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**Inquiry into the implementation of the National Disability
Insurance Scheme and the provision of disability services
in New South Wales**

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About MDAA

The Multicultural Disability Advocacy Association of NSW (MDAA) is the peak body for all people in NSW with disability and 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, with a focus on people from CALD / NESB with disability, their families and carers. MDAA supports the active participation of its members and consumers in all aspects of its work. The voices of its 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.

MDAA welcomes the opportunity to provide input in response to the terms of reference on the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales. In preparation for this submission, MDAA had numerous discussions with disability providers and hosted a consumer conference to consult and record the experiences of our consumers. This submission reflects their feedback, along with the experiences of our consumers and advocates generally.

Introduction

With many of our eligible consumers now taking part as participants in the NDIS, the MDAA welcomes the opportunity to comment on the implementation and effects of the scheme.

Despite the many issues we currently face during 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, on 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 appropriate supports.

In saying this, while we recognise the potential benefits of the scheme, its implementation has brought substantial changes to the market. The capacity of the workforce and the uncertainty or lack of funding has dramatically affected the ability for services to provide sufficient provision of disability services.

Implementation of NDIS plans and navigating through the changing market has also posed significant challenges for many of our consumers. Many of these challenges are unique to participants from CALD / NESB

MDAA insists that both the National Disability Insurance Agency (NDIA) and the State Government must support participants and a market place that is culturally responsive with information and assistance which is easily accessible regardless of language or disability. Considering the enormity of the changes taking place in the disability sector from block funding to individual funding packages, we are seeing a greater need for support for participants to navigate such a huge personal and cultural shift. Until the appropriate support is given, the possibility of providing choice and control to participants is dramatically minimised.

Comments

a. The implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability.

Our consultation on the Terms o Reference and in conversation with various consumers, we have seen that the new funding model has in fact been able to provide additional choice and control for some individuals. During our consultations,

one of our consumers noted that services such as 'Hireup' have allowed her to find a support worker who is able to complement and respond to her personal and cultural needs. Unfortunately, this consumer's experience of choice and control has not extended to many of our other consumers.

The limitations felt by our consumers stems from the difficulties they experience in interpreting and implementing their plan to begin with. 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 plans at all or, concede to using the first service they find.

There have been countless cases reported where participants have sat on approved plans for months before they got in touch with, or come to the attention of advocates, who then helped them connect with services and begin using their plans. The families we have worked with in this situation all report a lack of support stemming from inconsistencies in the information they are given and communication pathways affecting their ability to seek help from Local Area Co-ordinators (LACs).

MDAA understands the criteria pertaining to the allocation of support co-ordination funds and the role LAC's are to play in also assisting with plan implementation. It is our concern that despite the fact that NDIS participants from CALD/NESB have been recognised as a particularly vulnerable group, they are not deemed to fit the eligibility criteria on the basis of this vulnerability. As such they often do not receive funding for support coordination and are often put in a position where they are unable to utilise services and thereby lack choice and control.

Where support coordination is not provided we have yet to see LACs provide the necessary support to assist with plan implementation. Reportedly high work loads and insufficient staffing may be the cause for the large majority of our consumers feeling unsupported, or losing contact with their LAC altogether.

It is here that we believe the NSW Government could play a vital role in supporting people during the early stages of the NDIS. We call on the State government to

advocate for people from CALD / NESB with disability to urge the NDIA and LACs to fund support coordination at level that ensures people have the capacity to implement their plans. Furthermore, we ask the State Government to commit to ongoing funding for disability advocacy groups who continue to support individuals secure such support.

b. The experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans.

For people with complex care and support needs it is our experience that often, carers are having to persistently advocate on behalf of a participant to receive adequate support. At every stage from development, use and review of plans people with disability are having to fight against the interpretation of the terms 'reasonable and necessary'. Additionally, PWD also have to accommodate to a workforce that has not yet developed with an efficiently trained and experienced support staff. Carers and participants are often left feeling overwhelmed and exhausted and lose trust in the system and particularly with the NDIA.

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. Many are dependant on this equipment to support their quality of life and the unacceptable waiting times have put enormous strain on the individual, their family and other community services.

In some cases, when equipment is funded, we have experienced a problem with a lack of funding relating to consumables. While the equipment may be funded, for example a Bilevel Positive Airway Pressure (BiPAP) machine, the consumables such as the masks needed to use this machine are not funded. Without the masks the machine is not possible to use. Considering 45% of those with a disability in Australia are living either near or below the poverty line, (more than double the OECD average of 22% and are 2.7 times more likely to be at risk of poverty than

other OECD countries¹), unfunded consumables on specialised equipment put an economic and emotional strain on individuals and their families.

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.

His father is his sole carer and a brilliant self-advocate who persists with the difficulties of navigating through the system, despite English being his second language. Regardless of this, 'Y' and his father 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.

Further to this, 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 advocate, a plan that was initially allocated \$25,000 was increased by 10 times that amount to \$250,000. It is difficult to understand how this initial figure was reached, however, with the support of MDAA and other community services he was able to provide the required evidences.

Another issue of high concern lies in this area of what is deemed as constituting 'reasonable and necessary' supports. We have seen an alarming trend towards a lack of funds for people with complex needs stemming from a diagnosis which often holds a relatively short life expectancy. On more than one occasion we have seen

¹ Price Waterhouse Coopers, 2011. 'Disability expectations - Investing in a better life, a stronger Australia'. Multicultural Disability Advocacy Association of NSW Inc (MDAA)

requests denied for support or home modifications denied 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.

