



Submission to the Joint Standing Committee on the NDIS General Issues Inquiry

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The Neurological Alliance Australia is an alliance of 16 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular conditions or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia, the Childhood Dementia Initiative, the Mito Foundation, Polio Australia and Fragile X Australia.

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy.

The Neurological Alliance Australia represents nearly 2 million Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over \$50 billion.

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the Joint Standing Committee on the NDIS General Issues inquiry.

The focus of the comments provided in this submission are on key areas that will impact on people affected by neurological disorders or progressive neurological and neuromuscular conditions for which our member organisations provide services, support and advocacy. Included are comments provided by our member organisations and, in some instances, directly from people living with those conditions represented by the NAA.

The [Neurological Alliance Australia](#) is an alliance of national not-for-profit peak or national patient organisations representing adults and children living with neurological disorders or progressive neurological and neuromuscular conditions in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment in these conditions.

The Alliance represents nearly 2 million Australians¹ living with these conditions that have no cure, with an estimated annual cost to the Australian economy of over \$50 billion². This group includes adults and children, carers, families, friends and workmates whose lives have been affected by a progressive neurological or neuromuscular condition or a neurological disorder. The impact of neurological disorders and progressive neurological and neuromuscular conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing or minimising financial and emotional burden. The impact of these conditions on quality of life is substantial and well documented. For example, on average, the Quality of Life (QoL) as measured by the health state utility valuation (HSUV) of the Australian MS population is 31% less than the Australian population norm.³

Progressive neurological and neuromuscular conditions and neurological disorders are a set of complex and disabling conditions representing around 14% of NDIS participants⁴. While this broad group contains conditions with various characteristics, different disability trajectories and life expectancy, nearly all are degenerative, all are incurable and few have proven treatments. This results in significant disability and the need for expert

¹ Based on an aggregation of data from those NAA members who have commissioned prevalence studies

² Based on an aggregation of data from those NAA members who have commissioned economic impact studies

³ https://www.msaustralia.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

⁴ Based on aggregation of neurological primary disability groups in the NDIS quarterly reports (<https://www.ndis.gov.au/about-us/publications/quarterly-reports>)

information, specialised care and personal assistance which is responsive to individual needs.

The Alliance works collaboratively to identify and advocate for opportunities that will drive improved quality of life for people living with these conditions and funding to support research.

Summary of recommendations

The NAA recommends:

- 1. That the NDIA commits to educating and training staff and contractors about neurological disorders and progressive, degenerative, neurological and neuromuscular conditions.**
- 2. That the NDIA develops and implements a set of "guiding principles" to minimise reassessments where the condition's course is predictable, ensure greater flexibility to respond with accelerated reviews when increased supports are required mid-plan due to condition progression and improve consistency in decision-making.**
- 3. That the NDIA introduces a substantial core group of staff (a Neurological Community of Practice) with expertise in neurological disorders and progressive degenerative, neurological and neuromuscular conditions who can act as a point for referral for all NDIA staff and contractors.**
- 4. That the NDIA appoints a representative from the Neurological Alliance Australia to the Industry Chief Executives Forum**
- 5. That the NDIA establishes a Neurological Advisory Group.**
- 6. That the government allocate funds to create a skilled workforce to support young people to transition out of residential aged care.**
- 7. That the government introduce an independent pricing mechanism and work closely with providers to co-design any trials of new systems to ensure effective and efficient delivery of innovative services.**
- 8. That the NDIA revisit the objectives of Tier 2 to provide services and supports for disabled people outside individualised plans through the expansion of disability organisations' community development and capacity building programs**

Core issues

The NAA and its member organisations have made numerous submissions to NDIS-related inquiries in recent years. The most recent submission was to the Joint Standing Committee on the NDIS inquiry into the Capability and Culture of the NDIA in December 2022 and we commend this submission and the recommendations made therein to you.

Overall, our core issues remain the same.

Lack of understanding

The conditions we represent are complex, and often degenerative and progressive. As such, support requirements do not reduce across time.

These conditions and disorders are generally poorly understood, so clients face a range of interlocking issues that potentially undermine service level trust and resilience (e.g. multi morbidities, misdiagnosis, delays, working with multiple practitioners simultaneously, feelings of not being believed).

Lack of NDIA staff knowledge and training affects the quality of assessment and care received by clients and their families (e.g. having to repeatedly explain their conditions, refusal of reasonable requests, inconsistent decision making, psychological impacts in part due to not being believed and respected).

