

Submission  
No 170

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL  
DISABILITY INSURANCE SCHEME AND THE PROVISION  
OF DISABILITY SERVICES IN NEW SOUTH WALES**

**Organisation:** Muscular Dystrophy NSW  
**Date Received:** 8 August 2018

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Partially  
Confidential

8 August 2018

Hon Greg Donnelly MLC  
Chair  
Portfolio Committee No. 2 – Health and Community Services  
NSW Parliament  
[PortfolioCommittee2@parliament.nsw.gov.au](mailto:PortfolioCommittee2@parliament.nsw.gov.au)

Dear Hon Greg Donnelly MLC,

**Muscular Dystrophy NSW response to the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.**

Thank you for inviting Muscular Dystrophy NSW to provide input into the NSW Legislative Council's Portfolio Committee No. 2 has commenced its inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales (NSW). Muscular Dystrophy NSW welcomes this inquiry.

Our community consists of Australian children and adults living with neuromuscular conditions and their families.

Neuromuscular conditions are rare and complex degenerative conditions, marked by relentless, progressive disability. There are different condition trajectories and life expectancy for the more than 60 neuromuscular conditions. All people experience muscle wasting and fatigue and a significant percentage have cognitive, working memory and language deficits. As muscle wasting progresses heart, respiratory and gastrointestinal muscle function is often affected.

Following community consultation, we have uncovered challenges that are both general issues for all participants of the NDIS and specific challenges, affecting those with complex progressive, degenerative conditions.

Please find our response to the relevant terms on the following pages. The issues we raise in this submission are relevant for NDIS service provision throughout NSW and Australia. Please do not hesitate to contact us if you require any further information on any of the issues we have raised in this response.

Yours Sincerely,

Charlotte Sangster  
**General Manager**

## **Muscular Dystrophy NSW response to Terms of Reference for the inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.**

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

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

### ***The practical application of the NDIS for those living with complex degenerative conditions:***

The insurance model underpinning the NDIS is challenging in its application for people with neuromuscular conditions given:

- a) The progressive nature of the conditions
- b) The need for increased support in all NDIS support categories over a lifetime, rather than decreased support
- c) Overwhelming fatigue and chronic pain as features of neuromuscular conditions. In many instances these symptoms are not obvious and limit skills development and independence in the management of individuals' NDIS Plans. In advanced conditions, recovery following participation in an activity can take days.
- d) The need to plan for supports to maintain, rather than improve, function and independence, rather than to improve function and independence.

### ***The need for specialist knowledge during the planning process and funding allocation process:***

Understandably, NDIS decision makers – the National Access team, planners and Local Area Coordinators have limited specialist expertise to make consistent, informed decisions when working with people with neuromuscular conditions, and as a direct result, many are not receiving appropriate and adequate supports in their NDIS Plans.

The lack of knowledge and expertise of decision makers may affect all stages of the planning process. Examples include:

- a) Service access requests being denied, in particular for ambulant people with significant cognitive, working memory and language deficits
- b) Currently the leukodystrophies and spinal muscular atrophy are the only conditions included on the Conditions which are likely to meet the disability requirements in section 24 of the NDIS Act. Conditions such as severe forms of muscular dystrophy do not make the list
- c) Support Coordination not being consistently offered and in several cases, planners have refused requests from participants.

- d) Assigning inadequate funding in NDIS Core Supports, including insufficient daytime support and night time "active" supports, to frequently change the position of the person in bed, manage equipment and monitor power to life-saving and essential equipment, including respiratory equipment

*66 yrs, living in regional Qld with Limb Girdle muscular dystrophy: My greatest problem is to match the funding to the commitments they give you at the meetings. There is little truth in the given commitments to the final budgets provided.*

- e) Making equitable and consistent decisions in the 'Review of a Reviewable Decision' process. Because of the Planners' lack of knowledge of neuromuscular conditions, many members of our community are required to lodge requests for these reviews.

*From 48 yrs, living in Brisbane, with Fascio Scapulo Humeral Muscular Dystrophy: I would also say the lack of knowledge and connection from the planners in the past has been the biggest issue, especially at the beginning when I really needed that support.*

***Over-estimation of informal supports:***

Unfortunately for carers and their family members with progressive, neuromuscular conditions, NDIS Planners have failed to meet reasonable expectations of funds allocated in the *NDIS Plan's Core Supports*, by relying upon informal support to continue to provide an inappropriately high level of caring and assistance. There seems to be an assumption that the "positive, natural supports" in a person's life will pick up the short-fall.

Many carers are ageing and exhausted, having provided years of care. Several have musculoskeletal injuries as a result of a life time of lifting, yet many or all of the hours they have spent in this role are counted in NDIS Plans as informal supports.

Families who have been providing most or all of their family member's care have been waiting for the introduction of the NDIS for some relief of their full-time caring role to perform other reasonable roles such as parent, friend, worker, sibling, and grandparent.

***The value of therapeutic supports and necessity of assistive technology:***

Therapeutic supports are invaluable for minimising the effect of the physical disability and delaying progression, yet for people with neuromuscular conditions, the evident value of therapeutic supports is diluted by NDIS rules and generalist expertise of decision makers.

