2020

MDAA Submission to the National Disability Strategy Position Paper-July 2020

Multicultural Disability Advocacy
Association of NSW Inc. (MDAA)

About this submission

This submission is produced by the Multicultural Disability Advocacy Association of NSW Inc. (MDAA) in response to the *National Disability Strategy Position Paper, July 2020 (NDS)*. By way of participation in this submission, consultations were held between MDAA consumers and various stakeholders such as the National Ethnic Disability Alliance (NEDA), the Inner West Disability Forum, as well as various academics within the disability sector. The submission talks to various aspects of the NDS, particularly ways in which the NDS can be informed to provide more inclusionary measures for people with a disability, policy reform and areas in need of focus within the disability sector, community awareness and a well-informed engagement strategy. The submission goes on to provide key recommendations to take on board for government as well as non-government organisations to consider.

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.

Consultation with MDAA

Key themes:

- Improving community attitudes across all outcome areas
- The role non-government sector plays to improve outcomes for people with a disability

The panel expressed their satisfaction of the six outcome areas of the current NDS and proposed two new outcome areas, namely 'basic social inclusion' (encompassing individual and community based social inclusion) as well as stating that 'accessible housing should be included as focus areas for people with a disability.' It was noted that a certain number of people with disabilities are unable to access the support they need to be able to live independently within their communities. The government-funded accommodation support is available to only small percentage of people with a profound disability, and even those on emergency waiting lists can wait several years for housing assistance.

There was a strong desire to raise disability awareness among communities through various channels such as media campaigns i.e. television, social media, etc. It was noted that various projects such as Community Voices and Women's Network should be funded, and the need for free mediums such as radio, Youtube, zoom etc. to ensure that the community is spreading the word.

In instances of emergencies such as the bushfires as well as the Covid-19 pandemic, the panel was of the view that information accessibility and support for people with a disability is an area in need of improvement. COVID-19 testing centres are considerably further away for people with a disability and individuals who are vision impaired felt as they were left behind i.e. needing assistance to put a mask on, etc. people with vision impairment have not been proper guided with COVID safety staff. Similarly, the NDIS has been facing a shortage of support workers across the board during the pandemic, as well as funding shortages to support people with a disability in their personal care. There has also been a large shortage of assistive technology consultants.

Even though employers are giving flexible working policies there is not enough to bring people inthey're scared- they should know that people have the option to work from home, or that there is a stable office to work from home. Assistive technology is available if they are willing to work from home. Using web camera software to help people.

It was also emphasised that people with disabilities encounter many difficulties in seeking, obtaining and retaining employment. Entrenched discrimination and/or misconceptions about the adjustments required for some people with disabilities by the employer continues to be the biggest challenge for those seeking work. Qualified candidates with disability are often screened out or overlooked simply because of their disability, hence enforcing discrimination. Many people with disability are also underpaid or unsupported in the workplace. Moreover, by enabling people with disability become less reliant on government income support the economy can be better supported.

Recommendations:

- Systemic policy change and providing information in accessible format
- Equal employment opportunities and making the systems more accessible: improve public service employment rates of people with disabilities and the record of participation of people with disability in organisations serving and supporting people with disabilities (policy changes within organisations)

- The progress of the NDS should be made available to the public at least every 6 months due to transparency and ongoing opportunities for reform
- ❖ A client-focused approach when it comes to consultations with policy makers and people with a disability
- More of a focus in the NDS for accessible housing

NEDA consultation

Key themes:

- Government to invest in creating more awareness
- > Improving community attitudes across all outcome areas
- Engagement plan for people with a disability

A consultation that was facilitated by NEDA included 11 pre-selected members of MDAA consisting of people with disabilities and their carer's. The following questions were considered during the consultation as per below:

- What has changed for you or in your community over the past 5 years?
- What are the things you want to see improved in your life or for people with disability and why?
- What helps you to participate in the community, including to work or study?
- What do you think could be done to help improve the attitudes of people in the community towards people with disability?
 - What parts of your life do you think would improve the most if people in the community had better attitudes towards people with disability?
- How can governments involve people with disability in delivering the Strategy?
- Should governments tell you more about what they are doing under the National Disability Strategy and whether things are improving, or not, for people?
- Do you think organisations, businesses and governments work together well to create a more inclusive Australian society? How could this be improved?
- Do you think governments are clear about what they do to support people with disability?
- Are there organisations other than governments and disability organisations that you think could be more involved in helping to improve the lives of people with disability?