For example, many people with ME/CFS are unable to access the NDIS due to poor understanding of the condition (especially post-exertional malaise). For those with ME/CFS who do access the NDIS, the process seems to be an initial rejection of their application, which forces patients to appeal. Many obtain access following an appeal, which means they did meet the requirements initially. This causes a large amount of unnecessary stress, lost energy and expense.

Existing training materials about these conditions, appear not to have been widely used nor consistently applied.

Invisible disabilities

The conditions we represent often manifest in “invisible disabilities” such as brain fog, incontinence, severe fatigue and pain.

A CSIRO publication in Australian Health Review entitled, “*Do people with multiple sclerosis receive appropriate support from the National Disability Insurance Scheme matching their level of disability? A description of disease burden and societal costs in people with multiple sclerosis in Australia (BAC-MS)*” published in September 2021 correlates disability with the approved package value. The study has found ‘striking variability in packages approved’ citing restricted mobility as the main driver or decision-making factor. This finding appears to be consistent with the idea that **visible disability is more**

easily understood than invisible disability or functional impairments such as cognition decline.⁵

Thin markets and long waiting times

People with neurological and neuromuscular conditions living in rural, regional and remote areas often face long waiting times to access services and support, including allied health professional support. Long waiting times can mean that a person's initial request is no longer relevant by the time support is provided, especially if symptoms worsen. In a recent example, an NDIS participant living with MS in northern Tasmania has been unable to obtain access to an occupational therapist (OT) for an assessment for urgently needed assistive technology. It is likely that this assessment will now be undertaken by video. The participant acknowledges that this solution is suboptimal but concedes, "it is better than nothing". One NAA member organisation reports a 12 month wait for an OT appointment in Tasmania at present.

Need to improve communications from the NDIA

Participants sometimes feel that the supporting documentation they have obtained from neurologists and allied health professionals, often at great expense, time and effort, is neither understood nor taken into account by NDIA decision-makers. This material is essential to the care and wellbeing of the participant, as interventions by healthcare professionals as soon as possible after diagnosis can often slow the progression of disability and thus the quantity of NDIS funds required. For poorly understood conditions with no biomarkers or approved treatments, these supporting documents are an essential part of building the case of disability and need for NDIS support.

Some people are unable to clearly articulate their own condition or their own needs over time, so the burden of explanation falls on family members and carers. There is an inequitable emphasis on self-advocacy; people without a support network and those with cognitive and behavioural challenges do poorly in NDIS assessment processes.

Participants do not always understand why their access has been denied or their plans cut. The NDIA needs to adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations. One NAA member organisation reports that "even when the NDIA provides timelines to participants the NDIA does not always adhere to them or meet them; we see time and time again these timelines being blown out".

⁵ Lechner-Scott et al, *Do people with multiple sclerosis receive appropriate support from the National Disability Insurance Scheme matching their level of disability? A description of disease 'burden and societal cost in people with multiple sclerosis in Australia'* (BAC-MS), Australian Health Review, 2021, 45, 745-752
<https://www.publish.csiro.au/ah/AH21056>, 21 Sept 2021

Inconsistent decision-making leading to plan inequities

A lack of understanding of the complexities of neurological and neuromuscular conditions leads to inconsistent decision-making and inequities in plans.

For example, a lack of understanding of mitochondrial disease (mito) leads to a focus on more easily understood disabilities, usually sensory. People with mito are being accepted into NDIS because of their early presenting vision and/or hearing impairments. Then, when their underlying condition (mito) progresses, they face the unusual process of 'adding a disability', even though their underlying condition has not changed, but simply progressed.

Accessing “complex support coordination” (level 3 provides an extra \$90/hour) is difficult once general support coordination has been allocated – this is inconsistently applied by the NDIA, and funding depends on the knowledge of the particular NDIA planner, leading to inconsistencies in outcomes. Huntington’s Australia estimates that 70% of their support coordination work is at level 3 but 98% of funding is at level 2. (This estimate is supported by an independent NDIS accreditor.)

Plan flexibility and plan management

Most of the conditions represented by the NAA are unpredictable and some are often fast progressing. This is particularly true of the conditions under the childhood dementia umbrella. In these cases, greater flexibility within the system is needed to respond with accelerated reviews when increased supports are required mid-plan due to condition progression. It is frequently reported within the childhood dementia community that the "change of circumstance" process can often take several months and families are left without critical supports in the interim.

