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# Submission to the Disability Royal Commission-Aged Care

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# **Submission to the Disability Royal Commission- Systemic Advocacy**

## **Aged Care Services: Abuse/ neglect of elderly individuals from linguistically diverse and non- English speaking backgrounds**

This submission involves findings from a consultation held by the Multicultural Disability Advocacy Association (MDAA): a peak body that promotes, protects, and secures the rights and interests of people with disability, their families, and carers from culturally and linguistically diverse (CALD) backgrounds in NSW. The consultation focused on ageing issues for people with disability, highlighting neglect by services for older people with disability.

### **Consultation participants**

The participants included in the consultation were elderly people living in NSW (between the ages of 51 to 79) with a range of disabilities and coming from various multicultural backgrounds. The range of participants included:

- 51-year-old male carer for parents with disability from the Philippines



- 61-year-old female with a disability and a carer for her son with cerebral palsy from Pakistan, who also has a physical disability herself
- 75-year-old female with vision impairment from Bulgaria of Jewish descent
- 61-year-old female who is Australian and a carer for a vision impaired person
- 76-year-old female from Greece with hearing impairment and a carer for her mum who is 98 years old
- 79-year-old female who was born with polio and has a physical disability. She lives alone with no relatives and is isolated. She is from the Philippines
- 73-year-old female with vision impairment, lives with her sick husband also caring for a sister with various medical issues. She is from Yugoslavia
- 71-year-old female carer for a brother with down syndrome. She is from Chinese/Indonesia

### **The main challenges experienced by MDAA's consumers in relation to Aged Care Services**

The consultation highlighted a range of challenges experienced by consumers with the *My Aged Care* service, outlining a poor standard of service within the system compared to other aged care services used. Some of the challenges included:



- having to organise and collate their information during the application process on their own
- waiting long periods of time for the assessment process outcome
- a lack of communication and information between health services and aged care services, and:
- the use of technical language making it harder for consumers who lack technological skills to navigate through the online process.

Overall, the main challenges have resulted in several difficulties for consumers particularly from CALD backgrounds, from accessing services (Gaans, 2018). Throughout the consultation, ageing consumers from CALD backgrounds made it clear that they want services that are more tailored to their needs and preferences, and that the existing options given to them were either confusing or meaningless (Australian government Department of Health, 2019). In this consultation, the sentiments felt by the participants relating to their experiences with aged care services are like that of the sentiments echoed in the ‘Carers NSW CALD Focus Groups Report, 2018.’

## **1. Issues with access and Information to Services**

Most elderly people from non-English-speaking backgrounds (NESB) face difficulty in accessing *My Aged Care* and according to the ‘Australian Institute of Health and Welfare 2018,’ their percentage of access is quite low in comparison to other groups.

One reason for the difficulty of NESB people accessing aged care services is that many community organisations and service providers who work to assist the



individual, start service provision where the client is then referred to another location or service somewhere else by the Regional Assessment Service (RAS).

Many participants mentioned that Service providers and Aged Care Services are not using interpreters, and they are often waiting a long time before they can consider arranging interpreting services to assist them effectively, causing several delays in relating to their access for assistance.

The consultation raised concerns with the eligibility criteria relating to service access, as screening does not effectively consider CALD issues and concerns, social isolation, interaction with community, and language issues.

Another issue raised was the complexity of the language used by government departments causing confusing for CALD people. Contents, phrases, and terminology are not translated accurately for CALD clients resulting in a lack of engagement and understanding. It was also noted that *My Aged Care* does not replace alternative community access help.

Participants also noted the great difficulties in navigating through different stakeholders such as *My Aged Care*, to Regional Assessment Services.

## **2. Isolation and lack of support**

Many ageing clients from CALD backgrounds with a disability noted that they do not have family members or relatives living with them. Given they live alone they feel isolated from their communities, and it is known that isolation increases the risk of not finding urgent help particularly if an accident were to occur within their home.

### 3. Language barriers

*My Aged Care* initial assessment and other aged care services do not offer options for clients to communicate with staff in other languages, therefore making it difficult for clients to effectively communicate their concerns and needs with workers upon consultation.

