Care website. The advocate called the older person's preferred Home Care Package provider to discuss whether they would accept them on a package immediately and plan what services could commence now and what may need to be put on hold until services under the Transition Care Programme had finished.

The provider arranged a face-to-face meeting with the older person and their family member to discuss signing the agreement and developing a care plan to commence after their Transitional Care Programme supports had ended.

Case example 39

An older person receiving services under the Transition Care Programme in a residential aged care setting had expressed a desire to return home. They had talked to their provider about returning home, but the provider did not support this request and raised concerns about their decision-making ability. A capacity assessment was requested but would not be available for several weeks. The older person communicated that they wanted to be in their own environment when undertaking the capacity assessment. The older person's representative expressed concern that staff had based their concerns on the older person's presentation following surgery. The representative was also concerned for the older person's mental health if they were not permitted to return home while waiting for a capacity assessment.

An advocate provided information to the older person and their representative to facilitate self-advocacy.

The older person was able to return home with a referral to My Aged Care for an aged care assessment. The older person's previous Commonwealth Home Support Programme services were also reinstated as an interim measure.

Flexible care

Case example 40

A person called an OPAN member on behalf of a friend who was receiving services under the Transition Care Programme following a hip replacement. In discussion with an advocate, they raised concerns about the quality of care being provided to their friend through the Transition Care Programme. They shared that their friend was often left in bed and isolated in their room due to COVID-19 lockdowns and not getting the therapy required to recover. The isolation and lack of therapy appeared to have an impact on both their physical and mental health. The friend of the older person was provided with information on ways to support the older person in raising concerns with the provider.

Diverse and marginalised groups

OPAN members provided support in 5,907 cases involving older people from diverse and marginalised groups.

These groups include:

- **people from Aboriginal and Torres Strait Islander communities**
- **people from Culturally, Ethnically and Linguistically Diverse backgrounds (CEALD)**
- **older people living in rural or remote areas**
- **older people who are financially or socially disadvantaged**
- **veterans of the Australian Defence Force or an allied defence force including the widow or widower of a veteran**
- **older people who are homeless or at risk of becoming homeless**
- **Forgotten Australians (former child migrants and The Stolen Generations)**
- **older people separated from their children by forced adoption or removal**
- **older people from lesbian, gay, bisexual, trans and gender diverse or intersex communities.**

The most common issues raised across these groups related to language barriers, service access in rural and remote areas and culturally appropriate care. OPAN members also shared that there was an increasing number of enquiries relating to housing and the risk of homelessness. OPAN members have noted that cost of living pressures appears to be taking a toll on older people, especially older women living in rental accommodation.

Low supplies of public housing remain a significant issue for many older people, especially in remote and very remote areas. One OPAN member reported an older person had been waiting four years to access priority public housing. OPAN members report that access to secure and safe housing influences an older person's ability to receive home care services. Lack of suitable housing can increase the risk of older people being prematurely placed into residential aged care and or experiencing prolonged stays in hospital.

Diverse and marginalised groups

Language barriers

It is well known that the aged care system is complex and can be difficult to understand and navigate. These complexities can be exacerbated for people from CEALD backgrounds and for Aboriginal and Torres Strait Islander peoples. OPAN members have observed how language barriers can hinder older people's experiences at every stage of their aged care journey. Aged care advocates have supported older people to overcome language barriers when accessing aged care and engaging with My Aged Care and aged care assessment processes. OPAN members have reported that a broader range of translated resources, including resources developed in Aboriginal and Torres Strait Islander languages and other languages that are less common would support the uptake of aged care services among diverse and marginalised groups.

OPAN members are particularly concerned about aged care providers who are not taking the time to explore all options for effectively communicating aged care information with older people from CEALD or Aboriginal and Torres Strait Islander backgrounds. Many older people have sought aged care advocacy support because they did not understand important aged care documents such as service agreements due to language barriers. Advocates have been involved in numerous cases where older people without English proficiency have signed home care service agreements without understanding the terms and conditions written into their agreement or support plans.

There have also been many instances where older people have not been aware of their responsibilities in relation to fees and charges and have become significantly distressed when their aged care provider has informed them that they owe money (refer to case example 41). This lack of communication results in unnecessary misunderstandings.

OPAN members have reported on cases where care managers have not used interpreters or translators to engage older people from CEALD or Aboriginal and Torres Strait Islander backgrounds in important discussions about their care. With limited access to interpreters and translated materials many older people are not able to exercise their right to make informed decisions about their care. There have also been many circumstances where the care needs of individuals have been overlooked because of language and communication barriers (refer to case example 42).

Diverse and marginalised groups

OPAN members report that advocates are often engaged to support older people to overcome language barriers that occur during care delivery. Many older people from CEALD backgrounds express a preference for support workers who speak their preferred language. Advocates have been able to support some older people to find service providers that can meet this need. In some circumstances, there are simply no support workers available in the required language. In these cases, advocates have supported both older people and aged care providers to explore other strategies to overcome language and communication barriers (refer to case examples 43 and 44). In these cases, advocates have supported both older people and aged care providers to explore other strategies to overcome language and communication barriers (refer to case examples 43 and 44). Strategies to assist in identifying and having an older person's care needs addressed have included the use of prompt cards, non-verbal cues and visual pain scales.

