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MDAA Responses to the NDIA Support Coordination Discussion Paper

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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) 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. This year, MDAA has supported more than 600 individuals with advocacy services. 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.

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, particularly in relation to Support Coordination, it will ease much of the stress currently experienced by our community of people with disability from CALD background.

This submission reflects the feedback and experiences we have received from our consumers and our team of advocates who work directly with them.

Responses to the Support Coordination Discussion Paper

To support these responses, MDAA has included two extensive case studies located in the Appendix on pages 9-13.

Inclusion of support coordination in plans (Questions 1-5)

What factors should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant's plan?

While supporting hundreds of individuals with their NDIS plans through our advocacy service, it continues to be our concern that NDIS participants from CALD/NESB who

experience language barriers and may be unfamiliar with accessing disability supports, often do not have Support Coordination funded in their NDIS plans. This means that people from CALD/NESB with disability are often put in a position where they are unable to implement their plan, utilise services and exercise true choice and control. MDAA strongly believes that funded Support Coordination is vital as it enables NDIS participants, particularly from this group, to understand and interpret their plan, navigate a new disability service market, and achieve plan goals.

MDAA understands that the Support Coordination Standard Operating Procedure (SoP) that guides Local Area Coordinators (LACs) and Planners in their decisions on whether to include funding for Support Coordination, does not specifically highlight the need to consider CALD as an indicator of the potential need for support coordination. From our previous advocacy around this area, we understand that indicators include; having limited family and social networks, having a support network that might be at risk, identifying as Aboriginal or Torres Strait Islander and living in remote communities, forthcoming life transitions, being newly diagnosed or recently acquiring a disability and having very low levels of community participation.

While we support these as strong indicators of need, **we stress the importance of considering people from non-English speaking backgrounds with disability as an identified vulnerable group and explicitly including them within this list. Furthermore, this support should not be limited to a participants' first plan but should continue to be funded until a proper evaluation can be made of their capacity and confidence to continue utilising their plans in a meaningful way.**

How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?

Once funded for support coordination, the interaction of support coordinators particularly with LACs, is crucial in establishing an initial connection with participants. 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 initial support from NDIS supports such as LACs. The role of Support Coordinators is often unclear to many of the people we

support and as such, this initial support and effective interaction between LAC's and Support Coordinators holds greater chance for an increased level of utilisation of support coordination.

Stemming from this, MDAA stresses the need for better handover procedures between various NDIS supports. Often 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. Lack of communication and clarity often means that for 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.**

Role of support coordination (Questions 6-8)

What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

MDAA believes that the initial function a Support Coordinator should perform is to help participants understand and interpret their plan. Following this, Support Coordinators should work together with participants to build on both formal and informal supports. Importantly, Support Coordinators should build on the capacity of individuals in this way by making sure a variety of possible connections to services are presented to the participant. No decisions should be made on the behalf of a participant regarding cost or choice of services. Our interaction with Support Coordinators when supporting MDAA consumers has demonstrated that often participants are *directed* to particular services. This is concerning as it does not work towards building capacity, establishing participant choice and control, and has in some cases demonstrated a serious conflict of interest between the support coordinator and service provider. For some participants from CALD/NESB who may not have access the necessary information to know their rights and ownership over their NDIS plans, including negotiations with providers, there is a greater likelihood that they do not have full choice and control over the services they receive.

Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?

Unsurprisingly, areas such education, accommodation and employment are often a priority for people with disability. National data continues to show that people with disability still experience greater risk of poverty and serious barriers to inclusion in education and the workforce. On this basis, Support Coordinators play an important role not only in assisting participants reach their plan goals, but also in ensuring the NDIS as a national scheme assists in addressing these greater issues.

As a disability advocacy organisation, MDAA has assisted hundreds of individuals with issues relating to education, accommodation, and employment. From this work, we know firsthand the complexities of assisting consumers navigating these spaces and liaising with various departments. **We believe that without targeted support coordination services for these areas jeopardises the effectiveness of support received by individuals, as well as the overall quality of work performed by a Support Coordinator.** Consumer feedback supports this view as we receive noticeably better feedback from participants who are lucky enough to have a Support Coordinator that can effectively help them in these areas. It is important to note that assistance in areas such as education, accommodation, and employment, which are fundamental rights for Australians, should not come down to luck.

Quality of Support Coordination (Questions 9-13)

Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

MDAA would like to acknowledge the quality of work and support provided by some Support Coordinators. We have seen Support Coordinators who know exactly how to connect people to services and who also understand that the best way to do this is to build the capacity of the participant and do so in a culturally responsive way.

However, the majority of the current workforce we have encountered are hard to get in contact with and offer very little support for capacity building. Moreover, the lack of disability and cultural awareness training is evident in the interactions had with participants.

