



Multicultural Disability Advocacy

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**Submission to the Joint Standing Committee on the
National Disability Insurance Scheme:**

**General issues around the implementation and
performance of the NDIS.**

08 March 2019

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Issues and Key Recommendations

Support Co-ordination:

Recommendation: That all participants be funded for support co-ordination for the first two years. This is particularly necessary for CALD consumers as many are still not fully aware of the NDIS; many lack confidence; experience cultural barriers and may have no prior experience of accessing the service system.

Recommendation: Better handover from LAC/Planner to Support Coordinator. Often there is no handover or very little information is provided in the Request for Service which means that participants need to tell their whole story again when they begin with a Support Coordinator even after they have had a lengthy planning meeting with a Planner/LAC.

Recommendation: The role of any informal or mainstream supports, including engagement with advocacy services, should be explicitly clarified. Engagement with such services should not disqualify a participant from receiving Support Coordination.

Inaccessible information:

Recommendation: MDAA stresses the need for less jargon to be used and information to be made accessible to people from CALD backgrounds. This includes addressing the lack of anticipated need for translators. Processes and information should be easy to follow, consistent and presented in a culturally appropriate way.

Unreasonable waiting times:

Recommendation: That the timeframes stipulated in Section 204 of the NDIS Act 2013 must be adhered to.

Greater need for staff training:

Recommendation: That all LACs and NDIA staff are provided with adequate training to support them to work effectively and responsively with people from cultural and linguistically diverse backgrounds. Training at a minimum should include; cultural competence and disability awareness training.

Lack of education for clinicians and communication with Allied Health professionals:

Recommendation: Greater communication and training for mainstream health services on their role in securing access to the NDIS. Reports from GP's and clinicians plays a crucial role in securing access to the scheme. This must be acknowledged and appropriate communication channels and supports need to be provided.

Continued advocacy funding:

Recommendation: Continued funding for advocacy is essential. Organisations such as MDAA assist people with issues across a variety of systems and levels of government. Education, transport, immigration, health and other community services will not be covered by the NDIS. We must ensure people are not slipping through the gaps.

Background

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak body for all people in NSW with disability, their families and carers, with a focus on those from a culturally and linguistically diverse (CALD)/non-English speaking (NES) background with disability.

MDAA has more than twenty years of experience working with people with disability and supports the active participation of its members and consumers in all aspects of its work. The voices of our members and consumers informs MDAA's systemic advocacy work thereby contributing to positive change for people with disability from CALD / NESB in policies, procedures, practices and service delivery in government and non-government agencies.

In analysing the latest data for our services, it became clear that issues with the National Disability Insurance Scheme (NDIS) were taking a lead in the advocacy assistance we provide. Our latest report from the last financial year showed that out of the 27 issue areas we address, 37% of our consumers were seeking assistance with NDIS related issues. This was followed by accommodation and entitlements/subsidy related matters at 33% and 20% respectively. For this reason, MDAA has hosted consumer conferences and forums to consult and record the experiences of our consumers.

Despite the many issues arising from the initial implementation of the NDIS, MDAA would like to acknowledge the much-needed change in the disability sector that the scheme has brought with it. We strongly support the premise on which it is based and recognise the importance such a change has had, in particular that of a person-centred approach to provision of services as well as a focus on individual choice and control. We believe this is the right step towards upholding the rights of people with disability in Australia. Further to this, we believe the opportunities that come from this change will allow persons with disability from diverse cultural backgrounds to receive greater access to culturally responsive supports- once the market develops.

Yet, while we recognise the potential benefits of the NDIS, there are a number of systemic issues that are significantly impacting its effectiveness as a national scheme. We believe that if these issues are addressed it will ease much of the stress currently experienced by our consumers and other service providers.

This submission reflects the feedback and experiences we've received from the consumer conferences, forums and consultations MDAA organised with our consumers and advocates.

Support Co-ordination

The limitations felt by the people we support stems from the difficulties they experience in interpreting and implementing their plan. From receiving a plan to finding and accessing the services they have been funded for has often meant that without additional support they are either not able to start using their funding at all or, concede to using the first service they find.