OPAN members are concerned that many aged care providers are still not utilising free translating and interpreting services available to them when discussing care needs, fees, and service agreements. Older people from CEALD and Aboriginal and or Torres Strait Islander backgrounds are being financially, psychologically and socially impacted by this.

Case example 41

An older person from a CEALD background sought advocacy support to address concerns relating to Commonwealth Home Support Programme (CHSP) fees and charges. With the support of an interpreter, the older person explained they had never been required to pay a fee for domestic assistance, but they were now being charged $12.50 per hour. They queried this change with their CHSP provider but when the provider tried to explain the reason for the change, they did not understand. The older person shared that they felt very scared as a debt had accumulated and been passed to a debt collection agency.

An advocate contacted the service provider to enquire about the fees. The provider explained that the service contract with the older person outlined that a fee waiver was in place for the first year of service and then they would be required to start paying the hourly fee. The advocate brought to the provider's attention that language barriers had prevented the older person from clearly understanding the terms of the contract and the fees and was fearful of the debt collector. The provider expressed concern for the older person and agreed to conduct a home visit to discuss the fees and outstanding balance.

The provider met with the older person and clearly explained the charges and implemented a payment plan that was affordable for them.

Diverse and marginalised groups

Case example 42

The family member of an older person from a CEALD background sought aged care advocacy support to address concerns about language barriers in the older person's residential aged care home. The residential aged care home had not been able to provide staff that speak the same language as the older person, making communication difficult.

As a result, staff were often unable to determine the older person's pain levels, provide them with emotional support or engage them in diversion therapy. The family member has repeatedly asked the residential aged care provider to find solutions to language and communication barriers but these requests have remained unresolved.

Case example 43

Aged care advocacy support was provided to an older person from a CEALD background who is living with dementia. As the older persons' dementia progressed, they experienced a reversion to their first language. This made it difficult for care staff to communicate with the older person when delivering support with activities of daily living. The advocate worked with the aged care provider to explore communication solutions as there were no staff available to communicate in the older person's preferred language. One word prompt cards were introduced in both languages. This enabled the support workers to engage more effectively with the older person and reduced the frustration experienced by the older person.

Case example 44

An older person from a CEALD background sought aged care advocacy support because they were finding it difficult to attend appointments. Language barriers meant they were often unable to read signs and ask for directions.

The advocate supported the older person to understand the transport and social support options available and how to access these services through My Aged Care. The advocate also provided information on utilising the Translating and Interpreting Service (TIS) and other translation apps which may assist the older person in asking for directions and attending appointments.

Diverse and marginalised groups

Rural and remote communities

While the issue of aged care access has been addressed in other sections of this report it is important to highlight the experiences of older people living in remote and very remote communities where access issues are often intensified. OPAN members report that older people living in remote and very remote communities have very limited access to aged care services. In some remote areas there are no aged care providers at all and older people must either go without care or move to an area where care is more accessible. Ageing in place is not an option in many remote communities.

Workforce supply is insufficient to meet the demand for aged care in many rural and remote communities. OPAN members have noted that many providers servicing rural and remote areas operate at or near capacity and are selective about accepting new clients (refer to case example 45). Older people with high-level needs, experiencing mental health challenges or living in squalor and hoarding conditions have found it particularly difficult to source aged care providers. Staff shortages are an underlying issue with some aged care providers regularly cancelling services or only offering a reduced suite of services because they do not have the staff to fill shift vacancies. One OPAN member reported that while visiting a residential aged care home in a remote community one of the home's staff members discussed workforce shortages and shared that they had been rostered to work a 10 day roster at 10 hours a day. This raised concerns about the quality of care being provided with residents observed to be sitting in front of the TV for long periods of time.

Limited availability of staff and resources in rural and remote areas can result in inadequate care and support for older people (refer to case example 46). In many instances, experiences of inadequate care in rural and remote locations are similar to experiences of inadequate care in urban settings including poor quality of care, issues with communication and aged care provider transparency, errors with fees and charges, inconsistent staff and unexpected service cancellations. The challenge for older people in rural and remote areas is that their aged care provider may be the only aged care provider servicing their area. If care issues cannot be resolved, they do not have the option to change aged care providers as there are no other aged care providers to choose from. Thin markets in remote communities amplify the concerns of older people who fear their services will be reduced or withdrawn completely if they complain. Advocates continue to work with older people to strengthen their ability to self-advocate and understand their aged care rights including their right to complain without fear of retribution.

Diverse and marginalised groups

Case example 45

An older person living in a rural community was approved for a Level 2 Home Care Package but has been unable to engage a Home Care Package Program provider. Of the available providers in the area only one would consider accepting the older person as a client.

The registration process with this provider took considerable time due to concerns about the older person's hoarding issues and unmanaged mental health conditions. After 5 months of aged care advocacy support a Home Care Package service agreement was signed.

