

11 June 2021

Senator the Hon Linda Reynolds CSC  
Minister for the National Disability Insurance Scheme  
Parliament House

Dear Minister,

### The great divide between Australians with NDIS Plans and the over 65s on home care packages

We write on behalf of the estimated 30,000 Australians living with a neuromuscular condition. Neuromuscular conditions encompass more than 70 rare conditions including Duchenne muscular dystrophy (DMD), Facioscapulohumeral MD (FSHD), Becker muscular dystrophy (BMD) and Spinal Muscular Atrophy (SMA).

The Australian Government is to be commended for developing, implementing and funding the National Disability Insurance Scheme (NDIS) which has resulted in transformational changes in the quality of life for many Australians with disability. **Unfortunately, not all Australians are able to access NDIS plans even when they live with severe disability. It is difficult to reconcile how similar levels of disability are treated so differently based on a person's age.**

People with neuromuscular conditions who were aged over 65 when the NDIS came to their area are unable to access an NDIS plan regardless of the severity of their disability. Instead, they must rely on the aged care system – an alternative which frequently proves woefully inadequate in practice. As demonstrated in the case study below, the upper limit for a Home Care package (\$52,000 p.a.) can lead to a quality of life vastly inferior to that of a person eligible for NDIS funding. The case study below describes life for two men with BMD living with a similar level of disability. The men are real, de-identified clients of a state based MDFA member.

James is a 74-year-old man with severe physical disability as a result of Becker muscular dystrophy. He is ineligible for an NDIS plan because he was aged over 65 when the NDIS came to his area. Instead, James has a level 4 home care package of \$52,000 p.a. After his aged care supplier deducts its administration fee – he is left with approximately \$47,800 each year.

Bruce is 55 years old with the same diagnosis and a similar level of disability. Because he is under 65, Bruce receives support via the NDIS. His NDIS plan value is \$127,000 p.a.

Both James and Bruce live at home and have a similar level of need, including:

- Daily support worker hours for personal care and care during the night.
- Physiotherapy and occupational therapy surveillance and periodic blocks of treatment.
- Speech Pathology input for surveillance and management of deteriorating swallowing function.
- Power wheelchair with extras such as tilt in space, at a cost of >\$40,000.
- An ongoing need for the following equipment for person with physical disability, such as
  - o Hoist: \$7,000
  - o Shower commode: \$5-10,000
  - o Electric hi-lo bed and specialist mattress: \$9,000

In the past 12 months, both men have experienced progressions in their conditions, leading to reduced functional independence.

**Life for James:** James ekes out his funding, utilising an hour each morning and night for a support worker to assist with personal care. He is overdue for a new powerchair and has been saving so that he can afford one. Saving \$40,000+ for a new chair from a \$52,000 package will take years.

James's state based Muscular Dystrophy organisation has a charitable fund for people whose needs are not funded by government. In the past year, they have provided the following, using their charitable funds:

- 7 hours of home-based physiotherapy and occupational therapy for assessment, referrals, and management of urgent needs.
- Small items of equipment e.g. a fleece lined boot to manage a developing pressure area.

The organisation's allied health team have also referred James to the local hospital for assessment of respiratory and swallowing function, both of which are deteriorating. James has also been included on the organisation's waiting list for a power chair which are sometimes donated. Even though they should be bespoke items, the organisation will pay to adapt a donated chair to fit the needs of the client. James has been waiting for a donated power chair for a year.

**Life for Bruce:** Bruce has the following supports funded through his NDIS Plan:

- Support workers for 9-12 hrs per day including for community access twice per week, plus awake overnight shifts, three times per week.
- All allied health services that he needs as well as 6 weekly podiatry treatments.
- All equipment, including loans whilst he waits for equipment to be supplied.

**The men in the above case study have similar needs for support workers, therapy, socialisation, community access, and expensive equipment. It is, at best, shocking and appalling that the disparity in their standard of living is driven purely by their age and the source of their government funding.**

Situations like the one described in the case study are all too common for people with neuromuscular conditions. One reason for this is that the progressive nature of neuromuscular conditions means that people living with them have needs that increase over time - with pathways of progression often not evident before age 65. This means a person may believe he can live without the support of an NDIS plan, only to experience a significant progression after the age of 65 years and thus miss out on much-needed NDIS support. The fact that a person with an NDIS plan must relinquish their plan upon entering an aged care accommodation facility is also a concern for MDFA, our members and partners.

Mr. Bill Moss AO, a man who lives with Fascioscapulohumeral MD and who is also the founder of the FSHD Global Foundation Research Foundation Ltd discusses his experience:

*"Disabilities occur in many different ways and vary greatly in their severity and age of onset. In many disabilities the symptoms may appear mild before the age of 65; however, major and rapid deterioration can occur after the age of 65. As a result, people suffering from disabilities may not register with the NDIS before the age of 65."*

Mr. Moss recently wrote to the Prime Minister with a series of requests relevant to the above issues. MDFA endorses Mr. Moss's requests and in particular requests that the Government:

- Removes the age restriction from the NDIS eligibility criteria, enabling equitable access to the NDIS for all Australians with disability regardless of their age.
- Offers access to the NDIS for all people who are currently funded under the My Aged Care scheme and who but for their age, would be eligible for funding under the NDIS.
- Considers equity in future decision making related to NDIS eligibility of persons over 65 years.

On taking up your current role, you spoke of your desire to provide targeted, sustainable support to Australians in need. Reflecting on this, we urge you to consider whether the person aged over 65 in the case study discussed, is an Australian in need and how the Australian Government can possibly justify not providing adequate support.

We would be more than happy to meet with you on this issue should it be something you would like to discuss further. Please contact Ryan Talsma (Chief Executive Officer, Muscular Dystrophy Foundation Australia) via email ([ryan.talsma@mdaustralia.org.au](mailto:ryan.talsma@mdaustralia.org.au)) or mobile (0439 758 853) should you be available to meet with us on the important issues raised in this letter.

Yours sincerely,

**Ryan Talsma** FIML FGIA PMESA  
Chief Executive Officer  
Muscular Dystrophy Foundation Australia

**Charlotte Sangster**  
Chief Executive Officer  
Muscular Dystrophy NSW

**Jan Chisholm**  
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**Hayley Lethlean**  
Chief Executive Officer  
Muscular Dystrophy WA

**John Salmon**  
Vice President  
Muscular Dystrophy Tasmania

**Bill Baker**  
President  
Muscular Dystrophy Foundation ACT

Copies to:

The Hon Scott Morrison MP, Prime Minister of Australia  
The Hon Anthony Albanese MP, Leader of the Australian Labour Party  
The Hon Richard Colbeck MP, Minister for Senior Australians and Aged Care Services  
The Hon Bill Shorten MP, Shadow Minister for the National Disability Insurance Scheme  
Clare O'Neill MP, Shadow Minister for Senior Australians and Aged Care Services  
Other Members of the House of Representatives