



Federation of Ethnic Communities' Councils of Australia

Submission to the Office of the Inspector-General of Aged Care: Review of the administration of My Aged Care

14 June 2024



FECCA pays its respects to Aboriginal and Torres Strait Islander Elders past and present and recognise the land we live and work upon was never ceded. FECCA proudly supports the Uluru Statement from the Heart.

FECCA acknowledges that our work on behalf of multicultural Australia has learnt from and been enriched by First Nations peoples and organisations. We are committed to continuing to listen, learn and support First Nations peoples in the journey to a more inclusive society.

Who we are

The Federation of Ethnic Communities' Councils of Australia (FECCA) is the national peak body representing people from multicultural communities and their organisations across Australia. Through the membership of state, territory, and regional councils and their members, we represent over 1,500 community organisations.

What we do

For over 40 years, FECCA has proudly worked alongside culturally and linguistically diverse communities, the broader Australian society and government to build a successful, productive and inclusive multicultural Australia where everyone, no matter their background or how long they have lived in this country, has the opportunity to belong and reach their full potential.

FECCA draws on the lived experience of Australia's culturally and linguistically diverse communities and the expertise of its extensive and diverse membership to develop and promote inclusive, innovative, and responsible public policy that reflects the needs and perspectives of multicultural Australia. We are committed to building a strong, innovative, and inclusive nation that harnesses its greatest strength, the diversity of its people.

Foreword

FECCA welcomes the Acting Inspector-General of Aged Care's timely review of *My Aged Care* and its effectiveness in facilitating access to aged care and support for older persons in Australia. As the interface connecting consumers and aged care service providers, *My Aged Care* is the fundamental door for an older person's entrance into the aged care system and should support them to navigate a complex landscape of services and receive appropriate care.

FECCA has long advocated for the rights of older persons from multicultural communities and their carers to culturally appropriate access to aged care services. Evidence from community consultations, and recent findings from the *EnCOMPASS: Multicultural Aged Care Connector* program, has once again reinforced the importance of navigator services that are tailored for older people from culturally and linguistically diverse (CALD) backgrounds, providing holistic, trusted and person-centred assistance.

Appropriate access to aged care services is also dependent upon the quality of an individual's initial assessment through *My Aged Care*. As we move into the implementation of changes into the assessment process, FECCA expects that the new system will be able to reflect the specific needs of culturally and linguistically diverse aged care users.

We acknowledge the support with consultations received from the Southern Migrant and Refugee Centre (SMRC), the Australian Multicultural Community Services (AMCS), the Ethnic Communities' Councils of Victoria (ECCV), and the Chinese Australian Services Society (CASS).

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Introduction

Australia's population is not only ageing but becoming more culturally and linguistically diverse, with 1 in 3 people aged over 65 years in Australia being born overseas.¹ As a recent analysis from the *Centre of Excellence in Population Research* (CEPAR) has indicated,² the demographic shifts that Australia is experiencing place unprecedented and unique challenges on the aged care system. While there must be a wider provision of quality care services for an increasing number of older Australians, there is also a need to ensure that those services are inclusive, catering for the growing population of culturally and linguistically diverse older persons in Australia.

Within cultural and linguistic diversity, there is high diversity of experiences which impact on how people relate to Australian systems and institutions, such as having arrived as a refugee, being a recent migrant, or belonging to a gender or sexual minority. Some culturally and linguistically diverse (CALD) older persons speak a language other than English at home, and have limited English language proficiency, and these groups are more likely to experience challenges to navigate the Australian institutions. Thus, whilst approaches such as language accessibility, can benefit CALD older persons more generally, it is crucial to acknowledge the distinct and differing needs of individuals from CALD backgrounds to ensure that Australian systems are fair and inclusive.

As outlined in the exposure draft of the new Aged Care Act, the aged care system in Australia is moving towards a person-centred, rights-based approach.³ Nonetheless, whether an individual is empowered to make informed choices, access suitable care and fully exercise their rights is not only determined by their individual capability and resilience, but also by the social, familial, cultural, and religious networks they can access.⁴ For many older people from CALD backgrounds who are navigating a system in a different culture and language to their own, those social supports become even more critical.