Case example 46

An older person living in a regional area wished to remain living in their own home. The older person had previously required one person to assist them to mobilise from their bed to their shower chair and bathroom. An updated Occupational Therapy (OT) assessment identified the need for two people to assist. Their aged care provider advised that they would not be able to accommodate two aged care staff to visit the older person in the regional town where they live. As a result, the older person had not had shower assistance for 4 weeks.

A further OT assessment recommended the purchase of an electric bed and a wheelchair so the older person could be transferred from the bed to the shower in the wheelchair. Supply issues resulted in a significant delay in obtaining both the bed and the wheelchair.

Diverse and marginalised groups

Culturally appropriate care

OPAN members have identified the provision of culturally appropriate care as a significant area of concern. This concern has predominantly been raised in relation to residential aged care and spans a range of diverse groups including people from culturally, ethnically and linguistically diverse (CEALD) backgrounds, Aboriginal and Torres Strait Islander peoples, care leavers and older people from lesbian, gay, bisexual, trans and gender diverse or intersex communities.

Advocates have been involved in a range of cases where aged care providers have not demonstrated cultural awareness or competency. There have been cases where aged care providers have ignored requests for either male or female care staff. These specific requests had been made for cultural or religious reasons or because of past trauma experiences (refer to case examples 47 and 48).

Advocates have supported older people from lesbian, gay, bisexual, trans and gender diverse or intersex communities who have shared that their identity, sexuality, relationships and cultural needs and preferences were not understood, acknowledged or respected by aged care staff. In one case an older person and their partner shared that they cancelled all formal aged care services because they did not feel safe with the aged care staff. Instead, they had been relying on their informal support networks and these networks did not always have the capacity or capability to meet their increasing care needs.

There were a few cases where concerns were raised about the ability of aged care providers to support older people to maintain their religious and spiritual practices. In one case an older person shared that they had been a religious leader during their life and had expressed a need to remain connected to the church and other cultural activities. Their residential aged care provider was unable to provide transport or social support to assist this person to maintain their religious practices.

Advocates have also been involved in cases where older people's food preferences, cultural events and rituals have not been recognised or supported. One Aboriginal resident shared with an advocate the disrespect they experienced when their residential aged care provider did not acknowledge Reconciliation Week but celebrated the Queen's birthday and the coronation of the King. They had clearly stated their preference to abstain from participating in an event associated with the monarchy but their requests were ignored and they were told the celebrations should be respected. The older person felt their residential aged care provider lacked insight into the fact that there may be historical reasons why First Nations individuals may have objections to celebrating the monarchy.

Advocates have reported on a few cases where older people and their families have been labelled aggressive for raising and following up on their cultural concerns. There have also been cases where older people have expressed a fear of retribution (refer to case example 49). OPAN members have noted that older people who previously experienced trauma within institutional settings are particularly reluctant to voice their concerns in residential aged care.

Diverse and marginalised groups

OPAN members have suggested that in some instances staff shortages are impacting the provision of culturally appropriate care. Advocates have observed that some aged care providers are promising older people from CEALD backgrounds that they have 'appropriate staff' to meet their needs when they are onboarding them to the service. These promises are often later retracted because the aged care provider is unable to find 'appropriate staff.' OPAN members have also identified the need for increased and ongoing cultural awareness training to improve the cultural competency of aged care providers. One OPAN member highlighted the need for aged care staff, including those who have recently been recruited from outside of Australia, as well as within Australia, to be trained in being culturally responsive to the needs of Aboriginal and Torres Strait Islander peoples. The continued rollout of OPAN's Planning for Diversity workshop series will help to address concerns relating to cultural competency. These workshops equip aged care providers with practical information and tools to make their services more inclusive of older people from diverse and marginalised groups.

Case example 47

The partner of an older person living in residential aged care made multiple requests for aged care staff of a specific gender to provide care to the older person. This request was made for religious reasons. Management of the residential aged care home ignored the requests and labelled the partner as aggressive. As a result, the partner felt unsafe when visiting the residential aged care home and sought aged care advocacy assistance.

A specialist CEALD advocate supported the partner at multiple case conferences with the managers of the residential aged care home and eventually their concerns were understood and resolved.

