



2020

MDAA Submission to the Labor Multicultural Engagement Taskforce- December 2020

**Multicultural Disability Advocacy
Association of NSW Inc.**

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12/2/2020

About this submission

This submission is produced by the Multicultural Disability Advocacy Association of NSW Inc. (MDAA) in response to the *Labor Multicultural Engagement Taskforce*. By way of participation in this submission, consultations were held with MDAA consumers. The submission talks to various aspects of 'My Aged Care' services, as well as the experience of consumers with the National Disability Insurance Scheme (NDIS), putting forth recommendations for consideration. These recommendations will ensure that government services can provide more inclusionary measures for people with a disability from Culturally and Linguistically Diverse (CALD) and Non-English Speaking backgrounds (NESB), in areas of need within the disability sector, providing community awareness and contributing to a well-informed Labor Policy Platform.

About MDAA NSW

MDAA is a state-wide advocacy service for all people with disability, their families, and carers, with a specific focus on people from Culturally and Linguistically Diverse (CALD) and non-English speaking backgrounds (NESB). MDAA aims to promote, protect, and secure the rights and interests of people with disability, their families, and carers in NSW with the view to empowering communities through systemic and individual advocacy, advocacy development, capacity building and networking, as well as industry development and training.

MDAA welcomes the opportunity to provide a submission for Labor's Multicultural Engagement Taskforce to inform Labor's policies relating to CALD communities and their experiences in accessing various government services., particularly within the disability sector.

Consultation with MDAA consumers

1. Issues of access to federal government services

➤ My Aged Care

At a recent MDAA community consultation relating to experiences with the My Aged Care service level, consumers with disability from CALD communities reported several unsatisfactory experiences with the level of service offered.

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 (Aged Care Sector Committee Diversity Sub-Group, 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.'

a) 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 consumer 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 to arrange interpreting services in order to assist them effectively, causing a number of 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 consumers 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.

b) Isolation and lack of support

Many ageing consumers 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.

c) Language barriers

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

d) 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 1: This is a story of a woman with a CALD background 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 government

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 2: This is a story of neglect by services of a CALD 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.

e) 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.

f) 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.

g) 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.

2. Recommendations in informing Labor Policy

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.

b) 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

c) 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

d) 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

e) 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, worker's 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.

A 2015 publication by Deloitte on Carers Australia notes that over a fifth of Australia's population will be aged over 65 years, and the need for unpaid care will continue to grow. 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.

2. Issues of access to federal government services

➤ NDIS

MDAA held a Disability Engagement Forum with consumers and their advocates who have noted several concerns with the NDIS process such as:

- a reluctance to engage with NDIS related services due to cultural/language barriers and a lack of understanding of the complex application processes.
- Consumers on the NDIS have reported on issues with their plans such as not being granted funding for vital services which they were able to obtain after a very lengthy and tiresome Administrative Appeals Tribunal (AAT) process.
- Consumers who have been granted funding express frustrations on inadequate funding, inappropriate funding allocation, and support coordinators and planners who are not trained adequately in managing CALD consumers with complex disability.

There remains the real issue of the difficulty in filling out forms and collecting supporting evidence to prove the permanency of impairment (grey area).

The main challenges experienced by MDAA's consumers in relation to NDIS Services

- *The NDIS is inaccessible for CALD community members to make an enquiry: consumers have reported that when they approached the NDIA receptionist to make an enquiry about the NDIS process the NDIA representative was not qualified to provide basic information relating to the process and redirected*

the consumer to the 1800 hotline, without providing them assistance in a language they could understand.

