SUBMISSION TO THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

CONSULTATION PAPER 1

AGED CARE PROGRAM REDESIGN: SERVICES FOR THE FUTURE

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Federation of Ethnic Communities' Councils of Australia
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About FECCA

The Federation of Ethnic Communities' Councils of Australia (FECCA) is the national peak body representing Australia's culturally and linguistically diverse (CALD) communities and their organisations.

FECCA provides advocacy, develops policy and promotes issues on behalf of its constituency to Government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism to build a productive and culturally rich Australian society. FECCA's policies are developed around the concepts of empowerment and inclusion and are formulated with the common good of all Australians in mind.

FECCA has been a leading stakeholder on CALD ageing and aged care issues through committed policy and systemic advocacy. FECCA regularly undertakes consultations to inform its policy advice and to strengthen its collaborative links to communities.

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Question 1:

What are your views on the principles for a new system?

FECCA Response:

FECCA believes it is equally valuable to emphasize if not, to add the following: a) adopt a bio-psychosocial approach; b) develop an empowering ecosystem for older persons, carers and communities; and c) be guided by evidence and data.

Adopt a bio-psychosocial approach

Frailty is a global public health priority especially among the ageing as it represents the onset of risks that lead to negative health-related outcomes. In Australia, it is estimated that 4 million will be affected by frailty by 2050.[1] It is only right for the Royal Commission to highlight as core principle the need to "maximise independence, functioning and quality of life for older people."

However, conception of frailty is largely concerned about biological functioning (slow walking speed, tiredness, weakness and decreased physical activity) and assessment tools and interventions mainly focus on "chronological age-related bio-medical deteriorations".[2]

FECCA believes the aged care system must be cognizant of psychosocial domains and their critical roles in promoting recovery or maintaining physical health. Recent studies on biopsychosocial (BPS) health model define risks at older ages as: "the presence of Bio functional degeneration that can result in either cognitive (dementia), physical (illness) or impairments (limiting activities of daily living); as well as poor Psycho-emotional function and coping resulting in a lack of capacity to recover from strong psychological stresses; and inadequate Socio-interpersonal networks in the form of quantity and quality of relationships, lack of support and empowerment, and capacity to live independently."[3]

BPS approach understands that while each domain is distinct, they are inextricably linked. This is significant to older persons from culturally and linguistically diverse (CALD) communities as it recognizes their lived experience as migrants and the impact of existing inequalities to accessing services and resources in health aged care.

Older persons of multicultural backgrounds face barriers in communication. They have cultural and spiritual practices that vary from what the current aged care system offers mainstream older persons. This is further confounded among older persons of refugee backgrounds who survived traumatic life experiences such as war and famine. There is also the continuing tradition of mobilising and maintaining networks of support within families and communities among migrant groups.

Capturing older person's vulnerabilities in each BPS domain supports the principle that the aged care system must "deliver care according to individual need". The BPS approach is a holistic and comprehensive view of risks at older ages that provides more clarity in developing interventions, policy and planning.

Develop an empowering ecosystem for older persons, carers and communities

To address the multidimensional demands of older age would require the "support of effective interfaces with related systems, particularly health and disability" as the consultation paper noted.

FECCA urges the Royal Commission to accord same value and emphasis to social care and community care.

A panel of experts from countries with ageing populations reported, “Constrained social service spending may also lead directly to inefficient use of health care resources—for example, when patients are unable to be discharged from the hospital because of a lack of support available in the community.”[4]

The demand for home and community care are likely to increase over the long term as the cost of institutionalised care and long-term care rise. By 2050, it is expected that 80 percent of services will be delivered in the community.[5] It is imperative to create innovative ways to develop adaptive capability among older persons and their communities.

Programs that build and sustain the intrinsic capacity of older persons could focus on reducing health risks, enhancing capacity for self-care and removing barriers to adopt healthy lifestyles. Studies have indicated that building age-friendly physical environments and care networks at the community level are critical.[6]

Ageing well initiatives help older CALD persons and the CALD community gain knowledge, develop the motivation and build support networks to actively manage their own health and wellness outcomes. Culturally informed health literacy is important to achieving consumer-directed care.

