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Submission to the Aging and Disability Commissioner on the NSW Disability Advocacy Review

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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) backgrounds with disability. MDAA advocates for the rights and interests of all people with disability and works from a standpoint whereby culture and disability are viewed through the lens of diversity. We see diversity as a strength and promote this view in all areas of our work.

MDAA covers all areas of advocacy support including Systemic and Individual Advocacy, Advocacy Development, Capacity Building and Networking, Industry Development and Training. With more than twenty years of experience working with people with disability, MDAA 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.

Our organisation has seven offices located in various locations of the state, namely, Granville, Waterloo, Hurstville, Bega, Griffith, Newcastle and Wollongong. In the recent months prior to this review, MDAA advocates conducted another series of consultations and consumer forums with the people we support. These community gatherings, organised on an ongoing basis by our organisation, provided an invaluable opportunity for us to consult and hear from our consumers about their needs and the way they engage with advocacy supports. It was also an opportunity for us to focus on providing information and support on specific areas of need expressed to us during previous consultations. This submission reflects their feedback, along with the experiences of our consumers and advocates generally.

MDAA welcomes the opportunity to provide input into the NSW Disability Advocacy Review, particularly on the areas outlined in the relevant issues paper and looks forward to opportunities of continual engagement in areas of disability advocacy.

Introduction

The nature of disability advocacy has become increasingly complex in recent years stemming from a growing uncertainty of funding for advocacy organisations, huge changes in the disability sector with the introduction of the National Disability Insurance Scheme (NDIS), and with the increasingly evident societal shift to take on a social model of disability. 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 upholding the rights of people with disability in Australia. Further to this, we believe the progressive changes in social attitudes are allowing for positive change that will allow all persons with disability, including those from diverse cultural backgrounds, to exercise their rights and practice choice and control over their own lives.

Despite some positive changes reflecting a commitment to the *United Nations Convention of the Rights of Persons with Disability* (CRPD), people with disability continue to experience a number of substantial barriers in their ability to access supports and participate in civil society. This is particularly so for people from CALD backgrounds where the effects of the intersectionality between culture and disability must be acknowledged. Within this environment, disability advocacy organisations continue to play a vital role in all domains of life including education, housing, employment, health and transport. Our records show that during the last financial year (2018-2019) MDAA has worked with over 67 ethnic groups with the top five presenting issues being: NDIS, accommodation, entitlements/subsidies, finances and immigration.

Advocacy organisations help establish equity in the social changes outlined above, ensuring that their implementation and progression are done in a way that allows for, and maximises, the effect of these changes. Furthermore, advocacy organisations are also vital in identifying and addressing existing systemic issues.

When looking at the review of advocacy funding in NSW, MDAA stresses that the substantial gaps that still exist in achieving equality and equity for people with disability in NSW, and the important role advocacy organisations play in addressing these issues, be supported.

Feedback we have received from our consumers overwhelmingly points to the fact that people with disability still experience various forms of social exclusion. The social exclusion affecting our community significantly reduces our ability to keep our commitment under the CRPD as well as the state's *NSW Disability Inclusion act 2014*. The issues this presents are multi-faceted and is well documented by social scientists and community workers alike. We see clear evidence of their views that "social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of the people in society, whether in economic, social, cultural, or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole"[1].

This submission is written from the stance that advocacy organisations and specifically, the provision of individual advocacy and systemic advocacy, play a key role in enabling the NSW Government to ensure the rights of people with disability are maintained and able to be realised.

Patterns of need for people with disability in NSW.

Are there changing patterns of need that should inform the future provision of advocacy services; for example, emerging disability related conditions, changing circumstances giving rise to new or different needs?