### 4. Inaccessible transport

Participants expressed that the existing transport services (buses and trains) are not accessible for the aged with a disability. In addition to many of the issues faced by those with a disability, aged people experience other health conditions that make it difficult for them to appropriately access transport.

## CASE STUDY:

This is a story of neglect by services of a woman with a physical disability in a wheelchair and hearing impairment, who lives alone and has no support networks. She only receives 1 hour per fortnight for domestic help through a home care provider. She had been assessed by *My Aged Care* and has not been given more hours as she is seen to be 'managing well', despite her having a few falls. In one instance, she was found on the floor wedged between her wheelchair and the bed the following day, distressed and weak. Lately, she also has been eating take away meals because of weakening muscles, as she could not cut up vegetables and meat. She is not using Meals on Wheels as she finds it expensive. She wanted to sponsor a cousin from her country but was precluded to because a cousin is not a "member of the family unit" as per immigration regulations.

## **5. Use of improper /disrespectful language by health and community workers**

Participants expressed concerns that through their experiences, health and community workers treat and talk to the elderly with disability “*like they are children,*” and not capable in making decisions. They expressed that the overall quality of services provided to them falls short of the appropriate standards of care.

## **6. Economic insecurity**

Many of the participants noted that aged people with a disability depend solely on their pension for financial support, which sadly, is not sufficient to take care of their needs.

## **7. Little or no support for carers**

Carers experience a lot of financial difficulties when it comes to support, given that they depend on the Carers Allowance from Centrelink. Many carers find it hard to make ends meet, as they leave their jobs to become full-time carers for their family member with a disability. Many carers have raised concerns that the amount allocated to them through the carers allowance is barely enough to take care of their needs. They have also outlined that respite care services are also expensive, making it difficult for them to keep their ageing family members in respite care, or to assist them to be able to connect with their community.

## CASE STUDY:

This is a story of a woman in her 40s caring for her 92-year old mother. The carer is a single mother working full-time and had no choice but to leave her job to care for her mother, given she is on a level 2 care package. The daughter was very distressed given her mother's age, inability to look after herself and her frail physical state. She was hoping that her mother could be placed on a level 4 package considering her dire state. She was stressed and expressed annoyance of the aged care service not listening to her concerns and the urgency of the situation where her mother needed high-level care. After appealing to the service and waiting several months for a response from the Minister pleading for a higher aged care package, her mother had passed away before receiving a letter confirming that her mother does not meet the requirements for a level 4 package. She has expressed her disappointment with the system as a whole, not assisting her to provide the full-time care which was needed for her mother, as she had to leave her full-time job, resulting in her mother eventually passing away during the appeal process.



## CASE STUDY:

This is a story of a woman whose father and brother have dealt with issues relating to the aged care system and health care system. Her elderly father was dealing with a range of health issues that were neglected by aged care service providers, including the aged-care facility he was staying at. For this reason, she tried to access several hospitals to seek the appropriate medical supports needed as her father's condition was rapidly deteriorating. She expressed the hardships she endured trying to access proper health services for her father before his passing. She outlined that even though there was an agreement between private and public hospitals due to Covid-19 to support the elderly, that she was denied any support from the private hospital system. She stated: *"There are so many barriers that elderly people come across in many different areas and the system lets them down. There was a lot of discrimination also when I was trying to move my father to a private care facility, so he accesses better care."* Her brother who had a disability and who passed away at the age of 27, was admitted to an aged care facility given there was no room for him anywhere else, and she expresses that her brother experienced abuse in that age care facility:

*"They used my brother's disability as an excuse to do negligence. My brother suffered a brain injury, but his physical, emotional, mental health was completely ignored"*. She believes that they age care facilities her father was breached all the age care standards: *"They don't follow the age care standards."*