With appropriate support, older persons from CALD communities can be empowered to make full use of the CALD aged care diversity framework action plan. There can be huge gains in building “self-efficacy” – for older persons to not only KNOW but be ABLE to access aged care services when they need them. Various studies on self-efficacy have highlighted the importance of going beyond “building awareness”. Older persons must develop the confidence to engage the system and community-based support network do have a critical role to play.

Be guided by evidence and data

FECCA supports the call to develop policy directions based on evidence both from basic science and practice. There is a need to change policy-development approaches often characterized as “evidence-free policy” and “policy-based evidence”.[7]

Evidence starts from data gathering and what is very clear is that there is a significant lack of consistent and accurate data about the use of aged care services by CALD people.

The definition of CALD used in relation to aged care in the regular Reports on Government Services (ROGS) is likely to lead to a considerable underestimation of CALD target populations, service users and complainants. Data gaps about cultural and linguistic diversity are also reflected in research into ageing, dementia and a range of other issues. Many studies have English proficiency as an inclusion requirement for participants and, as a result, the experience of a significant proportion of the Australian population is not captured.

To gain an accurate understanding of CALD older Australians’ access to, use of and experience with aged care services, consistent definitions and measures of cultural and linguistically diversity should be developed, together with consistent processes for the collection and analysis of these data. The *Review of Australian Research on Older People from CALD Backgrounds*,

commissioned by FECCA in 2015 found that there was a need for engagement with CALD people to be included in initial study designs, including the provision of interpreters and other relevant language services.[8]

Various projects or interventions have been in place that have provided positive outcomes to older persons but have ceased due to changes in policy priorities. “It is important to understand that successful projects tend to develop iteratively over time—and sometimes over a long period.”[9] The aged care system must support opportunities to share learnings—both of successes and failures—from key projects across state boundaries. For successful models, it is only logical to support scaling up.

Question 2:

How could we ensure that any redesign of the aged care system makes it simpler for older people to find and receive the care and supports that they need?

FECCA Response:

Build a community-centric integrated care ecosystem

A seamless, integrated care system is essential and the Royal Commission’s proposed aged care system model must reflect this. The system must follow where the older person is. The age-old principle of ‘form follows function’ remains a good foundation for intuitive design.

FECCA believes it is time to develop a systems approach for community-centric population health approach that will integrate aged care services, residential aged care facilities, acute care, primary care and social services.[10] It will be crucial in ensuring aged care access is simpler for older persons and especially salient among older persons from special needs groups such as those from CALD backgrounds.

Among frail older persons, care coordination is of high priority. Models of care must address their needs by embedding joint initiatives with long term care facilities; nurse-led geriatric assessment at the emergency department; geriatric assessment clinics; and home-based palliative care services.

Address social determinants of health

Older persons and their carers make aged care choices in their homes and in the community. The aged care system must adopt and support upstream interventions that will address social factors influencing health choices and behaviours. This underscores the need to invest on building geographically based care ecosystem supported by a responsive healthcare, aged care, disability, and social care teams. It is important to build trust and relationships with these systems.

As discussed in Question 1, there is a need to orient systems around intrinsic capacity by developing community initiatives that ensure access to older person-centred services that support ageing-in-place. Various projects such as community wellness centres, multicultural associations etc that offer healthy lifestyle programs, social engagement activities, health screenings are critical entry points. They help build the knowledge and capability of older persons’ and their carers to understand and engage the systems while they are well, not at the point of critical need or crisis.

Develop BPS risk assessment tool
To support a seamless, integrated care system, a risk screening tool must also be used to understand the vulnerabilities (bio-psychosocial (BPS) domains) of community-dwelling older persons and reach them before the onset of critical and limiting diseases. Such tool can help establish community-based interventions and a population level risk mitigation strategy and planning tool that is evidence-based.