We have come across countless cases where participants have sat on approved plans for months before they seek the assistance of an advocate, who then helped them connect with services to begin using their plans. The families we have worked with in this situation all report a lack of support from their Local Area Co-ordinators (LACs), the NDIA or in some cases, where provided, have not been able to establish an effective working relationship with their support coordinators.

It is our concern that NDIS participants from CALD/NESB who experience language barriers and may be unfamiliar with accessing disability supports are often not considered eligible for Support Coordination. This means that people from CALD/NESB are often put in a position where they are unable to implement their plan, utilise services and exercise choice and control.

Further to this, we are also aware that participants are not provided with funding for Support Coordination depending on their engagement with community and mainstream supports, including advocacy services. MDAA strongly stresses the need to clarify the nature of this support and for it not to be assumed that mainstream services have the capacity to offer long term support to participants for plan implementation.

Where funding for support coordination is provided, MDAA stresses the need for better handover procedures from LACs/Planners to Support Coordinators. Often there is no handover or very little information is provided in the Request for Service which means that participants need to tell their whole story again when they begin with a Support Coordinator even after they have had a lengthy planning meeting with a Planner/LAC. Insufficient handover also means participants, particularly those from CALD backgrounds are often confused about all the different people and their roles e.g. Planner/LAC/Support Coordinator. Clear and consistent messaging is needed from NDIA to support people to understand and navigate the system particularly in knowing who to contact for what.

Where support coordination is not provided we have yet to see LACs provide the necessary support to assist with plan implementation.

Recommendation 1:

That all participants be funded for support co-ordination for the first two years. This is particularly necessary for CALD consumers as many are still not fully aware of the NDIS; many lack confidence; experience cultural barriers and may have no prior experience of accessing the service system. Through an education and mentoring role the Support Coordinators can educate the participants of the processes.

Recommendation 2:

Better handover from LAC/Planner to Support Coordinator so participants do not need to tell their whole story again when they begin with a Support Coordinator even after they have had a lengthy planning meeting with a Planner/LAC. Insufficient handover also means participants, particularly those from CALD backgrounds are often confused about all the different people and their roles. Clear and consistent messaging is needed from NDIA to support people to understand and navigate the system particularly in knowing who to contact for what.

Recommendation 3:

The role of any informal or mainstream supports, including engagement with advocacy services, should be explicitly clarified. Engagement with such

services should not disqualify a participant from receiving Support Coordination. Support Coordinators and LACs rely on advocacy services to support participants in finding and negotiating with services.

Complex jargon and inaccessible information.

Feedback we have received clearly shows that letters and information given by the NDIA were difficult for our consumers to understand and NDIA decisions were hard to interpret.

As an example, when a person with disability from a CALD background receives correspondence from the NDIA, it is usually in English and not in their language even if they have asked for translation or translator. Complex jargon has made also made verbal communication ineffective. Our advocates have consistently reported this in their experiences when supporting consumers in NDIS meetings with LACs and Planners. It has been noted that the way staff communicate is not simple and clear. Many people from CALD or NES backgrounds can speak some English, but the use of complex jargon combined with the stress means the communication link is broken fairly quickly. This leaves participants confused and unable to fully communicate their needs affecting the final plan that is produced.

When making any enquiry, participants are constantly redirected to the 1800 number even if the person has gone to speak to an NDIA representative in person at a local office. The 1800 number starts with a recording in English with no option to access an interpreter.

Of greater concern, is the fact that even if a CALD community member visits the NDIA in person; an interpreter is not offered. NDIA Reception staff ought to be trained in using TIS and offer to call immediately to facilitate their enquiry as a normal course of action.

Inaccessible information has made accessing the NDIS particularly difficult. Our consumers do not know what kind of evidence is needed to apply for access and gathering specialised reports such as OT assessments can be complicated and expensive.

Recommendation 4:

MDAA stresses the need for less jargon to be used and information to be made accessible to people from CALD backgrounds. Processes and information should be easy to follow, consistent and culturally appropriate. Importantly, staff should be confident in offering and using interpreters.

Lack of education for clinicians and communication with Allied Health professionals

Our consumers have found it difficult to know the type of evidence they are required to provide to demonstrate eligibility for the NDIS and have stated language barriers as a main barrier affecting their ability to access the scheme.