**(a) MDAA recommends better access to information and services:**

- There should be one service provider to work with the consumer from start to finish- from commencing with the application process, to service provision. Culturally and Linguistically Diverse (CALD) specific organisations are better placed do the intake and assist with linking the consumer to other services they may need.
- Service providers should always use interpreters when undertaking assessments, book interpreters in advance and steer away from the habit of using family members to interpret for them.
- Information sessions should be organised on the navigation of *My Aged Care* in av variety of languages.
- Consideration needs to be taken of the various literacy levels of consumers. Service providers should use simple English terminology for consumers who have limited English skills.
- The creation of simplified glossary of terms to be translated in a variety of languages
- The consumer's cultural and traditional values must be taken into consideration during assessment, as well as the fact some elderly consumers from CALD backgrounds have no support in place and tend to revert to native language as they grow older.
- Advocacy would be essential to assist with ensuring consumer rights are upheld. The message needs to be sent out to consumers that there might be alternative ways to seek help outside of *My Aged Care* if need be. Advocacy can assist with referrals pathways to services and provide support to

consumers to navigate the services. Advocacy organisations can be funded to assist with navigating the system.

- Establish partnerships with CALD specific services and support existing partnerships and networks e.g., CALD support. Work in partnership with multicultural organizations
- Adequate language interpreters especially for new and emerging ones should be made available considering populations as each state has different CALD cohorts. Consideration should be given to all communities.

***(a) MDAA recommends improving service provision to eliminate isolation and lack of support:***

- Allow for some consideration regarding the Carer Visa application for applicants without 'close family members' from overseas, and consideration be given to other relatives also
- The Government should work with multicultural organisations and provide funds for activities for the elderly, where they can feel included, safe, welcomed, and be heard, as well as improve social connection within the ageing community
- Fund better services that will take care of the welfare of the elderly

***(b) MDAA recommends improvement in service provision to combat language barriers:***

- The *My Aged Care* call center should recruit bilingual staff to reflect the older CALD population



- There should be a *My Aged Care* multicultural hotline due to finding it difficult to use TIS to contact *My Aged Care* directly

***(c) MDAA recommends improving issues relating to the lack of transport to access services:***

- Provide accessible transport services that will make the ageing feel included as well as reduce the anxiety of using transport services when going for appointments and other social outings

***(d) MDAA recommends improving financial support:***

- Besides the pension there should be some financial support for the elderly to pay for services that are expensive. For example, ongoing medical services

***(f) MDAA recommends improving support services:***

- There should be a reduction in the cost for respite care, and an appropriate increase in the carers allowance
- The Government should provide free training for carers

***(g) MDAA recommends improvement in cultural sensitivity training:***

- Train professionals on respect and value for the elderly to develop a capability framework which will describe the important behaviours, attributes and knowledge for people who work with aged people. Creating support tools to help service users, workers, and service providers to implement and use the framework.



- Train professionals on providing culturally responsive services.
- Include education on aging and disability to school's curriculum so that young children can learn from an early age how to care, support and be compassionate to the elderly.

### **Summary of Recommendations:**

- Provide options for caring for older people with a disability

A 2015 publication by Carers Australia, Work and Care notes that over a fifth of Australia's population will be aged over 65 years, and the need for unpaid care grows. Their research further shows that 1 in 8 employees are in a caring role.

These numbers are set to increase by 2027. It is evident that options need to be considered such as the current intake measures for immigration, by expanding the Carer Visa to give our older Australian a better quality of life when being cared for by their family members, rather than going in a nursing home. Many people with a disability have noted that they are reluctant to go into a nursing home due to the many ongoing abuses and sub-standard services provided.

- Improve the *My Aged Care* system and provide an easy pathway to navigate access which include making resources easy to understand, provide plain English assessments and having more bi-lingual staff.
- Align *My Aged Care* services to NDIS processes to enable a person-centred service and promote greater choice and control.
- Develop more programs for older people that will address isolation and develop their technical skills to help in communication.

Given the Disability Royal Commission focuses on systemic change, MDAA would like to bring the findings of the *consultation into people with aged care and disability* to the



attention of the Royal Commission in hope that it would shed light into the main issues suffered by individuals who want to access quality care by service providers.