According to a study, using the outcome of a BPS risk assessment tool, "vulnerable adults can be linked to care management and depending on their individual domain needs may be referred to either or all: community-based nursing and primary care (B), counselling and support services (P), and community inclusion activities (S)."[11]

Question 3:

What is the best model for delivery of the services at the entry point to the aged care system—considering the importance of the first contact that older people have with the system? This includes looking at services provided by phone and website as well as face-to-face services.

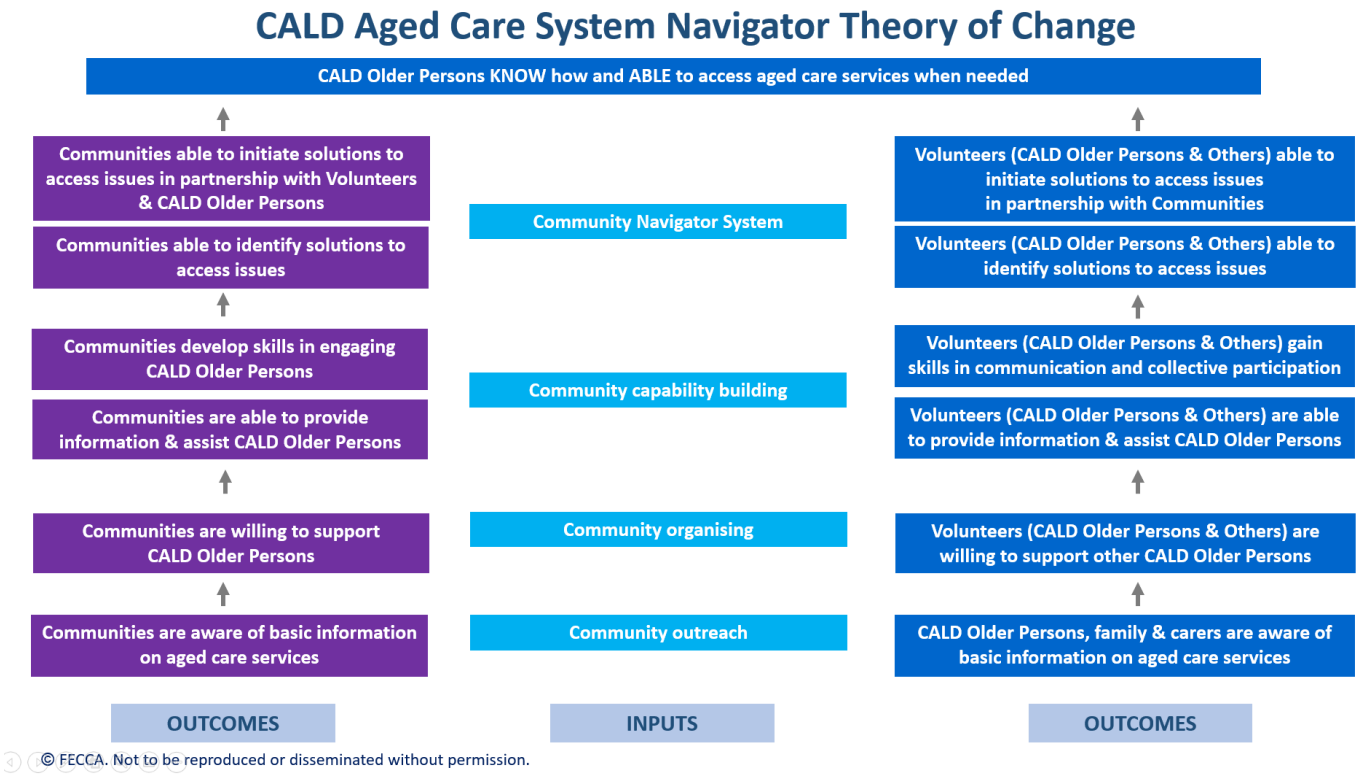
FECCA Response:
Aged Care Navigation with appropriate bilingual bicultural support and multilingual communication resources/strategies is critical in CALD communities. FECCA, as the Community of Practice Lead for CALD Navigators, has these key insights from the ongoing pilot must be seriously considered:

a. The Aged Care System Navigator must be embedded in and approached as a system;
b. Aged Care System Navigator must interface between and among the aged care, health, disability, social service and community systems;
c. Asset based community development principles must be adopted; and
d. Communities are assets and should co-design a model and system that will work for their context.