The case study above sheds light on a lack of person centred planning for decision making with planners taking a general approach to those with a particular condition. It also raises concerns about the lack of consideration or weight carried by professionals in the field where decisions are being made by planners who have little knowledge of the person as an individual. We strongly recommend the NSW

Government take the lead in policy development to safeguard those with complex care and support needs.

(e) The provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme

As the language and market changes, and services are faced with increased funding pressure, many people are finding it increasingly difficult to access support services that will assist them if they are unable to access the NDIS.

Again, this is particularly so with individuals from CALD / NESB with disability. MDAA has been closely following the data from NDIA's quarterly reports where they have clearly identified low participation rates of people from CALD background. In consultation with our consumers, it is clear that there is still a large need for accessible information and engagement with communities on what the scheme is and how to access it. In the meantime, these individuals and their families are unable to find supports to provide assistance outside the NDIS. A simple example of this can be seen in the changes made to the accessibility of community transport. Not only is transport poorly funded within the NDIS, our consumers can no longer access community transport outside of the scheme as they once had, services are now available only at a price that is inaccessible for most.

During our consumer conference, when we asked the question of how people access support services if they cannot participate in the NDIS, responses included *'it's hard, we just try to make do by ourselves'*.

We urge the State Government to ensure services, including community transport services, continue to receive an adequate level of funding for people who cannot access the NDIS. While the low participation rate of CALD people with disability may not be a matter of ineligibility but inaccessible information and cultural barriers mean that services providers must be open to offering assistance to those not yet able to access the Scheme. This is not currently the case.

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(g) Workforce issues impacting on the delivery of disability services.

Choice and control relies heavily on the availability of services and a properly trained workforce. High staff turnover in an industry already experience chronic workforce shortages and many with limited training or experience, has had notable effects on the delivery of services to people with disability. As an example, one of our consumers has had close to ten (10) different support workers within a few months. Each time a new support worker is allocated, the person with disability or carer must develop trust and provide the appropriate (and extensive) disability specific training.

Furthermore, the workforce has yet to develop in a way that allows participants from CALD background to truly take advantage of the person-centred nature of the scheme and access services responsive to their cultural needs.

In order to create a stronger workforce, we strongly recommend the State Government invest a greater focus in providing development opportunities including funded training in social services, cultural competency and disability. Request for State assistance in this regard is increasingly necessary as the NDIS pricing that service providers must follow does not leave services with the economic means by which to invest in staff training.

(l) Incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services.

It is estimated that only 10% of people with disability are likely to receive an individual funding package through the NDIS by 2019. Not only are disability supports harder to access without an NDIS plan, there has been confusion surrounding the responsibility of the NDIS or community services to meet specific needs. The multiple interpretations of the responsibilities pertaining to state run services and supports available through the NDIA has resulted in a number of individuals ultimately left without any supports at all. There needs to be greater collaboration and communication between State and Commonwealth regarding the

responsibility for health care supports. For many of our clients, the inability for the two to agree on their responsibilities has meant that they are refused support from either party. This is especially so in relation to mental health services and education, where both claim to be increasingly under-resourced to provide the expected level of support now expected of them.

Relating to this, the implementation of the scheme has relied heavily on individuals sourcing evidences 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 to complete her ARF. The need for participants to provide these evidences, and the efforts to which they go to attain them, cannot be understated. Despite these efforts however, if the pathways to acquire these evidences are economically prohibitive, participants currently have no other option then to rely on good will of community services to cooperate and to engage with advocacy supports.

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 seek assistance to appeal this decision, engaging 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.

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Recommendations

While significant challenges are being experienced generally by many participants, we feel it necessary to emphasise that many challenges are specific to CALD participants in a way that can only be addressed by specific considerations.

- 1) We call on the state government to advocate for people from CALD background with disability to urge the NDIA and LACs provide support coordination at a sufficient level to ensure people have the capacity to implement their plans. Furthermore, we ask the State government to commit to ongoing funding for disability advocacy groups who continue to support individuals secure such support.
- 2) We urge the State Government to ensure services, including community transport services, continue to receive appropriate levels of funding for people who cannot access the NDIS. This may not be a matter of ineligibility but the cultural shift currently taking place, along with the lengthy waiting times (often up to a year or more for a response on access) mean that there are many vulnerable groups of people who have not yet been able to participate in the scheme.
- 3) In order to create a stronger workforce, we strongly recommend the State invest a greater focus in providing and attracting people to development opportunities in social services and disability training and cultural competency training. Request for State assistance in this regard is increasingly necessary as NDIS pricing does not leave services with sufficient surplus to invest in staff training.
- 4) We recommend the State government assist in the greater success of NDIS implementation by providing further policy development and guidance. This could be done through a permanent commitment to the continuation of advocacy funding and wider community inclusion for people with disability and their carers.

- 5) The government must commit to long-term ongoing funding for independent advocacy services. CALD engagement in the NDIS is still much lower than expected. Acknowledgement of the need for independent advocacy for both participants and those who are not accessing the scheme is essential to upholding the rights of people with disability.
- 6) Insistence that the NDIA provide additional training for LACs and planners in terms of cultural competency, working with interpreters and disability awareness. This is based on the increasing realisation that the quality of a participant's plan is highly dependent on the competency of the LAC and planner.

MDAA would like to thank Portfolio Committee No. 2 –Health and Community Services, of the Legislative Council for the opportunity to address the issues highlighted in this submission. We look forward to the outcomes of the inquiry and are happy to discuss any of these issues in further detail.

Multicultural Disability Advocacy Association of NSW