Between 2021 and 2023, FECCA and 23 organisations delivered the *EnCOMPASS: Multicultural Aged Care Connector* program across Australia. With funding from the Department of Health and Aged Care, the EnCOMPASS program focused on embedding support workers - EnCOMPASS Connectors – within local communities to provide one-on-one support to older people of CALD backgrounds, their carers and families, through a strengths-based, no-wrong-door approach. Connectors also adopted a community development approach by conducting assertive community outreach, building local networks.

The EnCOMPASS evaluation has identified numerous challenges CALD older people faced when trying to access *My Aged Care*, such as: miscommunication between the service and clients due to

¹ See Australian Institute of Health and Welfare. *Older Australians*. Web report. Last updated 28 June 2023, <https://www.aihw.gov.au/reports/older-people/older-australians/contents/population-groups-of-interest/culturally-linguistically-diverse-people>

² Chomik, R, Khan, Fatima J and Temple, J (2024). *Migration and ageing: How cultural and linguistic diversity is set to boom among older Australians*. Research brief. ARC Centre of Excellence in Population Ageing Research, <https://cepar.edu.au/resources-videos/research-briefs/migration-and-ageing>

³ See FECCA's submission to the consultation on the exposure draft of the new Aged Care Act, which includes recommendations regarding navigation and the single assessment tool: <https://fecca.org.au/wp-content/uploads/2024/05/FECCA-Aged-Care-Act-Consultation-final-version.pdf>

⁴ FECCA consultations, Chomik, Khan and Temple 2024, EnCOMPASS evaluation (unpublished).

language barriers, the use of ineffective contact methods, a lack of transparency about the process, and lengthy delays experienced by users.⁵

Many of these findings are not surprising and highlight the persistent gaps and need for careful consideration of how *My Aged Care* can better meet the parameters for culturally responsive services. The *Aged Care Diversity Framework*, and the related action plan for service providers to support CALD older people, were collaboratively designed years ago and continue to provide a sound reference for what quality in aged care services would look like.⁵ They could inform the current reforms, including those associated with access and assessment via *My Aged Care*.

Recent consultations with older people

In the process of preparing this submission, FECCA, with the support of community organisations and the Ethnic Communities' Council of Victoria, has conducted three face-to-face consultations with older people who have accessed *My Aged Care*, or their carers, in the last five years as follows:

1. Dandenong, Melbourne, VIC – supported by Southern Migrant and Refugee Centre (SMRC)
 - 10 Participants, 5 women/5 men
2. Maidstone, Melbourne, VIC – supported by Australian Multicultural Community Services (AMCS) and the Ethnic Communities' Councils of Victoria (ECCV)
 - 10 Participants, 8 women/2 men
3. Meadowbank, Sydney, NSW – supported by Chinese Australian Services Society (CASS)
 - 10 Participants
4. Online Survey – administered by FECCA and distributed by supporting organisations
 - 21 Respondents

Findings

Overall, the findings from the consultations and survey confirm that many of the challenges CALD older people have faced with *My Aged Care*, and which have been raised in various occasions by FECCA, continue to occur. Good communication is fundamental for older people to be able to understand the processes, participate in the assessment and make informed choices, yet uneven language support continues to be a barrier. Beyond language, access to social networks that are well versed in the Australian aged care system and can help people to 'advocate' for their needs is also important. Lack of knowledge of the existence of *My Aged Care*, or services such as care finders, as well as fear of interacting alone with government services, can lead people to delay seeking support, with critical consequences for health. Finally, once older people connect to *My Aged Care*, delays in assessment also present risks, especially in a context where people may have to wait for months until they can effectively receive the services they need.