Systemic issues relating to the role of the government when it comes to the disability sector and the policy process in the disability sector were main issues of concern for the group. The lack of community awareness on dealing with disability issues and understanding the concerns of people with a disability regarding a range of issues including: access on public transport, places and information, non-discrimination (treating them fairly), freedom to make their own choices and independence, equal job

opportunity, full participation and involvement as part of the community, security, equal protection, including funding for advocacy are areas of focus in need of attention.

The group acknowledged the governments hard work in 'bridging the gap', however, they have also outlined the fundamental lack of community awareness when it comes to improving the mindset of wider communities relating to disability and the large role carers play.

Recommendations:

- Develop awareness and understanding among people about people with disabilities and how they could have equal footing in the society.
- Fair treatment and equal opportunity for people with a disability in the society they belong.
- Introduce a school curriculum about disability and how to understand the issues of people with disabilities. This would promote an attitude of respect towards people with disabilities, even among very young children.
- ❖ The government should educate everyone about the rights and dignity of persons with disabilities and their achievements and skills to combat stereotypes, prejudice and activities that might harm people with disabilities.
- Providing more job opportunities for people with disabilities with ongoing training and education
- Non-government level initiatives- MDAA is one ideal organisation that involved in helping to improve the lives of people with disability especially with CALD/ NES background.

Inner West Disability Forum Meeting

Key themes:

- Improving community attitudes across all outcome areas
- Engagement plan for people with a disability: How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

The feedback from the IWDF meeting fleshed out issues concerning lack of community awareness in that most individuals do not understand the mechanics of the disability strategy given that they are not exposed to the day-to-day issues faced by people with a disability, unless they have are caring for or personally know of an individual with a disability.

The group discussed a need in emphasis on the role of advocacy as an area to be further addressed within the NDS framework: many of which are experiences felt by those with a disability, their carers as well as advocates through the Disability Royal Commission (DRC) process. This includes the lived experience of vulnerability for people with a disability and what this means to them, and the difficulty for people with a disability in raising complaints. The group felt that if these lived experiences are addressed in the NDS framework, it would better equip individuals to respond to the challenges. Given Australia is a signatory to the UN Convention, they still have programs that are not working at the capacity that they should i.e. the NDIS process.

Participants believe that the stage 1 framework suggested by the NDS on its own cannot fully provide a pathway for improvement in the disability sector for the future, and have put forward various recommendations:

Recommendations:

- ❖ For the NDS to look to more reform that produce less discriminatory outcomes
- Co-designing a process where the role of advocates is paramount and talking directly with people with a disability about their needs
- Building resilience not captured in stage 1
- Response driven planning must be done in consultation with people with a disability
- Employment flexible work arrangements have now been adopted for people with a disability during Covid-19, as services can be delivered remotely
- Audio descriptions over the top of video mediums

Case Study- Support Coordination: NDIS challenges

Veronica has a degenerative spinal condition. In order to prevent further deterioration of her spine, Veronica must maintain a healthy weight. Veronica does this by having a well-balanced diet and light physical activity.

Veronica received funding in her NDIS plan for assistance with the cost of preparation and delivery of meals. The NDIS line item is 01_022_0120_1_1 and comes under Core Supports, assistance with daily life - daily activities so she can achieve her goal of maintaining healthy weight. This part of her plan is agency managed: the rest of her plan is plan managed.

Veronica asked her Support Coordinator for help to find someone to deliver meals to her using this funding. Veronica's Support coordinator signed her up to Kinella and she began receiving meals. She was not offered a choice between providers or given options, nor was any effort made to build her capacity to find a provider independently.

Veronica noticed she began putting on weight and was concerned about how this would impact her condition. She made a request to her support coordinator to change meal providers. Veronica has had success with Lite and Easy in the past, so she asked her Support Coordinator what the process was to change over to them. She was told by her Support Coordinator that all she would need to do is make the order with Lite and Easy, pay upfront and request a reimbursement from her plan manager. Her support coordinator said she would take care of cancelling the service with Kinella.

Veronica followed the instructions her Support Coordinator provided, she ordered from Lite and Easy, paid upfront for the food and submitted the invoice for reimbursement by her plan manger. When Veronica had not received reimbursement for the food preparation portion of the cost (NDIS agrees to cover the meal preparation cost only, a maximum of 70% of the total cost) she contacted her plan manager to find out why she had not been reimbursed.

After some investigation by the plan manager, it was discovered that her reimbursement request had been rejected by the NDIA as Veronica's funds for meal preparation are agency managed and would not reimburse her as Lite and Easy is not a NDIS registered provider. Veronica was left out of pocket for a total of \$168.00, which is a considerable sum for a person on a disability support pension.

