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# POSITION PAPER

## ISSUES OF AGEING PEOPLE WITH DISABILITY IN NSW AND STRATEGIES FOR SOLUTIONS

The Multicultural Disability Advocacy Association (MDAA) is 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) background in NSW. MDAA supports more than 800 CALD families with disability in NSW every year through its culturally responsive services. MDAA represents the voice of CALD communities living with disabilities in NSW.

According to the Australian Institute of Health and Welfare in 2016, 1 in 3 older people were born overseas; the majority of these were born in a non-English speaking country. Meanwhile, MDAA's consumer demographics shows that more than 30% of MDAA's consumers are ageing people living with disabilities. These consumers experience a number of challenges with My Aged Care, including a poor system within other aged care services. Some of the challenges include having to put together information on their own, waiting long period of time for the assessment process, lack of communication between health services and aged care services, lack of information that make sense to consumers because of the complex language used and a lack of technology skills to navigate the online processes of My Aged Care which results in difficulties in accessing the services by ageing consumers from CALD background (Gaans, 2018). Ageing consumers from CALD background want services that are tailored to their needs and preferences but they

mentioned that the choices given to them were either confusing or meaningless (Australian government Department of Health. 2019)

A consultation was arranged as requested by the Department of Communities and Justice who is developing their Ageing Strategic Plan which was held on 25 June 2020, moderated by David Donnelly, the consultant. The participants for the consultation were elderly people (between age 51 to 79) with disability from various multicultural backgrounds living in NSW. The participants for the consultation were

- 51 years old male carer for parents with disability from the Philippines.
- 61 years old female with disability and also a carer for her son with cerebral palsy from Pakistan who also has a physical disability herself.
- 75 years old female with vision impairment from Bulgaria of Jewish descent.
- 61 years old female who is Australian. She is a carer for a vision impaired person.
- 76 years old female from Greece with hearing impairment and a carer for her mum who is 98 years old.
- 79 years 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 years old female with vision impairment, lives with her sick husband also caring for a sister with various medical issues. She is from Yugoslavia.
- 71 years old female carer for a brother with down syndrome. She is from Chinese/Indonesia.

Carers NSW CALD Focus Groups Report in 2018 echoes the similar issues mentioned by the participants below:

## 1. Access and Information to Services

Most elderly people from Non-English-speaking background face difficulty in accessing My Aged Care. The percentage of access is low (Australian Institute of Health and Welfare, 2018).

One reason is that many community organizations and service providers do all the work, they start service provision and then the client is referred to another location or service somewhere else by RAS (Regional Assessment Service).

There is too much paperwork and online processes to access services and many elderly people are not computer literate, there is lack of understanding especially of the “”re-ablement”” and “wellness approach”.

Service providers and Aged Care Services are not using interpreters or often they are waiting a long time before they arrange interpreting services. This significantly delays commencement of services for CALD clients.

Concerns with eligibility criteria in service access have been raised as screening does not consider the CALD issues and concerns, social isolation, interaction with community, language issues.

Complexity of the language used by government departments are confusing for CALD Aged people. Contents, phrases, terminology are not translated accurately for CALD clients resulting in lack of engagement.

It is a myth that My Aged Care replaces alternative community access help.

Difficulty in navigating through different stakeholders such as My Aged Care to Regional Assessment Services, their pathways are difficult to navigate.

## Recommendations:

- One service provider to work with the consumer from start to finish- beginning of the application process to service provision. Culturally and Linguistically Diverse (CALD) specific organizations to do the intake and assist linking to other services.
- Service providers should always use interpreters when undertaking assessments. Book interpreters in advance. Do not use family members to do interpreting tasks.
- Organize information sessions on My Aged Care in variety of languages.
- Consideration needs to be taken of various literacy levels of consumers. Service providers should use simple English terminology for consumers who have limited English skills.

- Create simplified glossary of terms to be translated in variety of languages.
- Consumer's cultural and traditional values must be taken into consideration during assessment as well as the fact some elderly from CALD have no support in place and revert to native language as they grow older.
- Advocacy would be essential to assist with ensuring consumer rights are upheld. Get message out to consumers that there might be alternative ways to seek help outside My Aged Care. Advocacy can assist with referrals pathways to services and provide support to consumers to navigate services. Fund advocacy organizations to assist with navigating the system.
- Establish partnership 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 be made available considering populations as each state has different CALD cohorts. Consideration should be given to all communities.

## 2. Isolation and lack of support

Many ageing clients from CALD background with disability do not have family members or relatives living with them so they live by themselves in their homes and this makes them isolated from their communities. Isolation increases the risk of not finding urgent help if an accident occurs in their homes and unawareness of the wellbeing of the elderly in the community.

## Recommendations:

- Allow for some consideration with the Carer Visa application for those without "Close family members" from overseas and consider other relatives.
- Government should work with multicultural organizations 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 in the community.
- Fund services that will take care of the welfare of the elderly.

## 3. Language barrier

My Aged Care initial assessment and other aged care services does not offer options to clients to communicate with staff in other languages, therefore it makes it difficult for clients to communicate with workers when they contact them.

### Recommendations:

- My Aged Care call center should recruit bilingual staff to reflect CALD older population.
- There should be My Aged Care multicultural hotline due to finding it difficult to use TIS to contact My Aged Care.

## 4. Inaccessible transport

The transport services (buses and trains) are not accessible for the aged with disability. Besides disability, aged people experience other health conditions which make it difficult for them to access transport.

### Recommendations:

- 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.

## 5. Use of improper and disrespectful language and the poor service by health and community workers

Health and community workers treat and talk to the elderly with disability like they are children and not capable to make decisions on their own and the quality of service is not up to standards.

### Recommendations:

- Train professionals on respect and value for the elderly and develop a capability framework which will describe the important behaviours, attributes and knowledge for people who work with aged people and create supporting

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.

## 6. Economic insecurity

Many aged people with disability depend on their pension for financial support which is not sufficient to take care of their needs.

### Recommendations:

- Aside from the pension there should be additional financial support for the elderly to pay for services that are expensive. For example, medical services.

## 7. Little or no support for carers

Carers experience a lot of financial difficulties because they depend on the Carers Allowance from Centrelink because they had to leave their jobs to care for their ageing family member, the amount paid to carers are not enough to take care of their needs.

Respite care services are also expensive which makes it difficult for the carers to keep their ageing family members in respite care to be able to connect with their community.

### Recommendations:

- Reduce the cost for respite care, and increase carers allowance.
- Government should provide free training for carers.

### 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 I hour a fortnight domestic help from 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 so she could not cut up vegetables and meats. She is not using the 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.

## SUMMARY of RECOMMENDATIONS:

- Provide options for caring for older people with 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, so therefore options need to be considered such as in 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 which actually many people with disability are reluctant to go due to the many 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; plain English assessments; 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.