The implementation of the NDIS has relied heavily on individuals sourcing evidence from health and other community services for access to the NDIS. The strain this has had on community services is made evident in the increasing incidences of GP's charging patients to assist in completing the initial Access Request Form (ARF). In one instance, a consumer was quoted \$100 by her GP to complete her ARF. The need for participants to provide this evidence, and the efforts to which they go to attain them, cannot be understated. Despite these efforts however, if the pathways to acquire evidence are economically prohibitive, participants currently have no other option then to rely on community services to cooperate and to engage with advocacy supports.

MDAA advocates are regularly accompanying consumers wherever possible to appointments with medical professionals to request sufficient evidence be provided to support their request for access to the scheme. The identified issue lies with a clear lack of communication and education on two main things:

- a) What the NDIA deems the responsibility of the Allied Health system,
- b) The NDIA's definition of 'disability', hence, falling in their sphere of responsibility.

Having identified this, consumers and their advocates are still having trouble convincing the majority of health professionals to:

- a) Take the time and attention to fill-in the required form at all. This is despite notifying them ahead of time and requesting a double appointment because the
- FN190309/MDAA Submission- General issues around the implementation and performance of the NDIS.

reason for the appointment is to have them fill-in an NDIS Access Request Form, and;

b) To fill-in the form in its entirety and sufficiently, including:

- Use NDIA approved language e.g. be specific about the Primary and (if relevant) Secondary Disability and attach a letter/report as medical evidence,
- State that all efforts to correct the condition have been exhausted, hence clearly stating its permanency, and;
- Provide simple statements as to how the disability affects their ability to function on a daily basis in all 6 spheres: Mobility, Communication, Social Interaction, Learning, Self-Care, Self-Management.

Case study

A young man from a CALD background with muscular dystrophy who uses a wheelchair was seeking access to the NDIS. With the assistance of his parents and his GP, he applied but was denied access to the scheme on the grounds that he did not meet the eligibility criteria relating to the disability requirements as outlined in section 24 of the NDIS Act.

According to the NDIA, the family was unable to show 'substantially reduced functional capacity'. Section 24(1)(e) refers specifically to the ability of an individual to undertake activities including (but not limited to): Communication; Social interaction; Mobility.

In the time it took for the family to understand the reason for this outcome and to seek assistance to appeal the decision, they needed to engage with a variety of community services to gather further evidence and re-apply for access. More than a year had passed before they were able to be granted access to the scheme.

Recommendation 5:

Greater communication and training for mainstream health services on their role in securing access to the NDIS. Reports from GP's and clinicians play a crucial role in securing access to the scheme. This must be acknowledged and appropriate communication channels and supports need to be provided.

Lengthy waiting times.

In some cases, despite having medical evidence from doctors/treating professionals who have prepared a strong case for NDIS funding for a patient (daily or weekly supports/interventions), the appropriate funds are not allocated to fully support a client for the estimated 12 months of the plan. In these cases, review processes are taking too long to be triggered and completed, leaving consumers with limited or no funds for a number of months.

Our NDIS Appeal and Reviews officers have reported a significant amount of cases where they have requested internal reviews of NDIA decisions which have not been considered or actioned for longer than 6 months. In these cases, MDAA has had to directly refer over to the Administrative Appeals Tribunal (AAT) for a review. The whole process, and the time without essential supports, adds enormous amounts of stress to people with disability and their carers. The economic cost on the State to go through this formal process can also be avoided by creating more effecting processes when dealing with reviews.

It is urgent to address this issue for people with complex care and support needs. It is our experience that often, carers and advocates are having to persistently advocate on behalf of a participant to receive adequate funding for support.

Time delays during every stage of the process has been increasingly problematic. For NDIS participants with complex care and support needs in particular, we have seen equipment delays lasting longer than a year.

Case study

'Y' is a young boy with quadriplegic cerebral palsy, epilepsy and sleep apnoea. Despite sourcing several quotes and specialist reports he and his family have been waiting more than a year for a wheelchair.