Given the genetic cause of the childhood dementia disorders, it is not uncommon for there to be multiple children/young adults in a single-family unit with similar needs, but no mechanism to synchronise plan reviews. This results in significant administrative overhead for both the NDIA and the family. Plan reviews should be synchronised (as appropriate) when there are multiple members of a single household with the same condition.

Due to the complex nature of the conditions represented by the NAA, engagement of appropriate service providers is critical for participants. As such, many of our participants and their carers and families opt to self-manage their plans and it is important that all aspects of plan management can be self-managed with adequate funding provided for the associated costs.

Policy solutions

Improving NDIS education about neurological/neuromuscular conditions

Better education within the NDIA to improve understanding of people's changing needs over time, will help address the frustration felt by NDIS applicants and participants in accessing NDIS support, and having to explain their condition repeatedly before moving on to the essential conversation about their inevitable increasing care needs and the increasing levels of functional impairment that the condition is causing. In some cases, if people can receive appropriate supports, it can allow their symptoms or disability progression to stabilise. Without appropriate supports, a person's condition can deteriorate rapidly.

Recommendation 1

That the NDIA commits to educating and training staff and contractors about neurological disorders and progressive, degenerative, neurological and neuromuscular conditions.

Establishing a set of guiding principles

A set of guiding principles for neurological and neuromuscular conditions is needed. This would improve consistency in assessment and provision of adequate supports.

For example, for some neurological disorders or progressive neuro-degenerative conditions, an annual functional OT assessment to provide evidence of diagnosis and ongoing support needs is unnecessary. This would reduce the need for as many assessments and reduce costs (including unnecessary administrative appeals). This principle could be applied in particular to conditions such as the primary progressive form of MS and Machado-Joseph Disease, for example, where the condition's course is fairly predictable. People with ME/CFS often experience little change in their symptoms from year to year and if any improvement was to occur, it typically takes years. A 5-year re-assessment may be more appropriate.

Conversely, as described above under "Plan flexibility and plan management", greater flexibility within the system is needed to respond with accelerated reviews when increased supports are required mid-plan due to condition progression. This flexibility should include the synchronisation of plans when there are multiple members of a single household with the same condition and the assurance that all aspects of plan management can be self-managed with adequate funding provided for the associated costs.

Recommendation 2

That the NDIA develops and implements a set of "guiding principles" to minimise reassessments where the condition's course is predictable, ensure greater flexibility to respond with accelerated reviews when increased supports are required mid-plan due to condition progression and improve consistency in decision-making.

Condition-specific information and a Neurological Community of Practice

Several NAA member organisations (MND Australia in 2017, MS Australia in 2019 and Huntington's Australia in 2022) worked with the NDIA to develop and provide to the NDIA condition-specific "snapshots" to assist NDIA staff, such as planners or LACs (Local Area Coordinators), to better understand these conditions and improve their interactions with people living with Huntington's, MND and MS. The snapshots and accompanying videos set out the sort of information about these conditions one could reasonably expect NDIA staff to know.

Unfortunately, there is little evidence that this material has made any difference over time to interactions with people with MND or MS, especially those who experience invisible symptoms, symptoms that come and go or symptoms that rapidly progress.

We encourage the NDIA to expand this process with other neurological and neuromuscular conditions which the NAA represents, to ensure that NDIA staff have greater understanding of these conditions.

While the development of these materials was a good start, on their own they are insufficient to educate NDIA staff and shift interactions with people with neurological and neuromuscular conditions. For example, the MND Practice Guide is now *not* being well-utilised resulting in no consistent interactions with people with MND particularly when their condition rapidly deteriorates (noting that half die within two years of diagnosis).

Case study:

Person living with Motor Neurone Disease

Jeff waited three months after the report from his occupational therapist was submitted to the NDIS for a stand-up recliner chair. The delay was caused by the NDIS approval process rather than low stock from the supplier. This meant that Jeff could not sit in the lounge room if he was home by himself; he had to sit on or lay in bed during the day while his wife and kids were at work or school. If he did sit on the lounge, he had to rely on his wife or kids to lift him out of the chair. This impacted greatly on Jeff's independence.