Without structured information networks, people are falling through the cracks

Whilst the move towards a person-centred and rights-based approach in Australia's aged care system is positive, individuals need to be supported to understand a complex and changing system and be able to make informed choices about the care they need. The digitisation of government services allows for individuals to freely and easily access information on the internet about services

⁵ Department of Health (2019). *Actions to support older Culturally and Linguistically Diverse people A guide for aged care providers*, <https://www.health.gov.au/sites/default/files/documents/2019/12/actions-to-support-older-cald-people-a-guide-for-aged-care-providers.pdf>

they may need. However, for many older people from CALD backgrounds, a lack of English fluency or digital literacy has led them to rely on family and friends to assist them to navigate *My Aged Care*.

FECCA's recent consultations reiterated that older people from CALD backgrounds often find out about *My Aged Care* and the services available for them through their pre-existing social networks and familial networks, including cultural and ethnic clubs, hobby groups, children and wider family, or through local councils. Social networks are often the only information network they can access to find out about aged care services⁶ and other government supports:

"A lot of us who are ageing, we don't go out to find information because we don't know how to do it. We don't feel confident, we don't have much education because of the time we were born, and we didn't have those opportunities. We find out when someone we know finds out and it spreads." - Consultation Participant

With one in five older Australians experiencing social isolation⁷, an overreliance on social networks to convey crucial information about accessing aged care services is certainly concerning. Many older persons from CALD backgrounds are unaware of the services available for them, including through *My Aged Care*. At times they wait until they've reached a point of crisis to ask family or friends to help them find support: "I got to the point where I was getting so sick," an older woman shared, "my daughter was worried for me and got in contact with a friend who worked in aged care."⁸ As other participants agreed, it is typically by being "lucky enough to know the right people" – whether that be a friend, family member, or neighbour – which facilitates a connection to the *My Aged Care* system.

"I think My Aged Care has too little contact with residents. What I mean is that residents need to take the initiative to understand this service, rather than recommending this service to people in need. If my friend hadn't recommended this service to me, I wouldn't have known that there was such a service that I could apply for." – Consultation Participant

Newly arrived migrants and refugees face additional barriers to digital inclusion, with research finding humanitarian entrants to be the least digitally connected when compared to other cohorts⁹. Moreover, recently arrived migrants and refugees from a CALD background are less likely to be connected to social and cultural groups in Australia, which constitutes a further barrier to accessing information about aged care services. On the other hand, older people who have reported sound knowledge of the *My Aged Care* prior to accessing it, and have successfully navigated it without assistance, have acknowledged their computer literacy skills and strong social support networks as key to their experience. One survey respondent reported that accessing *My Aged Care* was "easy", but "only because I am computer literate."¹⁰ Individual circumstances play a key role in creating or limiting, access to *My Aged Care*.

⁶ Chomik, Khan and Temple 2024, FECCA consultations.

⁷ ARIIA (2022). *Knowledge & Implementation Hub. A review summary: Social isolation in older people*. Adelaide, SA: ARIIA.

⁸ FECCA consultations.

⁹ Australian Digital Inclusion Index (2020), 'Measuring Australia's Digital Divide: Australian Digital Inclusion Index Report', https://www.digitalinclusionindex.org.au/wp-content/uploads/2021/06/TLS_ADII_Report-2019_Final_web_.pdf

¹⁰ FECCA consultations.

“I do a lot of work with Carers Australia, and I didn’t know the service at all. I’m worried about the people who need these services and don’t know the system, how will they find it?” - FECCA Consultation Participant

Case Study 1.1 Hobby Groups Are Filling the Information Gaps

An aged care service user who participated in a recent FECCA consultation shared her experience connecting members of her sewing group to My Aged Care. After first accessing My Aged Care for herself, she began to support other women around her to contact the service and arrange care assessments. While at first, she was only helping close friends, nowadays she doesn’t know many of the people she assists. She leads a sewing group of around 50 women who meet every month. This group has become their path to find out about and get into the aged care system. They then go to their friends and families and share information more widely. While proud of the contribution that she makes to her community, as a trusted person that people approach to help with accessing aged care services, she is concerned about those she cannot reach. “It shouldn’t be the case that you need to be lucky enough to find the right people – there’s a gap in the system. If you don’t know the right people, it’s a catastrophe.”