As the NDIS develops and within the first few years of the scheme's complete rollout, we expect that recruiting Support Coordinators with strong experience and skills in the sector or performing this particular role is difficult. **For this reason, MDAA stresses the need for minimum qualification requirements or industry accreditation be in place for Support Coordinators.**

We have supported consumers whose Support Coordinators have never worked with people with disability before. The attitudes and practice that stems from minimal knowledge of the disability space is often detrimental to the current social change being led by the NDIA and disability sector generally, that of empowerment and full inclusion and participation of people with disability. MDAA is also concerned with the lack of cultural awareness training when working with people with disability from CALD/NESB and considers training in this area necessary for all NDIS supports.

For many, the general impression, as demonstrated through their practice, is that their job is to be a connector as opposed to supporting, building capacity and empowering participants to manage their own plans.

Building capacity for decision making (Questions 14-16)

The feedback we have received from our consumers, and our experiences advocating for people with disability has made it clear to us that the role of Support Coordination in building the capacity for decision making is critical yet undeveloped in current practice. This is most clearly evident in the case studies presented in the appendices of our submission.

The feedback we have received across our seven offices in NSW supports the claim that many Support Coordinators are just connecting participants to services rather than empowering them to learn how to do it themselves. MDAA has worked with consumers who are on their fourth plan and are still unsure about how things work and what exactly they are entitled to through their plans. We believe that this points directly to the lack of time and emphasis placed on the importance of capacity building within the support coordination role at any level.

MDAA is concerned that should support coordination pricing be determined, even in part, based on progression of participant goals and outcomes as is being explored in

the position paper, this may act as an additional deterrent for Support Coordinators to take the time to develop the capacity of individuals to understand their plan and the new disability service environment. The additional support required by people with disability from CALD/NESB to combat the existing information barrier means that they would be at a further disadvantage.

Clearer guidance and emphasis given to Support Coordinators on capacity building as a key role of their position is necessary. Capacity building as a concept especially when working with people with disability must be understood by all Support Coordinators further supporting the importance for there to be minimum qualification requirements or industry accreditation and training in place for all NDIA staff.

Adding to our previous point, the communication between NDIS supports, namely Support Coordinators and Plan Managers, also play an important role in this area. Many plan managers have already implemented a system in which participants must review and approve the payment on invoices from service providers. **MDAA supports its consumers' recommendations that this practice become mandatory for all Agency and plan managed participants. This provides participants the opportunity to exercise true control of their funding, build capacity towards self-management and prevent exploitation of people with disability providers.**

How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?

MDAA believes that Support Coordinators must display a duty of care when working with participants, and perform at least a basic level of advocacy support. If any instances of abuse, neglect, exploitation or misconduct by service providers are suspected, Support Coordinators should at a minimum raise these concerns, assist participants in liaising effectively with service providers, and if greater advocacy is required, to ensure participants receive assistance by referring them to an advocacy organisation. If a referral is made, Support Coordinators should work effectively with advocates to ensure appropriate information and documentation is passed on to reach the greatest results for the participant.

We acknowledge that the NDIS cannot do everything. Not only will many people with disability not be eligible for the scheme, many participants may require a greater level of advocacy to support them with various issues. For this reason, other systems need to be in place to make sure the rights of people with disability are upheld.

When exploring this issue, it is critical that funding for disability advocacy is maintained. Organisations such as MDAA assist people with disability with issues across a variety of systems and levels of government. The level of support in areas of education, transport, immigration, health and other community services will not be covered by the NDIS and as such, we must ensure people do not continue slipping through the gaps.

Summary of Recommendations

Recommendation 1:

Explicitly include people from culturally and linguistically diverse/ non-English speaking backgrounds with disability on the Support Coordination Standard Operating Procedure (SoP) that guides Local Area Coordinators (LACs) and Planners in their decisions on whether to include funding for Support Coordination.

Recommendation 2:

Support Coordination should not be limited to a participants' first plan but should continue to be funded until a proper evaluation can be made of their capacity and confidence to continue utilising their plans in a meaningful way.

Recommendation 3:

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 4:

MDAA supports the need for targeted support coordination services in areas such as employment, education, and accommodation. Not having these in place jeopardises the effectiveness of support received by individuals, as well as the overall quality of work performed by a Support Coordinator.

Recommendation 5:

MDAA stresses the need for minimum qualification requirements or industry accreditation be in place for Support Coordinators. We stress that it should be a requirement that staff are provided with adequate training and display competence in working effectively and responsively with people from cultural and linguistically diverse backgrounds. Training at a minimum should include cultural competence and disability awareness training.

Recommendation 6:

MDAA supports its consumers' recommendations that participants must review and approve the payment on invoices from service providers become mandatory for all Agency and plan managed participants. This provides participants the opportunity to exercise true control of their funding, build capacity towards self-management and prevent exploitation of people with disability providers.