Diverse and marginalised groups

Case example 48

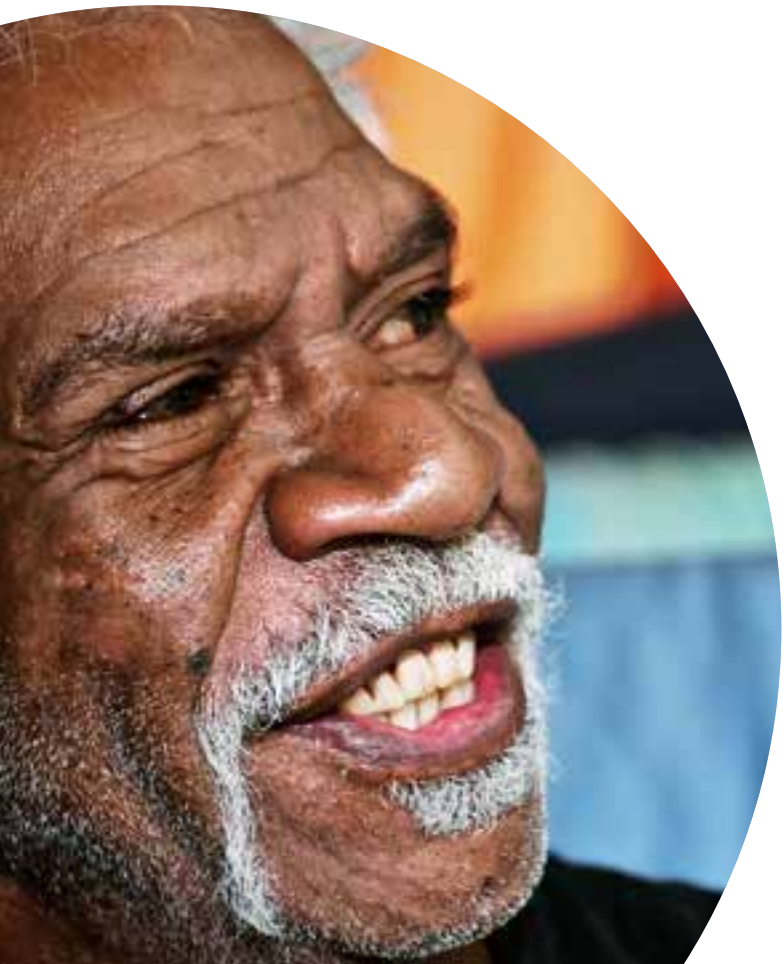
An older person seeking aged care advocacy support reported that aged care staff were ignoring their cultural requests during bathing and personal care sessions. The older person and their representative had tried on many occasions to address this issue with the management of the residential aged care home.

The management had promised that staff would be retrained to assist the older person in a more culturally sensitive manner, but no changes were made.

Case example 49

An older Aboriginal person sought aged care advocacy support to address concerns about their residential aged care home. Their concerns included staff not being trained in cultural awareness and as a result, they did not feel culturally safe. The older person told their advocate "I am absolutely terrified that staff would make my life hell" for bringing in an advocate. They shared that they had made a complaint in the past, and believed that staff at the residential aged care home had retaliated by not providing them with their prescribed medication until sometime after it was due. The older person advised that they had raised their cultural concerns with management recently and were informed that if they did not like how they were being treated they could leave.

An advocate suggested that the older person document neglectful behaviours by staff in a diary. The advocate contacted the manager regarding the concerns the older person had documented. When the advocate raised the concerns with the manager they dismissed and disregarded them. The advocate assisted the older person in making a formal complaint to the Aged Care Quality and Safety Commission. The advocate also supported them in developing a safety plan and identifying transfer options to other suitable residential aged care providers.



Abuse of older people

OPAN members were involved in 2,802 information provision and advocacy cases relating to abuse of older people in 2022-23. Financial abuse, psychological and emotional abuse, family conflict and the misuse of substitute decision-making[6] powers were the top issues presenting in abuse cases. These issues were often closely intertwined. OPAN members report that psychological and emotional abuse were often closely linked to other types of abuse particularly financial abuse.

Misuse of substitute decision-making powers

Qualitative reports from OPAN members indicate there was particular concern relating to the misuse of substitute decision-making powers. It was noted that individuals engaged as substitute decision-makers were often not aware of the responsibilities associated with their role, with many making decisions based on their own interests, or what they considered to be the best interest of the older person. OPAN notes the key to being a good substitute decision-maker is adopting a human rights focus, keeping the older person informed and supporting them to participate in decision-making according to their wishes and preferences.

OPAN members were involved in multiple cases where family members or friends acting as substitute decision-makers restricted an older person's access to social outings, family visits and in some instances medical appointments. Many of these cases occurred within a residential aged care setting and unfortunately on too many occasions aged care providers accepted the word of people claiming to be substitute decision-makers without sighting evidence that the relevant instruments [7] were in effect. As a result, some providers were taking direction from and accepting the decisions of individuals that had limited or no substitute decision-making powers at all. The case examples provided below present three examples from three different states and territories to highlight the breadth of this issue (refer to case examples 50 to 52).

OPAN members frequently observe older people being misheard, misrepresented and overlooked by aged care service providers in their rights and capabilities to make their own decisions. It has been suggested that factors influencing this practice may include:

- lack of knowledge about the role and enactment of substitute decision-making powers and human rights among aged care staff and the general public
- the convenience associated with consulting a substitute decision-maker compared to the more time-intensive process of supporting the older person to engage in the decision-making process
- ageist assumptions adopted by both substitute decision-makers and aged care providers.

[6] A substitute decision-maker is a person permitted under the law to make decisions on behalf of someone who does not have decision-making ability. Depending on the state or territory, a substitute decision-maker may be called an enduring guardian, an attorney, an agent, a person responsible or a decision-maker.