The introduction of the NDIS has brought with it several additional challenges for people with disability, their family and carers. Having now completed the roll-out of the scheme, these challenges have not yet begun to subside. Current estimations still predict that the scheme will only cover 10% of people with disability in NSW. For the 90% that remain outside the scheme, funding towards Information, Linkages and Capacity Building projects that aim to assist this group, while needed, don't cover the level or variety of support required to affectively represent or support all people with

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[1] Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E. & Patsios, D. (2007). The multi-dimensional analysis of social exclusion. Bristol Institute for Public Affairs, University of Bristol. Pg. 6.

disability. For many, a need and ability to access mainstream and specialist state services, has become even harder after the introduction of the NDIS.

From our own organisational experiences, not only do we still have consumers in need of assistance with access to the scheme, implementation of plans and reviews, we also have several consumers who are not eligible for the scheme or have not yet been granted access. Navigating disability service systems now that the NDIS has rolled out has become increasingly difficult for those who do not have access to the scheme as services have evolved, and eligibility criteria tightened, to suit the new environment. This is particularly difficult for CALD people with disability where all research indicates that they continue to fall through the gaps. Statistics from the Scheme's quarterly reports show that only 8.4% of the total 27% of CALD population with disability are accessing the NDIS. Greater advocacy is needed to increase this by promoting and guiding CALD people to access the scheme. It is here that specialist advocacy organisations, like MDAA, play a crucial role.

Areas of focus

Is it important to distinguish between different advocacy focus areas (e.g. information and referral, individual advocacy, group/systemic/representative advocacy) and different advocacy mechanisms (e.g. self-advocacy, campaigns, skills training, resource development)?

As an organisation that provides all types of disability advocacy as identified by the state's advocacy focus areas, we would like to stress the extent to which each area relies on and is informed by the other. While we agree that some form of categorisation to distinguish between different types of advocacy is important, we believe that the current focus areas identified do not acknowledge this relationship and does not allow for the flexibility required to adequately represent or describe how advocacy services are delivered and by whom.

We recommend that a similar approach be adopted as that of the National Disability Advocacy Program (NDAP) which accounts for a greater variety of advocacy categories. In saying this, an exact replica would not be appropriate as the issue of flexibility is still not properly met within the NDAP program.

Measuring outcomes

How could NSW best measure the outcomes of advocacy organisations?

MDAA supports the sector view that there is a need for improved methods for reporting outcomes, and therefore quality, of disability advocacy organisations. We believe that this may help in greater information around strategies to address systemic issues while also allowing for a way to truly capture the extend of outcomes through a person-centred approach.

MDAA would also like to see outcome measures reflecting the need for services to demonstrate culturally responsive practice in their service provision. This will allow gaps to be identified and appropriate supports be provided by the Government to enable disability services to develop competence in working with diverse people.

MDAA would support adopting the framework currently used by NDAP. We believe that being assessed against a set of standards, or standardised outcome measures, is an effective way to ensure organisations are providing ethical services in line with the social model of disability. However, in relation to reporting on outcomes to demonstrate effectiveness of services, we insist that the time and resources required to comply with reporting expectations must be provided. Further to this, the type of reporting at the moment, that relies heavily on quantitative data, does not adequately reflect the benefits and true outcomes of advocacy support. This is especially so when looking at differences between individual advocacy and self-advocacy. The true nature of outcomes from the services provided by our organisations, would best be demonstrated through a mix of both qualitative and quantitative data which would also show the social impact on communities.

We would be open to having a reporting framework developed by the State Government co design with advocacy organisations and people with disability but insist that the time and resources required for reported be reflected in the funding provided and be proportionate to the size of the organisation.

Factors informing the development of a new system for the provision of funded advocacy services in NSW

What are factors to be considered in seeking to provide services to meet the needs of special communities like regional and remote communities, CALD, LGBTI and indigenous people with disability?

Specialist advocacy organisations play a huge role in facilitating the ability to address the needs of specific communities. Using our organisation as an example, feedback from community members shows that MDAA is a trusted go-to advocacy organisation for CALD people with disability in NSW. The trust established with CALD people, through strong cultural awareness, has been a major factor in ensuring that we are able to provide effective advocacy support.