Jeff's bathroom modifications took two years to complete after the original quotations and report had been submitted to the NDIS. A long list of circumstances caused this delay, primarily administration issues. A part of his Occupational Therapist report was to include a body dryer to allow him to shower in privacy without a carer. The NDIS denied the provision of this device with the option to dispute the decision. Jeff did dispute this decision, as it would set his bathroom renovations back a further three months. One of

the verbal reasons the Review Committee gave was that Jeff did not need this device due to the length of time that he had been living with Motor Neurone Disease. At that stage, he had been diagnosed for 2 ½ years and therefore would not likely need the equipment for long. The Case Manager informed Jeff that he could dispute this decision again, which would probably take another three months.

After two years the bathroom renovation suits all of Jeff needs, but while decisions were caught up in “red tape”, he lost his independence to enable him to shower alone in privacy.

If this material was used by assessors, many other organisations would like to develop similar guides for their conditions, many of whom struggle to gain access to the NDIS due to poor understanding of their condition.

We encourage the NDIA to invest in education and to revisit the establishment of a Neurological Community of Practice, an initiative which had the potential to create change in NDIA’s approach to these conditions.

In 2020 the NDIA commenced the establishment of a Neurological Community of Practice (led out of the NDIA Head Office in Geelong) with the goal of establishing principles to guide planners as they work with participants with these conditions. This initiative was subsequently abandoned with no communication or consultation.

Recommendation 3

That the NDIA introduces a substantial core group of staff (a Neurological Community of Practice) with expertise in neurological disorders and progressive degenerative, neurological and neuromuscular conditions who can act as a point for referral for all NDIA staff and contractors.

Case study:

Rebecca, 45, is an ex-health professional, and a single mother with a one-year-old child. She lives with her widowed mother who is 79.

Rebecca’s sister had to give up her work for eight months to care for Rebecca after post-partum progression. Rebecca has secondary progressive MS, EDSS⁶ of 4.5. She can’t walk more than five metres unaided. She is at risk of falls and has fallen in the past. She experiences incontinence and has a clinical diagnosis of depression and anxiety. Rebecca has brain fog daily, chronic fatigue, cognitive processing difficulties and word-finding difficulty, and struggles to complete any paperwork.

Rebecca was contacted by the NDIA upon receipt of *access request form* to be asked “can you catch the bus and walk 10 metres?”; Rebecca answered that ‘it would depend on the day’ and was subsequently rejected over the phone.

⁶The Expanded Disability Status Scale (EDSS) is a method of quantifying physical disability in multiple sclerosis and monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of people with MS. The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability. Scoring is based on an examination by a neurologist.

Case study:

Kelly Engelhardt, 41, was first diagnosed with multiple sclerosis in July 2001, while studying teaching at university. Her teaching career was cut short as her condition worsened.

Married with two children, Kelly has now been receiving NDIS support for five years after her first application was denied.

While enormously grateful for the support, Kelly is frustrated by the NDIA's lack of understanding about her condition.

"I was out at the shops, and I just burst into tears. And I spoke to my neurologist, and he was like, 'Are you kidding me? They are asking you for proof that you can't be cured?' So it was really deflating. If they (the NDIS) don't understand about it not being cured, how are they going to understand what help I need."

"We all have different types of MS, within those different types we all have different degrees of disability and you need to understand everybody's case is completely different for what we need to make our lives better."

Kelly's mobility has dramatically declined in the last three years, and she requires the use of a wheelchair when leaving the house. Four months ago it was hard to go to the local shopping centre but she could do it. Now it has become too challenging and the impact on her health too great.

"I'm fatigued all the time, always so tired. It's the fatigue, the pain...I forget things easily."

In her most recent NDIS assessment, Kelly was left disappointed and baffled that her request to increase her access to an exercise physiotherapist from one hour a week to two hours a week was knocked back this year.

"I never wanted to stop working, I never wanted to rely on the government to help me with things. I am exceptionally grateful that the NDIS exists, more than I could ever explain, because it helps me. But I need help in some ways that are missing from the NDIS. To give me hope that the decline can slow down, that I can be a better mum and wife for as long as I possibly can."

Case study:

Daniel, a man living with the degenerative neurological condition Machado-Joseph Disease was funded for 2:1 ratio of supports 24/7 in his NDIS plan from 2018. Evidence was provided through an OT functional report, and subsequent reports were provided in later years demonstrating his functional decline. In 2021 the NDIA cut his funding to cover 1:1 ratio of supports only.