Similarly, the necessity for sophisticated assistive technology, as well as adequate funding for ongoing maintenance of this equipment, is not recognised by the NDIS rules or decision-makers. Examples of this issue include:

- a) Clinicians have the expertise to make decisions related to funding of essential complex equipment. NDIS Planners - without specialist expertise – are making these decisions, often to the detriment of the participant's ability to *live an ordinary life*. For instance, for a person with muscle function limited to movement of a finger, a *power chair composite* with

features such as tilt in space, power elevate, standing function, power recline, power leg rests, blue tooth and infra-red connectivity through the controller makes it possible to navigate and control an environment, to reduce muscle contractures, to play sport, to converse at the same height, in short to live ordinary lives. Because of the expense of this equipment and the lack of understanding that it is vital, this equipment is being under funded or not funded at all

- b) There are extended waiting times for approvals of necessary equipment e.g. wheelchairs, hoists, hi-lo beds, and home modifications, which are impacting the participants' ability to achieve the goals stated in their NDIS Plans.
- c) Again from : *I have put in for motor vehicle modifications back in March, early April with quite a thorough report from my therapist and still yet to have approved or rejected 4 months later. This impacts on me in a large way as travelling outside of my immediate local area means I am very reliant on others to get around when it simply doesn't have to be that way. My hi-lo bed was also very slow to get to me and was a real game changer when I finally received. Some nights before receiving this bed I would just say to myself, "I just want to go to bed!!!" as fatigue and challenges just to get into bed provided a real risk and danger of falls, sometimes taking up to a half hour to get into bed. Identifying some of the more immediate needs and fast-tracking them would be of great benefit.*
- d) There are instances of inadequate therapy funding allocations made in NDIS plans, with some planners and LACs stating that the participant should use Medicare Chronic Disease Management Plans to fund therapy services. This is not appropriate as the Medicare system is for health issues, and directed to the general population. In the case of those living with complex neuromuscular conditions, the Medicare system does not provide sufficient therapeutic intervention, and usually incurs significant gap payments.

### *Recommendations*

1. Consider the policy implications of the NDIS relevant to people with progressive degenerative conditions, to ensure the practical application of NDIS supports.
2. There are several recommendations for action which would vastly improve the quality of service that people with neuromuscular conditions are receiving from the NDIA.  
They include:
  - a. Implementing training programs and/or introducing specialist planners who work with people with neuromuscular conditions, starting with service access assessments and continuing through the entire NDIS planning process including reviews of NDIS Plans
  - b. Include a wider range of neuromuscular conditions e.g. different forms of muscular dystrophy, on the NDIS list of *Conditions which are likely to meet the disability requirements in section 24 of the NDIS Act.*
  - c. For the NDIA to engage and collaborate with the muscular dystrophy organisations which specialise in the support of people with neuromuscular conditions
  - d. By contractual arrangement, engage the muscular dystrophy organisations throughout Australia to develop and implement NDIS Plans for people with neuromuscular conditions

3. All people with neuromuscular conditions have complex progressive conditions and Support Coordination and Plan Management are imperative to enable efficient plan implementation and overcome challenges relating to cognitive disability and fatigue
4. In the Core Supports section of the NDIS Plan, review and update procedures for calculating *informal support* to ensure fair and reasonable decision making which takes into account historical underfunding which forced family members to provide 100% of the care
5. Review the procedure for assigning therapy hours with the understanding that prophylactic care is a positive investment in future function, which can delay progressions for people with neuromuscular conditions
6. Overhaul the assessment and funding of complex equipment for people with neuromuscular conditions to ensure that the officers of the NDIA have the expertise to make consistent and high quality decisions, and to ensure that participants are not affected adversely by delays in provision

#### **g) Workforce issues impacting on the delivery of disability services**

It has become harder to attract and retain skilled staff due to the casualisation of the workforce and our inability to offer permanent positions or contracts with a term longer than 12 months.

#### **(h) Challenges facing disability service providers and their sustainability**

As an organisation that is a specialist provider of information and individual advocacy for those affected by neuromuscular conditions as well as NDIS related services we have had to lobby to keep our funding which now sits under that FACS Transitional Advocacy Funding Supplement with no guarantee of how we will deliver these types of services in the future which are not covered as the NDIS clearly states that it will not fund disability advocacy, information or representation.

The NSW Government is responsible for the on-going funding of disability advocacy, information and representation in NSW but it has put all the disability advocacy, information and representation funding (\$13 million per year) into the NDIS.

Thanks to a strong community campaign the Premier agreed in April 2018 to continue to fund disability advocacy, information and representation in NSW for a further two years but the Government has no plan to fund disability advocacy, information and representation after 2020.

The NDIS is very important and a giant leap forward. But organisations under the NDIS umbrella are service providers, not independent advocates and may have a conflict of interest.

People with disability need long-term funding for independent disability advocacy, representation and information services to make sure we have a voice. People with disability who are advocates are an expert voice you can turn to when things go wrong. Especially for those who will not get NDIS funding.

The NSW Government needs to plan now for the long term, on-going funding for disability advocacy, information and representation organisations in NSW.