Communication barriers remain

Beyond initiating the connection with *My Aged Care*, consultation participants reported facing further communication and language barriers as they proceeded with the service. Phone contact with *My Aged Care* is the most preferred and primary contact method for CALD older people, over in-person service at Services Australia or the online portal.¹¹ However, communication barriers in phone calls with *My Aged Care* have been quite common, particularly with clients who don’t speak English or have limited English proficiency. In some cases, interpreting services have been offered to address these barriers. However, interpreting services are far from an easy solution: interpreters are difficult to find, take time to arrange, and may not be available for languages and dialects that have fewer speakers¹².

“I get nervous every time I call them because I’m afraid I won’t understand what they mean.” – Consultation Participant

Some have highlighted the unfair burden that the service places on the individual to overcome communication issues, reporting that *My Aged Care* was not proactive in offering an interpreter service when there was a clear language barrier. As a consultation participant shared, “Someone told me that interpreting service is available however, when I call them, I must speak English to request an interpreter.”¹³ Another user had a negative experience with an interpreter who had provided an incorrect translation which caused feelings of disempowerment and hopelessness.¹⁴

In some cases, phone calls with *My Aged Care* have been suspended after a few minutes if there was a communication barrier. This has occurred even when the individual had attempted to contact an interpreter.

¹¹ FECCA consultations and online survey 2024

¹² FECCA consultations and online survey 2024

¹³ FECCA consultations.

¹⁴ FECCA consultations and online survey 2024

“As I do not speak English at all, I cannot call My Aged Care or use the internet by myself. I have to ask my friend to help. I tried to use the 131450-interpreting service; however, they only provide 15 minutes service for each call. It is not enough as the waiting time for My Aged Care to answer the calls is usually over 15 minutes.” - Consultation Participant

When calls are suspended or timed out, clients are often called back from a private number, which means they may miss the follow up opportunity or not respond in fear that it is a scam call.¹⁵ Participants mentioned that receiving phone calls with no warning is not only confusing, but also does not take into consideration the anxiety they have experienced, particularly if they have language needs, when answering and speaking over the phone.¹⁶

The consultations indicate varying levels of competency within *My Aged Care* to address communication barriers, leaving older persons and their carers unsupported and subject to inconsistent outcomes. There needs to be data collected through *My Aged Care* on the use of language support to ensure quality services that reflect the actual needs of CALD older persons.

Clients and stakeholders of *My Aged Care* have access to free Translating and Interpreting (TIS). FECCA has previously highlighted that, despite the availability of these resources, they remain underutilized among CALD older people and services supporting CALD older people, who often do not know that the service is available or how to access it. In responding to this knowledge gap, *My Aged Care* agents must be trained and informed on how to utilise the TIS national service, and proactively mention its availability when engaging CALD older people with language barriers. There must be training provided on how to access and work effectively with the interpreters, and proactively engage their services to meet a user’s language needs. A consistent approach to improving communication and language support throughout *My Aged Care* will ensure that older persons are confident, comfortable, and supported in navigating the service.

“Because I am not good at English, they sent me a lot of letters and cards, but I couldn't understand them. But the only good thing I thought was that when they came to my house for a face-to-face assessment, they brought an accompanying translator, which made me very satisfied.” – Consultation Participant

Beyond language: the need for cultural awareness and safety

In addition to language and communication needs, the diverse cultural backgrounds which inform the specific needs of older people must be taken into consideration throughout their experience with *My Aged Care*. Outside of language barriers, cultural expectations and norms may limit individuals’ ability to ask for the care that they need.¹⁷ For instance: During assessment, for an older person’s voice to be heard and considered, they need to be comfortable ‘advocating’ for their needs. There needs to be a greater awareness by *My Aged Care* agents of the cultural differences that may limit people’s ability to do so.

“We are a generation that take care of ourselves.” Consultation Participant

¹⁵ EnCOMPASS evaluation (unpublished)

¹⁶ EnCOMPASS evaluation (unpublished)

¹⁷ FECCA consultations.