[7] Substitute decision-making instruments are legal documents where an individual authorises another person to conduct their financial or personal affairs on their behalf. Instruments can be both time-limited and enduring.

Abuse of older people

OPAN suggests that the understanding and implementation of supported decision-making within aged care services has been limited and is not applied in everyday aged care practice. OPAN developed a Making Decisions Factsheet to assist aged care providers in understanding how they can better support older people to make decisions even when there is a substitute decision-maker in place. This is a good first step however more needs to be done in this area as the aged care sector prepares for the introduction of the new rights-based Aged Care Act. Without appropriate intervention, there will continue to be issues around supported and substitute decision-making. Supported decision-making is a key enabler of rights-based aged care.

Case example 53 demonstrates how an older person, with access to aged care advocacy, can be supported to exercise their decision-making rights while at the same time addressing safety concerns raised by substitute decision-makers and residential aged care homes.

Case example 50

An older person was placed in residential respite care by their family member with the view that the placement would become permanent. The older person did not want to stay in residential aged care and expressed their preference to return to their home. The family member claimed to be the older person's appointed substitute decision-maker however the residential aged care provider had not sighted evidence confirming the older person lacked decision-making ability and their substitute decision-making instruments had been enacted. The provider would not allow the older person to leave the residential aged care home for appointments or social activities at the instruction of the family member. An aged care advocate met with the manager of the residential aged care home and explained that the substitute decision-making instrument was not active, as there had been no capacity assessment to determine whether the older person lacked decision-making ability. The advocate also noted that substitute decision-makers appointed for personal matters are not responsible for making financial decisions and a substitute decision-maker should not restrict access to community or social activities unless it is specifically stated in the instrument. The manager said they would reach out to their legal team for advice and may consider day trips for the client. The advocate also noted that the family member had not delivered the older person's hearing aids or glasses to the residential aged care home and the manager must address this to ensure that the older person was treated at their upcoming capacity assessment.

Abuse of older people

Case example 51

An older person had been placed in residential respite care by a family member and was told they were not allowed to return to their home. The older person had previously registered substitute decision-making instruments however these were not in the enduring phase as there was no medical assessment indicating the person did not have decision-making ability.

While in respite care the family member had changed the locks on the older person's home, taken some of their possessions, including jewellery and bank cards, and directed the residential aged care home to not allow the older person to leave or receive any visitors. The aged care advocate engaged by the older person provided information to the management of the residential aged care home regarding the rights of the older person, and the responsibilities of the residential aged care provider when asked to take direction from another party attempting to make decisions for an older person under substitute decision-making legislation.

The residential aged care provider acknowledged they had not sighted a medical assessment indicating the person did not have the capacity to make their own decisions and subsequently reversed the decision to not allow the older person to leave respite care or have contact with their friends. The family member was advised of the situation and returned the older person's house keys, jewellery and bank cards.

Case example 52

An older person experiencing moderate dementia was referred to aged care advocacy by their partner. The older person explained that they had previously lived in a residential aged care home in the town where they had lived with their partner. They reported that they had many friends at that residential aged care home and they also received visitors from family and friends that lived locally. The older person explained that a family member who had been estranged for a significant period reconnected with them a couple of years ago and claimed to be the older person's substitute decision-maker. The family member moved the older person to a residential aged care home in the town where they lived which was a significant distance from where the older person previously lived, and instructed the new residential aged care provider that the older person is not allowed to receive visits or phone calls from friends, other family members or the older person's partner. The family member also restricted the provider from supporting the older person to attend outings organised by the residential aged care home. The older person informed the aged care advocate that they were afraid of their family member and furious with their authoritarian behaviour.

The advocate identified that the family member had not provided either of the residential aged care providers involved in the case with documentation confirming that they were the substitute decision-maker. Both residential aged care providers took direction from the family member without sighting any evidence that they were the substitute decision-maker. This allowed the family member to move the older person, despite protests from the older person.

Prior to the older person engaging the support of an advocate the family member had applied for guardianship and administration via the relevant Civil and Administrative Tribunal (CAT). With no advocate at the CAT hearing to support the older person, the family member was granted administration (financial decision-making) for several years. The CAT decision made no reference to previous substitute decision-making arrangements suggesting that none were recognised or presented at the CAT hearing.

The advocate educated the provider about the need to sight relevant documentation. They have also informed the provider about the limitations associated with the family member's financial administration role and requested that the provider does not allow the family member to act beyond this role.

Abuse of older people

Case example 53

An older person living in residential aged care sought aged care advocacy support because a family member was acting as a substitute decision-maker and was attempting to restrict the older person from engaging in social activities in the community. Following consent from the older person the aged care advocate contacted the residential aged care provider and sought information about the substitute decision-making powers that were in place. It was confirmed that the instruments in place were only provided for medical decision-making. The manager of the residential aged care home expressed concern that the older person lacked insight in relation to alcohol consumption, finances and their physical health needs when accessing the community alone.