His Support Coordinator (MJD Foundation) communicated this as a 'catastrophic risk' to the participant and refused to direct his SIL provider to reduce the ratio of supports. In going through NDIA processes, a 12-month-old OT functional assessment report was deemed to be 'out of date' and could not be used as evidence. With a wait list for another OT functional assessment many months long, Daniel will run out of funding 3 months before his NDIS plan date.

In response to this issue, the NDIA has stated that the MJDF must fund the difference between 2:1 and 1:1 supports, despite the fact that his NDIS plan previously funded this for many years and he has a degenerative condition.

Establishing a neurological/neuromuscular voice within the NDIA

The establishment of a neurological/neuromuscular voice within the advisory and consultative structure of the NDIA would ensure fair representation and better support for our community and help to address many of the issues set

out in this submission in a constructive, co-operative way. The “neurological/neuromuscular voice” could be achieved in two ways:

A. Representation on the NDIA Industry Chief Executives Forum

The NDIA currently engages with NDIS provider peak bodies and provider representatives on improvements to the NDIS and the NDIA’s processes and practices through the Industry Chief Executive Forum (ICE Forum). There is currently no neurological or neuromuscular voice on the ICE Forum.

Neurological and neuromuscular representation on the ICE Forum would provide our member organisations the same opportunity for two-way collaboration as other organisations represented on ICE. This would assist the NDIA to test policies, practices and processes to improve the NDIS and to gather views and feedback on key issues.

For example, people with neurological and neuromuscular conditions usually prefer to access specialist services and supports from providers who understand and have long-standing expertise in their condition. Specialist, expert services and support also lead to better outcomes for participants.

The focus of the NDIA on gaining efficiencies by utilising large providers often means smaller, specialist providers cannot break even, especially if they are providing high quality, though small, allied health and support coordination services. A good example of this limitation on smaller providers is the 30-minute travel time claim limit for the time spent travelling to each participant, as set out in the NDIS Pricing Arrangements and Price Limits 2022-23. This limits participants’ choice and access to specialist expertise, and this in turn will lead to a smaller number of large, national, generalist providers and a reduction in specialist, expert services overall which may result in poorer and more costly outcomes overall.

The Forum would give the NDIA CEO the opportunity to engage directly with neurological and neuromuscular voices, which would assist in improving understanding of these conditions and patient needs.

Recommendation 4

That the NDIA appoints a representative from the Neurological Alliance Australia to the Industry Chief Executives Forum

B. Establishment of a neurological/neuromuscular advisory group

An advisory group representing the neurological/neuromuscular community would be of enormous benefit to the NDIA, to provide advice and recommendations on improving the NDIS for participants living with these conditions. The group could include clinical and allied health experts, service providers and people with lived experience. The Neurological Alliance Australia (NAA) is keen to assist the NDIA with the establishment of this advisory group.

Recommendation 5

That the NDIA establishes a Neurological Advisory Group.

2023 Federal Budget measures that impact on the NDIS

Overall, the NAA welcomes those 2023 Federal Budget measures designed to improve the NDIS. The funding commitments to improve the effectiveness and sustainability of the NDIS, to support quality and safety and to improve consistency and equity in decision-making for access and planning decisions for NDIS participants are measures that are reassuring to our communities.

The announcement by the Minister that, “Whilst the Scheme remains demand-driven, the NDIS Financial Sustainability Framework agreed by National Cabinet will provide an annual growth target in the total costs of the Scheme of 8 per cent by 1 July 2026, with further moderation of growth as the Scheme matures⁷”, will require further detail as to how this “cap” will operate. Applicants and participants will remain anxious about the impact on their own circumstances until further details emerge.

Other welcome NDIS-related budget allocation measures announced as part of the budget, include: better planning (\$73.4 million), flexible plans (\$63.8 million), strengthening independent living decisions (\$56.4 million) increasing the take up of evidence-based supports (\$29.3 million, trialling blended payment models (\$24.6 million) and \$48.3 million to crack down on fraud. The design and implementation of these measures will need careful co-design with participants and providers to ensure proposed improvements can be practically implemented and will not have a negative impact on quality services and participant safety.

Funding of \$7.6 million to pilot approaches to partner with communities to improve access to supports in remote and First Nations communities is welcome, once again, provided that design and implementation is co-designed with communities to ensure long term effectiveness.

Young people in residential aged care

An allocation of \$7.3 million was made in the budget to further reduce the number of people under the age of 65 living in residential aged care (RAC). The issue of young people with disability having to live in nursing homes is a perennial one. Despite overall reductions in the numbers of young people being admitted to and living in RAC⁸, there is still more work to be done.