The current Navigator measure has been limited to community outreach where the outcomes are essentially focused on and limited to building awareness. It is critical to aim for "self-efficacy" – for older persons to not only KNOW but be ABLE to access aged care services. They must develop the confidence to engage the system.

Building and sustaining such capability would involve interventions that will cover 1) community outreach, to 2) community organising or coordination, if you prefer, 3) community capability building and 4) building a community navigator system.

FECCA's proposed this framework to the Department of Health:



A system for aged care navigation

The aged care system must invest in harnessing and building the capabilities of both the Navigators and community agents to become part of the "navigating system". Community organisations and volunteers who are willing to provide support must be supported to develop or enhance their capability. The multiplier effect essentially creates a care ecosystem at the community.

To amplify and sustain what has been started, a Network can be organised where community partners and volunteers can discuss gaps and assess whether assets already exist in the community to help address these gaps. A Network could also look at potential solutions and elevate them to relevant organisations.

The proposed framework is a sustainable complement to a "geographically-based care ecosystem" discussed in earlier questions. An organised community led by "agents of trust" such as faith leaders, community leaders, etc can work alongside Aged Care Navigators.

Potential of an aged care navigation system

Creating a community-based navigation system would also create valuable entry points to deliver interventions for health literacy, self-care, risk screening, dementia community support and an integrated system to navigated beyond aged care.

Question 4:

People maintain their homes and gardens, do laundry, cook meals, get themselves to appointments and attend social engagements across their whole adult lives—some people may choose to pay others to do these things—but mostly they handle them with little assistance. As people age and need support with everyday living activities, how should Government support people to meet these domestic and social needs?

Response:

FECCA would like to again, highlight that there is a considerable body of evidence globally on the positive impacts of supportive environments at home and the community in building individual older person's agency to change health-related behaviours and maintain adaptive capability.

In Australia, a recent study concludes that "the use of a complex pattern of home and community care services was associated with delayed admission to permanent residential aged care (RAC)…" [12] This highlights the importance of continuing to provide such services as Social Support Group and Sector Support and Development activities within the Commonwealth Home Support Program (CHSP).

Maintain adaptive capability

FECCA contends that CHSP can function beyond the delivery of entry level services for older people. It is a key component for sustainable community-based care systems for ageing well and aged care especially in CALD communities. With the appropriate support, CHSP has the potential to develop local solutions to local problems and support early intervention and wellness/reablement outcomes.

The current CHSP services of centre based respite, social support, transport and meals services should ideally remain block funded and not be time limited. This flexibility supports the needs of the CALD older person.

Partner with allied health services

Allied health services should also be promoted as essential in responding to various needs of older persons. Various approaches could include developing partnerships with allied health in training care staff to understand a restorative and well-being approach to care, rather than the traditional model which focuses more on a clinical model of care.

Fund case management and language services

Another area to consider is incentivising case managers to develop true person-centred case management to fully optimise the package budget.

FECCA also calls for government to fund complex case management and language services as separate services in addition to the subsidy value of a home care package. Additional TIS costs when re-negotiating, seeking advice or otherwise discussing issues relating to their Home Care Agreement, care plan and budget are currently being paid for by CALD Australians through their package of care.

Develop workforce that understands care systems
FECCA further believes that flexibility of care and support for people who are ageing and who also have a disability can be achieved by developing a pool of workers skilled with understanding both the aged care and disability sectors. This will bring a range of flexibility of care and support and will promote linkage between the two sectors.

There are several potential changes that are only useful to redress limitations of the current design. Entry-level support will have to be approached within the context of a community-based system of care to be sustainable and relevant to the overall needs of older persons.

Question 7:

How could the aged care and health systems work together to deliver care which better meets the complex health needs of older people, including dementia care as well as palliative and end of life care? What are the best models for these forms of care?