The advocate provided the family member with general information about the substitute decision-making requirements in their state. The advocate also supported the older person to engage in discussion with their family and residential aged care provider. Together they developed a plan that ensured choice and control for the older person while also mitigating risk factors raised by the family and provider. The family's fears were alleviated, and the older person was also satisfied with the outcome.

Abuse of older people

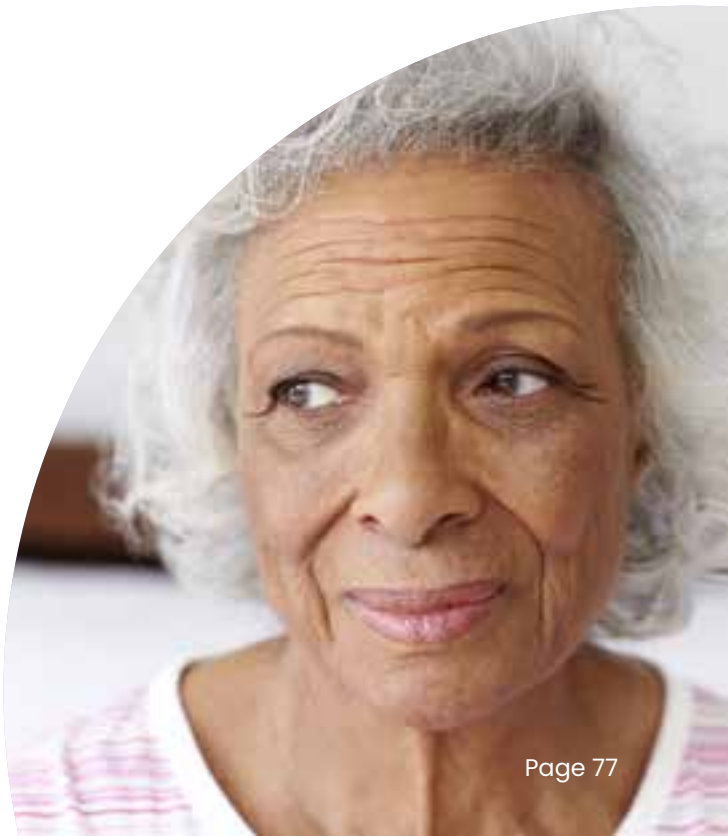
Financial abuse

Financial abuse presented as an issue in 36 per cent of cases relating to abuse of older people. OPAN members have observed that issues relating to the misuse of substitute decision-making powers are closely aligned with financial abuse. Throughout the reporting period, OPAN members were engaged in cases where substitute decision-makers acted without consent and disposed of an older person's personal possessions and/or took large sums of money for their own personal use. In some circumstances, this type of financial abuse commenced following a hospital stay or period of illness or vulnerability such as death of a spouse (refer to case example 54). OPAN members noted that older people often feel pressured by health professionals and family members to make quick decisions about appointing substitute decision-makers during these times.

There have been many cases where older people have expressed concern about potential financial abuse because their substitute decision-makers have not provided them with access to bank statements, or information on their financial affairs. For some, the first sign that financial abuse may be occurring has been when they discover that the fees at their residential aged care home have not been paid (refer to case example 55). For others, financial abuse has presented as substitute decision-makers not providing the older person with funds for small purchases such as coffee, magazines and new clothes (refer to case example 56). While these restrictions may be viewed by some as a milder form of financial abuse, they can have significant impacts on an older person's wellbeing and sense of personal agency.

In many instances, providers of residential aged care have played an active and important role in recognising financial abuse and have connected the older person with aged care advocacy support. In these circumstances, OPAN members have been able to provide information to older people about their options when experiencing financial abuse and this has often provided them with the confidence to address their concerns. In some cases, aged care advocates were able to support the older person to access a capacity assessment to confirm their decision-making ability and embark on the process of having their substitute decision-maker revoked.

Many older people experiencing financial abuse have sought support to engage directly with their bank and regain oversight of their financial affairs. On some occasions, the older person was able to recover their misappropriated funds, although this process often involves some challenges. Case example 54 demonstrates the challenges one older person living in residential care faced with addressing financial abuse in a timely manner with their bank.



Abuse of older people

Case example 54

An older person moved into residential aged care after their partner died. They appointed a family member as a substitute decision-maker for financial and personal decisions after much encouragement from that family member. The substitute decision-making documents were set up to allow financial decisions to be made immediately so the family member could provide support to the older person by signing residential aged care contracts, arranging sale of the older person's home, paying provider bills and providing the older person with access to money for living expenses.

After six months of living in residential aged care the older person contacted an OPAN member for support. The older person explained that they had been trying to obtain bank statements and financial information, but the family member kept saying that they were 'taking care of it' and the older person 'needn't worry'. The older person had never been diagnosed with a cognitive impairment and was seen by a doctor, who stated they had decision-making capacity.

An advocate connected the older person with a community legal service that assisted the client to speak with their bank, Centrelink, their residential aged care provider and the family member acting as their substitute decision-maker. With this support, the older person was able to obtain information that showed that the family member had taken thousands of dollars out of the older person's account without their permission and had been spending it on themself.