During this time Veronica left several phone messages, sent multiple emails, and finally sought the support of an advocate to help her with situation. When she finally spoke with her support coordinator her response was "I thought you understood the email, that is why I did not call you back" Veronica was baffled by this response and replied, "I would not keep trying to speak with you, if I understood what was going on".

Due to the large out of pocket expenses Veronica had incurred, she was unable to afford the co-payment required to purchase food from her original provider. This error by her support coordinator effectively meant she was without food the following week. She was left to choose between, relying on the kindness of others, subsisting on food rations or go into debt to eat.

Throughout this process, Veronica's main concerns has been maintaining her health to prevent further degeneration of her spine. Determined to change service providers, Veronica researched other NDIS registered providers with appropriate meal choices. Veronica found three providers that were suitable and delivered to her area. She contacted each provider requesting a quote for meals. On each occasion she was advised that her support coordinator would need to contact the service provider directly for the quote. Veronica does not have a plan nominee and has the cognitive capacity to make her own decisions, however each service provider refused to give her a quote for service without her support coordinator.

Veronica is currently receiving meals from her original service provider as they will only accept a cancellation of service through her Support Coordinator. Her Support Coordinator is yet to request the service to be cancelled which has led to the Kinella refusing to cancel or reduce the service booking. The knock on effect is, as the service booking has not been cancelled or reduced, even if Veronica finds another provider who meets her needs and is willing to quote the service, the NDIS will not approve the quote as she does not have any funds available.

Veronica showed great tenacity and resilience which is embodied by all people with a disability who must fight to have the most basic of needs met.

Academic Panel discussion

Key themes and recommendations:

All-of Government approach

❖ More inclusion for people with a disability

The panel acknowledged that since the previous NDS, the discourse and conversations surrounding disability in Australia has changed in that there are now resources available which pave the way for other platforms for redress including the Disability Royal Commission, and the NDIS, regardless of their current gaps.

The panel raised concerns relating to the need for stronger policy initiatives to be implemented in the disability sector and clearer responsibilities for the government to establish. They also emphasised on stronger engagement with people with a disability and addressing issues relating to the lack of diversity from CALD communities. This includes a stronger focus on children and young people with disability, and an overarching need for more disability inclusion strategies in Australia with a sole focus on gaining an insight into an individual's experiences and feedback.

Disability inclusion during emergencies was also discussed with safety measures put into place to assist people with a disability during the Covid-19 pandemic and the need to engage with the emergency response sector so that we can ensure that all AUS citizens are as safe as they can be. The panel felt that even though people with a disability are not a homogenous group, in a policy perspective, they are invisible outside of the scope of DSS.

The panel believed the organisational structure for the government in leading the way for policy initiatives could include 3 levels:

- 1. Organisational level including employers and co-workers
- 2. Personal level
- 3. Legal structures

The panel emphasised the need for a strong, visible and high-level commitment from a whole-of-government approach that is overarching with cross-portfolio leverage and commitment. This commitment would involve inclusion and transparency in the form of a report to parliament every year- delivered by the Premier or Prime Minister.

Disability inclusion issues were also addressed in the panel in relation to housing, given that the National Housing and Homelessness Agreement did not include people with disability, which is crucial given it is an area of emphasis in the Housing Strategy, 2020.¹

Recommendations:

- All-of-government approach needed for disability policy implementation as well as strong cross-portfolio expertise (Health, Housing, Transport, Tourism, Infrastructure, National Parks and Wildlife all have a role to play)
- Co-design the NDS with input from people with disability, with a transparent and independent monitoring mechanism and an action plan
- Findings to be reported on a quarterly basis and presented with the agency of people with a disability

¹ NSW Department of Planning, Industry and Environment (2020). *Discussion Paper: A Housing Strategy for NSW*. Retrieved from: https://www.planning.nsw.gov.au/-/media/Files/DPE/Discussion-papers/Policy-and-legislation/Housing/A-Housing-Strategy-for-NSW-Discussion-Paper-2020-05-29.pdf.

General comments

The findings from the various consultations acknowledge that although Australia has come a long way, particularly since the first NDS in 2011, there are various underlying issues that need to be addressed as outlined in the strategy, providing a sense of agency for people with a disability to lead the way with reform, with the view to shed light into their lived experiences at the policy table.

Improving the engagement strategy with consumers so that there is a clear engagement strategy that is more robust, having an all-of-government approach in consultation with a number of stakeholders for cross-portfolio involvement, as well as raising community awareness on various challenges faced by the disability sector are key suggestions to inform future NDS discussions.