⁷ <https://www.ndis.gov.au/news/9087-media-release-minister-national-cabinet-commits-sustainable-ndis>

⁸ <https://www.aihw.gov.au/reports/aged-care/younger-people-living-residential-aged-care/summary>

As identified by the Summer Foundation, what is missing from the budget is an allocation “for the skilled workforce needed to support this group to transition out of residential aged care”⁹.

Tailored expert support from an experienced allied health professional is required to assist young people living in RAC to make an informed choice about their housing, services and support options, identify those accommodation options available and help them to move. Access to support coordinators who do not possess this expertise will not result in successful outcomes.

Recommendation 6

That the government allocate funds to create a skilled workforce to support young people to transition out of residential aged care.

Implementation of findings from the Disability Royal Commission

The Disability Royal Commission has now been in operation for just over four years and is due to hand down its final report in September. The report will no doubt include many recommendations for improvements that will need to be implemented, especially in areas not covered by the NDIS.

Unfortunately, there did not appear to be any allocations in the budget to address these recommendations.

Impacts on service providers

As stated earlier, some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports, so changes to policies impact service provision are also important to us. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy.

The NAA joins the NDS in calling for incentives for providers to innovate service delivery; current pricing and payments have not created the conditions for innovation.

An independent pricing mechanism and government working closely with providers to co-design any trials of new systems will ensure effective and efficient delivery of innovative services.

The Fair Work Commission Determination on 3 March 2023¹⁰ in the aged care work value case, gave home care workers in the aged care sector a 15% pay increase which is funded by government. This decision has the potential to create rostering and payroll complexities for those service providers who

⁹ <https://theconversation.com/the-budget-includes-7-3-million-to-get-more-young-people-out-of-aged-care-homes-is-it-enough-205383>

¹⁰ <https://www.fwc.gov.au/documents/awardsandorders/pdf/pr751296.pdf>

employ home care workers in both sectors. There are also concerns (raised by National Disability Services) that the pay rise will disincentivise disability home care work, leading to NDIS participants missing out on home care services.

Recommendation 7

That the government introduce an independent pricing mechanism and work closely with providers to co-design any trials of new systems to ensure effective and efficient delivery of innovative services.

Revisiting Tier 2

One of the architects of the NDIS, Bruce Bonyhady, has said that the NDIS had become an “oasis in the desert”. This is largely due to the lack of services or supports for disabled people outside individualised plans.

“Tier 2” was part of the original design for the NDIS, between Tier 1 (broad community inclusion and awareness) and Tier 3 (individualised support packages.) According to the Productivity Commission¹¹, Tier 2 would provide referrals to other services for those not eligible for Tier 3.

The Commission’s Report details how the NDIS could work with existing not-for-profit community organisations, many of whom should be funded under Tiers 1, 2, and 3, to continue their work and to expand their community development and capacity building programs, including:

- Disability support services for those not eligible for the NDIS individualised plans
- Better access and inclusion in mainstream services
- Specific disability programs across systemic areas, such as housing, education, health
- Disability-led independent information about NDIS support services

In 2015, Tier 2 was renamed as Information, Linkages and Capacity Building (ILC) and a number of grant rounds were held from 2018. The program was meant to connect “to community and informal supports, mainstream service systems and individually funded packages (IFP), to enable an effective integrated response to disability which supports the choice and control of people with disability, their families and carers.”¹²

Whilst for many disability organisations, ILC funding represented a significant funding boost, projects were time-limited and “one-off” and did not provide any longer-term investment in those organisations. A DSS review of the program recommended that the short-term nature of the grants should be changed.

¹¹ <https://www.pc.gov.au/inquiries/completed/disability-support/report>

¹² <https://www.ndis.gov.au/media/241/download>

The NAA looks forward to a detailed revision of Tier 2 to fulfil its original objectives.

Recommendation 8

That the NDIA revisit the objectives of Tier 2 to provide services and supports for disabled people outside individualised plans through the expansion of disability organisations' community development and capacity building programs

Conclusion

In conclusion, the NAA is pleased to provide a submission to the Joint Standing Committee on the NDIS General Issues Inquiry. We look forward to working with the Joint Standing Committee, the Minister and the NDIA to make constructive suggestions for implementing improvements to the NDIS to ensure the aims and objectives of the NDIS are realised for people living with neurological and neuromuscular conditions.