The older person decided to revoke the family member as a substitute decision-maker and is currently in discussions with their bank to identify exactly how much money was taken over the six month period. Throughout this process the older person expressed frustration with the continual wait times associated with calling their bank. They could not easily access their bank in person, so the telephone was their only option. After trying unsuccessfully to get through to the bank on the phone, they had to pay for an aged care worker to take them to a bank branch the following week. This required the older person to outlay money to pay for the aged care worker and extended the time in which the family member could continue to access and remove their funds.

Abuse of older people

Case example 55

An advocate was approached by a residential aged care manager because they were concerned that a resident's fees were not being paid and that they could not contact the family member who was the resident's substitute decision-maker for financial decisions. The manager had spoken to the resident and the resident asked to see someone about the issue. The aged care advocate met with the resident who explained that, although they had decision-making capacity, they had asked their family member to manage their bank account and bills because it was not easy for them to get to the bank. The resident said they felt embarrassed when they discovered that their residential aged care fees were not being paid.

The advocate helped the resident to get copies of recent bank statements and the resident discovered that $40,000 had been taken from their account. The advocate enlisted the support of the local community legal centre who were able to assist the resident to remove the family member as substitute decision-maker and recover some of their funds. The resident now manages their own funds, having learnt with the help of the solicitors, how to do online banking.

Case example 56

An older person in residential aged care had enacted a substitute decision-maker for financial decisions. The older person reported they were not given any spending money and their magazine subscription had been cancelled. The older person explained to the aged care advocate how upsetting it was to be unable to purchase tea or coffee from the cart when it came around or buy new clothes when needed.

The advocate supported the client with a referral to a legal service to help them explore their options for reviewing or revoking the substitute decision-maker.

Abuse of older people

Family conflict

Family conflict presented as a sub-issue in 31 per cent of cases relating to the abuse of older people. Reports from OPAN members suggest that family conflict most often involved adult children. Family conflict presented in a range of different circumstances many of which were highly distressing for the older person. In some instances, conflict occurred between family members when there was a disagreement about the aged care needs of the older person. On other occasions, family conflict involved one family member accusing another of neglecting the care of the older person.

There were many cases where conflict ensued after a family member placed an older person in residential care against their wishes. One OPAN member shared that an older person had reported that his family had 'dropped him' off at the residential aged care home and told him he could not return home. This was highly distressing for him as he was concerned for the future of his home and pets. OPAN members have observed that this often transpires after a hospital admission. In many instances, the older person is under the impression that they are going into residential care for a short period of respite care, and later find out they have been placed on a permanent basis.

In some abuse cases, conflict occurred between the older person's family members and their appointed substitute decision-maker. In some of these cases, family members have accused the substitute decision-makers of poor decision-making or abuse and in other cases, the substitute decision-makers have attempted to restrict family members and friends from visiting and providing support to the older person (refer to case example 57). OPAN members have also been involved in multiple cases where family members (not appointed as substitute decision-makers) have attempted to override the decisions of the older person. This scenario often leads to conflict within the relationship between the older person and the family member particularly when the older person stands up for their right to make decisions about their own life. Case example 58 demonstrates how older people, when equipped with information about their rights, can work with their aged care provider to regain control of decisions and manage family conflict.

OPAN members report that abuse of older people appears to be increasing due to the current economic climate and associated housing and rental shortages. Advocates have been involved in several cases where issues of housing, financial abuse and family conflict have been closely intertwined. In many of these cases the older person has allowed family members to live in their home rent-free or has transferred the title of their home to a family member on the proviso that the family member would provide care for the older person in their home (refer to case example 59 and 60). When family conflict occurs, the older person is often placed in a position where they feel unsafe in their own home or are fearful that they may become homeless.

Abuse of older people

OPAN members are active in providing information and referrals to older people experiencing family conflict. Common referral pathways include community legal and family mediation services. OPAN members report that older people experiencing family conflict are often reluctant to accept referrals for support services because they are concerned about retribution, exacerbating an already volatile relationship, and the potential withdrawal of care and support from friends and family members.

OPAN members find that in these types of situations, connecting the older person with home care services can be a good preventative measure as it can ensure that the older person has regular access to people outside of the family home who can notice abuse and provide support if required. This approach also allows for alternative aged care arrangements to be established where there are concerns that a family member may withdraw care.

Case example 57

An older person contacted an OPAN member to discuss concerns about their adult children restricting their partner from visiting them while receiving palliative care in their residential aged care home. They sought support to ensure their partner had the legal right to continue to visit. The older person advised that they wanted their partner to be able to visit and provide emotional and social support, and advocate for them when they could no longer advocate for themselves. The older person shared that their adult children were opposed to the relationship and this issue had caused conflict within the family. The older person expressed that they felt unseen and unheard by their family. They wanted to have their relationship respected by their children and not be treated like 'an incompetent old person'.