FECCA Response:
Promote later life planning
Extended family, religious beliefs and other cultural considerations often result in CALD communities paying scant attention to later life planning. Barriers to effective end of life planning include: the sensitivities that underpin losing one's decision-making ability; legal costs; trust, family conflict; lack of prior experience in country of origin; and handing over control of finances. [13]

Given these cultural barriers and sensitivities, there is a need to promote later life planning and to develop effective and culturally informed communications approaches for individual CALD communities. These services and rights need to be understood in the context of these barriers and sensitivities and accessed if desired.

FECCA recommends the development of a national CALD education strategy on issues and services relevant to planning in later life.

Support better understanding of dementia
FECCA supports initiatives of the National Ageing Research Institute (NARI) in developing a CALD dementia research framework and innovations in language support among older persons with dementia living in rural and remote communities.

Question 8:

Caring for people with diverse needs and in all parts of Australia has to be core business—not an afterthought. How should the design of the future aged care system take into account the needs of diverse groups and in regional and remote locations?

FECCA Response:

Better CALD representation

FECCA has long advocated for CALD representation at on critical Government Aged Care advisory bodies including the **Aged Care Sector Committee** and the **Aged Care Financing Authority**. Diversity indeed remains an afterthought if a third of the number of old Australians is without a voice in these key policy platforms.

National accreditation

FECCA also calls for the development, implementation and provision of a nationally accredited cultural competency program for the aged care sector. The Aged Care Quality and Safety Commission need to be well-versed in the nuances of ageing in a country that is culturally, linguistically and spiritually diverse and the associated challenges this brings, particularly for people living with dementia. The impact of the migrant /refugee journey on subsequent physical and mental health should also be considered.

FECCA highly recommends for accreditation standards to require a CALD strategy from all organisations providing aged care services. This strategy must be captured in their strategic management portfolio. Additionally, new providers applying for Approved Provider Status must demonstrate the inclusion of a CALD strategy in their organisational policies and procedures.

Recognise and develop bilingual and bicultural workers

Bilingual and bicultural workers are an important part of the workforce and their competencies should be valued and recognised by formal recognition/accreditation processes. Additionally, FECCA recommends that bilingual and bicultural workers should be appropriately remunerated for the professional deployment of their language and cultural skills.

Staff development and training around cultural competency in aged care service delivery must be mandated to be delivered on a regular basis by all service providers. This is particularly important considering the typical staff turnover within the aged care workforce. This training should provide specific attention to areas such as:

a. End of life care for culturally and linguistically diverse groups
b. Cultural attitudes and perspectives of death and dying
c. Cultural attitudes and perspectives of palliative care
d. Cultural attitudes and perspectives of dementia
e. How to deliver culturally appropriate personal care
f. How to connect with communities who may assist with providing volunteer services to benefit and enhance CALD social connectedness
g. Multi-level cultural competency training which targets boards of management, senior and middle management and quality staff as well as personal care, allied health and clinical staff
h. This training should also include an assessment feature. There also needs to be a follow up mechanism where the training is evaluated post implementation to understand whether it has made a difference to the way that care has been delivered.

Support ethno-specific services
FECCA is concerned around the viability of ethno-specific services competing in an open market and less regulated aged care landscape. Under the current highly competitive framework, many of these services find it difficult to remain trading without specific assistance and subsidies from the government. Providing incentives for generalist aged care organisations to partner with established ethno-specific community organisations where they would share in revenue streams by providing cultural intelligence in aged care service provision. Additionally, it is important to understand marketing and advertising to reach to diverse audiences.

Priotise carer support
Informal and hidden carers are a cohort of people that FECCA is most aware of in the community. Any carer group may be 'hidden'' for varying reasons but in some CALD communities may be more likely to be hidden than others. While a person's ethnicity can play a role in how carers negotiate the caring process, it needs to be placed in a broader cultural context in which other social, economic and political factors play an equally significant role. Carer support should be integral and front of mind when designing what the future of home care will look like in the Australian aged care landscape.