Recommendation 7:

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.

Appendix

Case study 1

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

Erica 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 maintain a healthy weight. This part of her plan is agency managed; the rest of her plan is plan managed.

Erica asked her Support Coordinator for help to find someone to deliver meals to her using this funding. *Erica'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.

Erica 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. *Erica* 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.

Erica 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 manager. When *Erica* 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 *Erica's* funds for meal preparation are agency managed and would not reimburse her as Lite and Easy is not a NDIS registered provider. *Erica* 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 *Erica* 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" *Erica* 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 *Erica* 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, *Erica's* main concerns has been maintaining her health to prevent further degeneration of her spine. Determined to change service providers, *Erica* researched other NDIS registered providers with appropriate meal choices. *Erica* 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. *Erica* 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.

Erica 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 *Erica* 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.

Erica 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.

Case study 2

Maria has significant and permanent disabilities which affect all facets of her life preventing her from doing even simple tasks. Her disabilities include chronic degenerative spine disease and other bone and joint conditions, as well as psychosocial disability and heart conditions.

Once approved for NDIS funding including support coordination, *Maria* eagerly engaged the services of a NDIS registered cleaner. She requested support to clean the outdoor area of her home.

Unfortunately, the cleaning service that was provided resulted in significant damage to her home, went against the parameters of her initial request and has contributed to physical and psychological harm to *Maria*.

Maria contacted her Support Coordinator to ask for assistance with this matter but was disappointed by the level of support and guidance she received in raising her concerns.

“I felt really let down by my support coordinator, I thought she was supposed to help me with these kinds of things... I trusted my support coordinator; she chose this service provider, so I thought they were good”.

“When I asked her why she had not called me back she told me she was busy helping someone with a crisis. I said I’m in crisis, I’m in extreme pain and I don’t have enough money for the treatment I need, I am in crisis too!”

“I explained to my support coordinator I had a signed service agreement, the agreement set out their obligations and [the service provider] was not meeting them... My support coordinator said [the service provider] told her that I had asked for it... because I agreed to the service, I was not entitled to have the damage repaired. I corrected her, I had not requested high pressure cleaning, I explained what happened, [the service provider] told me it needed to be done”.

Maria had high expectations of her Support Coordinator when she signed up for the service. She was looking forward to being supported to understand how the NDIS works, finding the services she needs and ultimately navigating the scheme successfully. After phoning her Support Coordinator to explain the extent of the damage to her home, she said, “I don’t know what I can do to help you, why don’t you get your advocate to help?” “I told her you are the one that has all of the documentation. I will have to take this further”.

She has contacted her Support Coordinator on multiple occasions seeking support to resolve this issue. She explains that her support coordinator has not answered calls or not responded to voice mails as her needs were prioritised lower than other participants.

This has been an arduous and exhausting experience for *Maria*. It has damaged her both physically and psychologically leaving her drained and mistrusting of service providers.

Maria’s support coordinator did not support her to find a new service, rather has ignored her phone calls and messages.

Further to this, *Maria’s* support coordinator has not properly explained or built her capacity to understand why she is not able to use her NDIS funding to pay for additional Chiropractic treatments. When beginning her NDIS plan, *Maria’s* chiropractor provided her with the relevant line item to claim payments from the NDIS. *Maria’s* chiropractor explained that she receives treatments that are not chiropractic but he is referred to a Chiropractor as it is a commonly understood title, he provides *Maria* with treatment accepted by the NDIS. He sent her the details of the treatments he provides her also with the relevant NDIS line item.

When *Maria* relayed this conversation to her support coordinator with the offer to email her the information provided by her Chiropractor, her support coordinator told her “Not to bother”. Her support coordinator stated it is not covered under the NDIS with no further explanation.

In addition, as both [the service provider] and the Support Coordinator as NDIS registered providers, both have agreed to abide by the NDIS Terms of Business for Registered Providers. Registered providers are mandated to notify the NDIS if there has been a breach of any law or disability service standards. Both service providers are complicit in this breach as neither notified the NDIA.

The NDIS Terms of Business for Registered Providers outlines the expectations of quality of service to be provided to NDIS participants to ensure they are able to achieve their individual outcomes.

The Terms of Business for Registered Providers clearly states:

“Registered Providers must act in good faith and in the interests of the participant”

Throughout this ordeal, it is evident that neither service provider nor support coordinator, has acted in the best interest of *Maria*. *Maria* was been left at the mercy of an unscrupulous service provider, who took advantage of her, coercing her to accept service she did not want or request. At best, she was left with inadequate support from her Support Coordinator during this point of crisis, which falls squarely in her purview.

“How about duty of care? I don’t understand why the Support Coordinator did not assist me to find another suitable service, rather she is agreeing with [the service provider’s] suggestions”.