The ongoing conflict was causing distress and anxiety for the older person. An advocate supported the older person to talk to their residential aged care provider and have their partner recognised as a partner in care. In exploring other potential options to address the older person's concerns it was suggested that the partner could be appointed as substitute decision-maker. While the older person was happy with this idea the partner was not. The partner did not want legal decision-making powers or the potential accusations that the family may raise if they did take on this role. The partner only wanted the right to be with the older person and support them in their palliative care.

As the case continued relationships between the family members, the older person and the partner became more tense and combative. After attempting many different avenues to address the older person's concerns the older person was supported to document their wishes in an advance care directive while they still had capacity. This helped to reduce the anxiety the older person had about having their palliative care needs met in the future.

Abuse of older people

Case example 58

An older person living in residential care sought aged care advocacy support because they felt that their lifestyle choices were being overridden by a family member. They said this was creating conflict within the broader family and was affecting their emotional wellbeing.

An advocate supported the older person to understand their rights and the older person chose to self-advocate. The older person arranged a meeting with their residential aged care provider to discuss their lifestyle goals and seek support from their provider to manage the family conflict within the residential aged care home. The residential aged care provider advised they were committed to ensuring all goals were achieved.

Case example 59

An older person contacted an OPAN member because they felt bullied by their children and were concerned that this was going to impact their living arrangements. The older person had previously owned the property where they lived, however, they had recently placed the deeds to the house in their family member's name under the proviso they would continue to live there until they died. The older person was concerned that the family member had changed their mind and they risked being evicted from their home.

The advocate listened to the older person's concerns and referred them to a family mediation service. The advocate also connected the older person with a legal service, and confirmed that the agreement was legally binding and therefore the older person could not be evicted.

Abuse of older people

Case example 60

An older person contacted an OPAN member with the encouragement of a hospital social worker. The older person was due to be discharged from hospital and there was concern about abuse being experienced in their home environment. The older person had recently had two family members move in and take over their home. They were refusing to move out and were taking advantage of the older person financially.

The older person sought information on their legal rights and expressed a desire to have the family members move out of their home and stop the financial abuse.

The advocate validated the older person's rights to be safe and content in their own home and provided them with the contact details for legal services. The advocate also provided information about how the police could assist with evicting the unwanted family members. During this process, the older person revealed that their partner had recently died and they would be returning to their home without any care in place. The advocate provided information on aged care support options available through My Aged Care. The older person expressed that they felt more empowered and knowledgeable about their options to have a safe and comfortable home life.

Conclusion

This report has drawn on both quantitative and qualitative data from over 36,000 instances of information and advocacy support to provide insights into the experiences of older people accessing and receiving government-funded aged care services.

The National Aged Care Advocacy Program (NACAP) is designed to support older people to understand and exercise their aged care rights and raise and address concerns with their aged care providers. As a result, this report shares the experiences of older people who had issues with their aged care service. It highlights the common issues that were raised via aged care advocacy and demonstrates how with access to the right information and advocacy support, these issues can often be resolved.

While this report addresses a wide range of issues, the key themes are as follows.

- **Service availability:** the supply of aged care services is often not meeting demand. This is most evident in the delivery of the Commonwealth Home Support Programme and in rural and remote areas.
- **Communication:** older people's attempts to communicate with their aged care provider are often not responded to, making it difficult to address care concerns. Options for effectively communicating with older people from CEALD or Aboriginal and Torres Strait Islander backgrounds are particularly overlooked by aged care providers.
- **Choice and decision-making:** aged care service supply issues results in many older people feeling they have no choice and control over who delivers their service, when the services are delivered, and the types of goods and services that can be delivered. In the residential aged care setting, providers often make decisions on behalf of an older person, or prioritise the decisions of family members or substitute decision-makers, over the views and preferences of the older person.
- **Fees and charges:** price increases, unclear statements and budgets, fees and charges errors and accumulated debts have continued to cause stress and confusion for many older people receiving Home Care Packages and living in residential aged care.

Workforce shortages were identified as an influencing factor for many of the key issues presented in this report. Workforce shortages have been observed across all aged care program types and appear to be most significant in rural and remote communities. Workforce shortages are contributing to issues with service availability, communication and quality of care concerns.

The case examples in this report have highlighted the importance of the NACAP. Through the NACAP, older people and their chosen representatives can access education about their aged care rights, independent information to support them to self-advocate and make informed decisions and aged care advocacy when they require support to raise and address their concerns. Access to aged care advocacy support will remain vital as the aged care system continues its journey of reform.

Acronyms

ACAT: Aged Care Assessment Team

CAT: Civil and Administrative Tribunal

CEALD: Culturally, Ethnically and Linguistically Diverse

CEO: Chief Executive Officer

CHSP: Commonwealth Home Support Programme

FAOs: Financial Advocacy Officers

MPS: Multi-purpose Service

NACAP: National Aged Care Advocacy Program

NATSIFAC: National Aboriginal and Torres Strait Islander Flexible Aged Care

OPAN: Older Persons Advocacy Network

OT: occupational therapist

RAS: Regional Assessment Service

SCHADS: Social, Community, Home Care and Disability Services

STRC: Short-Term Restorative Care Programme

OPAN Older Persons Advocacy Network

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