Case Study 1.2 Community Connectors are Key

From 2021 to 2023, FECCA and 23 community organisations delivered the ‘EnCOMPASS: Multicultural Aged Care Connector’ program. Through this program, specialist support workers, called EnCOMPASS Connectors, were embedded within their local communities to provide one-on-one support to older people of CALD backgrounds in navigating the aged care system¹. The program evaluation emphasised the crucial role that Connectors played in making the My Aged Care connection work for clients – particularly through their ongoing practical and emotional support for clients who had complex social and medical needs. Connectors helped clients honestly articulate their needs, kept the assessment process moving, and provided assurance throughout unclear and inflexible interactions with My Aged Care¹. There was no following up from My Aged Care – Connectors did this for clients who would have otherwise slipped through the cracks.

Some older people may find it difficult to communicate with government agencies. Previous experiences of harmful and difficult interactions with government services may also contribute to individuals feeling unsafe and uncomfortable. An elderly Macedonian woman shared a negative interaction with Centrelink: She needed language support but was not assisted by a staff member who spoke her language. This experience caused her severe anxiety and stress and undermined her sense of safety in accessing government services. Noting other similar experiences and their effects on users, a bicultural worker shared, “going to a place where you’ve had a lot of bad experiences makes you feel very close-minded and reluctant.”¹⁸

Community connectors and bicultural workers play a crucial role in supporting CALD older people and their carers, particularly those who are more reluctant to seek help or have trouble articulating their needs. Despite their value, they have not adequately recognised within the system. While the Care Finder program was launched in 2023 to “support older Australians who might otherwise ‘fall through the cracks’ to access aged care service,”¹⁹ there is very little awareness of the program amongst CALD communities, and trust needs to be built.

FECCA has consistently called to embed and leverage the pre-existing relationships between bicultural workers and CALD older persons in the structure of the aged care system. This may be achieved by adding grant funded services which enable bicultural staff to provide community engagement and outreach, care management and navigation, which are currently provided informally under the *Commonwealth Home Support Program* (CHSP)²⁰.

Consumers need a trusted organisation to assist in navigation - it makes sense to fund service providers to support their cohorts. We as service providers know consumers intimately, they disclose their needs and preferences to us, and we understand the level of support required for each individual. - Survey Respondent

¹⁸ FECCA consultations

¹⁹ AHA (Australian Healthcare Associates) (2024). *Evaluation of the care finder program: First evaluation report*. Report to the Australian Government Department of Health and Aged Care, <https://www.health.gov.au/sites/default/files/2024-05/first-report-on-the-implementation-of-the-care-finder-program.pdf>

²⁰ FECCA (2021). *Aged Care for All. Response to the Final Report of the Royal Commission into Quality and Safety in Aged Care*, https://fecca.org.au/wp-content/uploads/2022/03/FECCA-Response-to-Final-Report-of-Royal-Commission-into-Aged-Care-Quality-and-Safety_Discussion-Paper-2.pdf

The responsibility to maintain a culturally appropriate and safe experience for CALD older persons cannot lie solely with bicultural workers and Connectors; *My Aged Care* must ensure that its service, as a whole is culturally appropriate and inclusive of all users, regardless of their linguistic or cultural backgrounds.

Once your foot is in the door, you are slowed by delays and a lack of ongoing support

Another persistent theme in FECCA's consultations with CALD older people and carers who had recently accessed *My Aged Care* were the lengthy delays they experienced at multiple stages of the process. Many reported long phone wait times, with hold times often reaching 45 minutes and users experiencing multiple, confusing, redirections between services. The process of receiving a care assessment through *My Aged Care* has been called "long and frustrating."²¹ People had waited anywhere from 2 weeks to 12 weeks to receive an assessment. One woman's assessment took 6 weeks to be completed after her initial contact with *My Aged Care*, even when she had flagged in her screening call that she had broken her back and urgently needed home care.²²

Many reach out to *My Aged Care* for assistance when they are at a breaking point and need urgent care. Users are usually not aware that they can describe their situation as a crisis and receive priority assessment. A community connector who had a friend access *My Aged Care* shared that she had attempted to call back and update the priority level of a friend's assessment, who was in a crisis state and needed urgent care. However, she was told by the services that once a case is filed, the priority level cannot be updated²³. There needs to be greater awareness for users of *My Aged Care* to know they can ask for a priority assessment if they need one. The service must inform and empower users to flag their situation at the first point of contact, so that they are not left waiting for too long in a critical condition.