The importance of organisations that can engage with communities with an awareness of the intersectionalities that play a role in creating additional barriers for people, is particularly important when working with people in distress and experiencing disadvantage. Word of mouth and face to face interactions play a big role in awareness and access to services for our communities and many of the specialist disability advocacy organisations have only developed this connection to communities over quite some time.

This connection and expertise allow us to adequately represent, as we do, the voices of CALD people at all levels on society. MDAA actively participates in several advisory committees, provides community engagement opportunities for people with disability to other services and agencies and ensures that within a multicultural Australia, our Government can protect the rights of all its citizens.

Additional factors to be considered include the knowledge specialist organisations provide to the wider disability sector. Organisations such as MDAA are regularly contacted to provide information to other services on current issues facing CALD communities as well as best practice approaches to working with their clients.

What level of independence from the disability support system should advocacy organisations have in order to be eligible to be funded? /

What types of resources will be required to meet future demand?

MDAA would like to address the above questions outlined in the issues paper together. We strongly support the view that independent advocacy is critically important in providing an ethical service, where true choice and control of people with disability can be exercised. In saying this, the voice of people with disability drives the delivery of services and identifying levels of true or perceived conflicts of interest require in-depth evaluations from all members of any given organisation. We believe traditional services such as personal care, day programs and supported accommodation present a clear conflict of interest and should not be categorised under the same areas as advocacy organisations. However, services such as Support Co-ordination under the NDIS, which MDAA is currently providing, can indeed present a potential conflict of interest but we argue that this can be managed by strict organisational policies, procedures and continuous staff training.

For MDAA, there was a clear need expressed by people from CALD background to assist in implementing NDIS plans in a way that gave people options and choices that were culturally responsive. MDAA was encouraged by then Ageing Disability and Homecare (ADHC) to engage in Support Coordination as they saw a need among CALD communities and acknowledging MDAA's expertise and experience in this space. Having also identified this gap and based on evidence and experience of many years advocating for rights of people with disability, MDAA decided to support CALD consumers with Support Coordination. Additionally, with the uncertainty of funding, organisations were forced to implement such strategies to support the sustainability of their organisations. Before making this decision however, the organisation consulted with governance committee members and staff to establish whether the provision of Support Coordination would align not only with our mission and vision, but also our goals and values as outlined in MDAA's latest annual report. Following this evaluation, and after consulting with CALD consumers, MDAA put in place policies and procedures in order to mitigate any conflict of interest that may arise in line with principles of choice and control.

Having said this, if the funding given to disability advocacy organisations was adequate and sustainable, MDAA would only need to provide this service until the NDIS matures and stabilises, and people from CALD backgrounds with disability face less barriers to implementing their NDIS plans.

We stress that the lack of financial resources, capacity and uncertainty of funding for disability advocacy organisations, play a huge role in this area and call on the NSW to commit to long-term advocacy provision in NSW.

Recommendations

- The inability for federal programs to adequately cover the advocacy support currently provided for state-based issues, requires the NSW Government to keep funding disability advocacy.
- A commitment to long-term disability advocacy funding by the NSW Government to address state specific issues so that the rights of people with disability are upheld in an increasingly complex environment.
- Additional resources be provided to meet the needs of CALD, ATSI and LGBTQI people with disability.
- Specialised advocacy organisations receive adequate financial resources to continue addressing additional gaps and expertise they contribute to the sector as a whole.
- Changes and expectations for reporting on advocacy outcomes be proportionate to the size of each organisation and appropriately funded and an evaluation framework be developed in collaboration with people with disability and advocacy organisations.
- In order to implement and respond to the changes produced through this review, a ‘roll-over’ funding period of 2 years be provided. It must be acknowledged that organisations would need more than a year should they choose to wrap up, merge or undergo any other major organisational changes.