Create potential partnerships in rural and regional areas
Lastly, the needs of CALD ageing in rural and regional areas are becoming critical. While most attention goes to the urban areas, there are several rural areas in which CALD groups have aged in place and are now coming forward with aged care needs. This is a particularly difficult area as very few of these locations contain groups with the critical numbers to support an ethnic specific or multicultural aged care services. Therefore, consideration needs to be given to the structuring of mainstream services, issues of cultural competency and potential partnerships which could be developed to deliver aged care services to these groups.

Question 9:

What are the strengths and weaknesses of the current financing arrangements and any alternative options that exist to better prepare Australia and older Australians for the increasing cost of aged care?

FECCA Response:
Various studies have investigated the pros and cons of current aged care financing framework in Australia and have explored alternative models internationally.[14]

FECCA believes the main principle in redesigning aged care financing is to make sure it meets the needs of the ageing population. Funding mechanisms must support an integrated system where barriers to collaboration are reduced, compensation for treatment complex cases are met, and incentivize acute and institutionalised care to work with community providers and stakeholders.[15]

Consider life course impacts
Funding mechanisms should also put in critical consideration the understanding of how life course impacts on women's capacity to build old age income and financial support. Single women who do not own their homes are especially vulnerable under current frameworks. This is a global phenomenon that merits serious analysis and response as any aged care financing framework would need to factor the cost of informal care, a role often borne by women.[16]

Again, this further supports the need for a system approach and for investments in upstream interventions that will mainstream planning for longevity risks. Financial planning needs to be introduced at earlier life stages. Primary care and self-care are also essential to manage costs to the healthcare system.

Question 10:

How would the community be assured that the services provided under this model are delivered to a high standard of quality and safety?

FECCA Response:

The processes to accredit and monitor aged care services generally do not cater adequately for the needs of ageing Australians from a culturally and linguistically diverse background. FECCA recommends the following:

a. Accreditation must be performed by officers of the Aged Care Quality and Safety Commission who have undergone targeted training to assess the outcomes of care for CALD older people.
b. There must be a representation of cultural diversity within the staffing cohort of the Aged Care Quality and Safety Commission.
c. When interviewing CALD older people during the accreditation process, the Aged Care Quality and Safety Commission should commit to utilising face to face interpreting and translating services to ensure that the older persons from CALD backgrounds fully understand the questions being asked.
d. Interview questions by the Aged Care Quality and Safety Commission need to be open ended and not closed resulting in a ‘’yes’’ or ‘’no’’ response.
e. Utilisation of interpreter and translating services must be mandatory to assist aged care providers to deliver the accreditation standards in a manner which fully considers the needs of CALD older people.
f. A low risk non-compliance judgement to care recipients where their cultural needs are not being met must not be acceptable. The absence of culturally appropriate aged care is considered a high risk to a CALD older person’s health and wellbeing.

FECCA also urges that the regulatory processes consider the challenges faced by CALD older people and adopt the recommendations to monitor and assess service outcomes. For example:

- Can the service demonstrate what proportion of their customers are from a CALD backgrounds?
- Does the service collect, produce and make available for public knowledge CALD specific data?
- What strategies are in place to cater for CALD specific needs in the area?
- How does the service engage and communicate with CALD residents, especially those residents not proficient in the English language?
- Does the service conduct dedicated programs for CALD residents?
- How do they draw meaningful feedback from their CALD residents?
- What is the make-up of the workforce? Does it reflect the diversity of their resident cohort?
- Does the service employ bilingual bicultural staff?
- Does the service consult and plan with other organisations in order to deliver effective services and programs for CALD residents? If so, how are they demonstrating this?

- How is the service conducting their professional development regarding CALD cultural capability? It needs to demonstrate that practical and engaged training is helping to achieve heightened outcomes for residents and should be assessed and reviewed periodically.
- Is diversity management reflected in the values and mission of the organisation, as well as its policies, procedures and workforce development principles and practices.
- Is the multicultural staff cohort appropriately trained to deal with the complexities of the aged care system in Australia? This should address the inherent attitudes towards staff from diverse cultural and linguistic backgrounds by non-CALD residents and staff.

FECCA recommends that a separate standard is inserted and accredited against and this could be titled ‘Responding to Diversity’.

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