Users generally felt unsupported throughout their assessment process, with a lack of checking in and communication from *My Aged Care*. Most felt frustrated at a perceived lack of action and results beyond their assessment. Consultation participants used expressions like being "very persistent", "need to chase it", "be assertive" and "agitate" to describe how they needed to act in order to receive a result. Others received "no updates" once their assessment had been completed.²⁴

No worker helped in the process of organising the assessment, I don't understand what to do. Isolated older people need a lot of help to go through the My Aged Care application and assessment.
— Survey Respondent

Overall, the process of receiving a care assessment through *My Aged Care* has been described by users as an impersonal and harsh experience where they are not seen as individuals needing care.²⁵ Some said it was "brutal" and "makes you feel empty". One user said, "it's like going through a storm to get to a rainbow," and another said, "Seeing the outcome is great but trying to get there is not."

²¹ FECCA consultations.

²² FECCA consultations.

²³ FECCA consultations

²⁴ FECCA consultations.

²⁵ FECCA consultations, EnCOMPASS Evaluation (unpublished)

Case Study 1.3 When Is It 'Too Late'?

A difficult experience with a delayed care assessment was shared at a recent consultation. A woman had helped her elderly sister access My Aged Care, and notified the staff member that, in addition to requiring home support, the client had Stage 4 breast cancer, and needed urgent and timely care. Once the assessment had been completed, they didn't hear back from My Aged Care for a long time afterward. The woman was contacted about the services and care package her sister had been allocated a month after she passed away.

Conclusion and recommendations

A lot of the discussions around the aged care reform have been technical or directed towards the challenges of implementation for Government and service providers. It is fundamental to keep in mind that ultimately, the measure of improvement in the system will be determined by how effective it will be in providing quality care for *all* older people, with dignity and respect. In the adaptation to the various changes that are occurring and will occur in the coming years, older people need to be supported with accessible communication, education about their rights and assistance to access services.

Within this context, *My Aged Care* can play a key role in helping older people to feel supported and to receive care plans that are appropriate and can enhance their quality of life. In view of Australia's increasingly culturally and linguistically diverse ageing population, cultural and language factors can no longer be considered a 'minor issue'. As the entry point to the aged care system, *My Aged Care* must ensure that all CALD older people who are eligible to accessing aged care services can also benefit from a person-centred approach that acknowledges their differentiated needs and allow them to participate in critical decisions that impact on their life and wellbeing.

For that to be achieved, **FECCA recommends** that:

1. Cultural competency training and training on how to use language support services be a requirement for *My Aged Care* agents, and the *My Aged Care* workforce adheres to the same competency standards as providers and quality assessors, with regard to training in cultural safety, anti-discrimination and trauma-informed service delivery.
2. The collaboration between *My Aged Care* and care finders is strengthened, so that the more vulnerable older people who are supported by care finders can be served timely with dignity and respect.
3. *My Aged Care* collects consistent data around language uptake and quality of language services used, particularly phone interpreting services, and actively informs users about the availability of language support services.
4. There is transparency around the screening and assessment process, with more regular communication around assessment timelines and outcomes so that people are not left waiting with no knowledge of when they might be able to access care, or serious health implications. Those who have a priority that needs to be assessed must be able to indicate that in their screening and have access to the status of their case.

5. The Government funds community-based education channels to provide regular, linguistically and culturally accessible information for CALD older people, their families and carers, on how the aged care system in Australia operates, including the *My Aged Care* functions, and their rights as users. This educational effort should build upon pre-existing community networks that CALD people already access and include face-to-face sessions in a safe environment.
6. The value of cultural connectors and bicultural workers as key supports in community be better understood within *My Aged Care*. These workers can help clients navigate the complex aged system and remove some of the burden from older people and their carers, however, their role is often not understood or under-estimated.