- *Lack of anticipated need for translators:* The 1800 number starts with a recording in English with no access to an interpreter. When CALD communities visit the NDIA an interpreter is not offered.
- *Lack of education for Clinicians:* There is great difficulty in advocates with access requests as it is difficult to convince health professionals to take the time and attention needed to fill in the forms and to do so sufficiently i.e. funding NDIA approved language by being specific about the primary and secondary disability, stating that all efforts to correct the condition have been exhausted as well as stating its permanency. There is also an evident difficulty in clinicians providing statements as to how the consumers disability affects their ability to function daily in all 6 spheres: mobility, communication, social interaction, learning, self-care and self-management.
- *Insufficient funding allocation:* Consumers reported several funding allocation issues with their plans, forcing them to apply for a review which could take several months to be resolved.
- *Increase in ATT matters:* More consumers are taking matters to the AAT as the NDIA will not fund what the participants want, resulting in several matters at the AAT being overturned.
- *Correspondence sent to NDIS participants in English only:* It was reported that letters sent to NDIS participants are in English and are not easy read. For example, when a person with disability makes an access request for the NDIS and is deemed not eligible they are advised by letter in English which quotes the legislation to advise the reason as to why they are not eligible for NDIS. There is no provision for easy read or translating services. Also, as the person with disability is not accepted to the NDIS, they do not have a nominee who is able to receive this information on their behalf.
- *There are additional access barriers for CALD people with psychosocial disability:* For example, the Evidence of Psychosocial Disability Form which is to be completed for people with disability with a psychosocial disability listed as their primary diagnosis, usually requires two separate clinicians to complete the form. Part B of the form to be completed prior by a support worker or appropriate person to the completion of Part A by psychiatrist, GP, or the most appropriate clinician. If the completion of the form does not occur in this order, the person with disability will need to visit their psychiatrist, GP, or the most appropriate clinician on 2 occasions to complete the form. This not only cost the applicant more money, but it is also using valuable resources that should be used for treatment.

Most often on discovering the rigmarole of completing the Evidence of Psychosocial Disability Form a CALD person with disability will disengage with the process.

3. Recommendations in informing Labor Policy

- a) MDAA recommends that NDIS staff be trained/ skilled in the disability sector-** It is recommended that there be more training and skill development for NDIS staff when dealing with matters that requires knowledge of the disability sector. Unions have reported over several years that NDIS contractors are not well-equipped in dealing with complex, emotional cases that need a specific knowledge set from within the disability sector. It is recommended that hiring staff who are knowledgeable and skilled in the disability space, can provide a more person-centred and holistic approach when assisting consumers with their plans and therefore, provide a better chance for the consumer to receive the appropriate level of funding and care. At the same time, they will be able to assist the consumer closely in achieving their needs and aspirations.
- b) MDAA recommends that NDIS staff be trained/ skilled in liaising with CALD communities:** Consumers have reported dissatisfaction within the NDIS service level process particularly when it comes to the unavailability of interpreters. The NDIS process would benefit from measures to become more streamlined to be more accessible and transparent for CALD communities. Cultural awareness training for staff is also recommended for a smooth transition and positive outcomes and experiences for CALD communities.
- c) MDAA recommends a process of less referrals to the AAT and more assistance for consumers through the NDIA:** Upskilling staff and ensuring that they are knowledgeable within the disability sector and CALD community would lead to less referral to the AAT and less instances of consumers applying to review NDIS decisions. Working closely with consumers and hiring the appropriate staff will provide more positive outcomes and ensure consumers are not faced with having to pay legal fees, wait several months for support, and avoid having to navigate the complex AAT system. Funds can be put toward training staff, supporting staff with decision making, providing consumers with more agency and flexibility when it comes to their plans and funding, and provide a platform for consumers to be heard about what directly impacts them.
- d) MDAA recommends more training for CALD consumers to navigate the review process:** The review process coupled with avenues for the AAT are quite complex, lengthy and confusing, particularly for CALD consumers who do

not understand the process given language barriers. Consumers in need would benefit greatly by more assistance and resource to help them navigate the appeals process as many consumers feel anxious and hesitant to follow the appeals path, even if they are entitled to.

- e) MDAA recommends more suitable questions to be posed to consumers during planning stages:** Planners, Assistant Directors, Senior planners and other staff at the NDIA should prepare more suitable questions for consumers during the initial planning stages such as: *“were you previously receiving supports before the NDIS? If yes, what were you funded for and was that for both your costs as well as the cost for any support you required? Were the costs only for any support you required?”*
- f) MDAA recommends more tailored plans to meet needs of consumer:** It is recommended that the NDIA should be more open and tailor a plan based on what the consumer was funded for previously if the consumer was receiving funding through state or territory government system before the NDIS rolled out and replaced the state system.

We welcome further discussion on any aspects of our submission.

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