'Y' and his father, who is his sole carer, have had to wait unreasonably long for a decision to be made on essential equipment. The process has taken an enormous toll on the physical and psychological well-being of the family.

In the cases where complex care and support needs require greater funding allocation we have seen drastically underfunded plans undergo lengthy review processes. There has been a much greater need for participants and/or their carers to self-advocate and/or to find assistance to navigate through the review process.

As was the case for one of our consumers, after numerous appeals and through what he describes as a relentless psychological and emotional battle, with the assistance of an MDAA advocate, his plan that was initially allocated \$25,000 was increased by 10 times that amount to \$250,000.

MDAA has been supporting an increasing number of parents who have been waiting up to 6 months to be contacted back by an Early Childhood Early Intervention provider for their young children. Access to early intervention therapies should be made available for children under 6 years as a matter of urgency. This is especially because the NDIS has created an environment where disability services are very hard to find and access without NDIS funding.

Recommendation 6:

That the timeframes stipulated under legislation¹ be reviewed and adhered to.

¹ National Disability Insurance Scheme (Timeframes for Decision Making) Rules 2013 made under section 204 of the National Disability Insurance Scheme Act 2013 (the Act). Accessed: https://www.legislation.gov.au/Details/F2016C00388/Html/Text#_Toc392594571 FN190309/MDAA Submission- General issues around the implementation and performance of the NDIS.

Staff training on cultural competence and disability awareness

Another issue of high concern lies in staff without sufficient training making decisions on what are 'reasonable and necessary' supports. We have seen an alarming trend towards a lack of funds for people with complex needs and on more than one occasion we have seen requests denied for support or home modifications for people with diagnosis' such as Motor Neuron Disease.

Case Study

'A' has Motor Neuron Disease and has requested funding for a ceiling hoist to access the lower floor of his home and to allow him the choice of going out into the community. A ceiling hoist would also mean A's carers are safely able to transfer him from his bed to the shower chair.

A plan review reversed the approval of funding for home modifications stating that a ceiling hoist would not represent value for money. 'A' was told by his planner that she did not believe transporting 'A' downstairs with the hoist would be safe in the future due to a loss of core support that is generally a symptom of Motor Neuron Disease (MND).

What the planner has not considered, was the type of Motor Neuron Disease affecting 'A' is bulbar, targeting throat and voice muscles rather than his limbs and body. Essentially, what is most affected in this type of MND is not the core, but 'A's breathing and speaking.

The alternative proposed to 'A' was that he move downstairs into the front room of his home. This alternative would eliminate privacy and dismisses the need for him to access the top half of his home.

Despite the support of various professionals, including reports from Occupational Therapists, support letters from leading academic professors in the field of MND and with the assistance of an advocate 'A' is still engaged in a lengthy review process.

MDAA strongly recommends better training of LACs and NDIA staff. This is more apparent for our CALD consumers who are marginalised due to culture and language hence have difficulty navigating through the new system. It is vital that LACs and NDIA staff be given cultural competence and disability awareness training.

Communication from the NDIS needs to be simple and consistent. The NDIS needs to use language that everyone can understand, and more attention needs to be paid to the needs of people who come from culturally diverse backgrounds.

Recommendation 7:

That all LACs and NDIA staff are provided with adequate training to support them to work effectively and responsively with people from cultural and linguistically diverse backgrounds. Training at a minimum should include; cultural competence and disability awareness training.

Outside the NDIS

The latest NDIS Quarterly report still reports low access rates of people from CALD backgrounds into the NDIS. The barriers discussed throughout this submission are only some of the possible reasons for this. In the meantime, people we support are struggling financially and often need to budget and prioritise disability supports for other essential needs. Our consumers reported going to food banks, sourcing food vouchers or going to family, friends or their religious communities for help.

We acknowledge that the NDIS can't do everything. Not all people with disability will be eligible for the scheme and for this reason other systems need to make sure they also work for people with disability.

Recommendation 8:

Continued funding for disability advocacy is essential. Organisations such as MDAA assist people with disability with issues across a variety of systems and levels of government. Support in areas of education, transport, immigration, health and other community services will not be covered by the NDIS. We must ensure people are not slipping through the gaps.