

Submission
No 121

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

Organisation: Motor Neurone Disease Association of NSW
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The Motor Neurone Disease Association of NSW Submission

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

Submitted online

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Summary

Thank you for providing the opportunity to comment on the NDIS implementation in NSW. The Motor Neurone Disease Association of NSW (MND NSW) has supported the idea of an NDIS since its inception and believes that personal choice and person centred care are at the heart of a disability scheme that values individuals.

While issues discussed below paint the NDIS in a poor light it should be noted that, on the whole the Scheme is working well for the vast majority of the participants. Where it struggles is with people with acquired, rapidly progressive disease causing disability.

MND NSW acknowledges that the NDIS is a work in progress and will be for at least the next 5 – 10 years given its size and complexity.

However, issues that are within the control of the NDIA such as trust in people providing referrals and expert advice are too often ignored. NDIS Planners and LACs, often without any expertise in a specific disease ignore and override expert advice that has been paid for by the NDIS.

Always to the detriment of the person with a disability.

Motor Neurone Disease

Motor neurone disease (MND) is a progressive neurological disease in which the muscles that enable us to move, speak, breathe and swallow fail to work normally. MND is uncommon and it is estimated that approximately 550 people in NSW currently have the disease. A person living with MND has a limited life expectancy, with the average being two to three years from diagnosis, or three to five years from the onset of first symptoms. In the most severe cases, a person might live for only months after diagnosis. However, about 5 to 10 per cent of people with MND will experience a slowly progressive form of the disease and survive for more than ten years. There is no known cure for MND.

Submission

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

The implementation of the NDIS has been fraught. Inconsistent implementation across jurisdictions and the lack of a top down approach has meant each new jurisdiction, when being rolled out across NSW has often not taken learnings from previous areas and often disregarded direction from the NDIA.

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

In January 2017 **all** plans for people with MND in NSW were inadequate and needed review. This has improved dramatically however the planning process and subsequent reviews are often drawn out (4-6 weeks). Expert advice is often ignored by Planners who have little or no understanding of complex needs of particular diseases such as MND

(d) the effectiveness and impact of privatising government-run disability services,

The privatisation of allied health services has led to less collaboration across disciplines. MND is a complex rapidly progressive disease that requires allied health professionals to consult with each other to provide the best outcome for participants. The privatisation of these services has led to less collaboration and opportunities for multidisciplinary case conferencing resulting in less effective strategies when dealing with a complex disease with constant changes in functional ability.

There is further division between private and public providers due to the changing responsibilities between health and NDIS. For example, dietitian services and speech pathology supports relating to swallowing are not included under the NDIS and seen as a Health responsibility as the NDIA considers this as preventive health care measure rather than maintaining/improving a participant's level of independence and social/economic participation.

For people with MND swallowing related muscle loss is NOT preventable

Strategies can be put in place to maintain safe swallow for as long as possible and maintain nutrition due to swallowing loss. Speech pathology is seen as being provided by NSW Health if it is a swallowing issue and by NDIS if it is a communication issue resulting in even more therapists needing to be involved. This is particularly difficult and confusing for participants.

(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme,

There is a high degree of buck passing between state and federal agencies for all people with disability who are both eligible and ineligible for the NDIS. Of particular concern for those NSW residents diagnosed with a disability aged 65 or over is the lack of access to assistive technology through EnableNSW. People eligible for or receiving assistance from an Australian Government Aged Care Home Care Package (Level 1, 2, 3 or 4) are ineligible for assistive technology from

EnableNSW. With rapidly progressive neurological disease access to expensive aids and equipment is prohibitive through Level 1-4 Home Care Packages.

According to the My Aged Care website “You can also use state-based aids and equipment programs and access specialised aids and equipment schemes where there is a need for support.”
<https://www.myagedcare.gov.au/help-home/home-care-packages/aids-and-equipment>

In NSW a person with a disability can't.

(h) challenges facing disability service providers and their sustainability,

Employers face an annual increase in salaries under the Fair Work Commission's Annual Wage Review – 3.5% in July 2018 and the Equal Remuneration Order of approximately 3% in December 2018. The annual price review from the NDIA for Coordination of Support was 2.11% from July 2018.

At this point costs outweigh income threatening sustainability.

(i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services,

Each Local Health District must decide whether they will be an NDIS provider. To date none have. This has caused a breakdown in areas such as multidisciplinary care. Where once health, disability and community care workers worked in a coordinated manner it is now disjointed.

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales, and

As alluded to above in (e) disability is not confined to people under 65. Over 50% of people with MND are 65 or over when diagnosed. This creates a two tier system where those not eligible for the NDIS face a shortfall in services as there is a finite amount of funding in packages 1-4 and a rationed number of Level 3 and 4 packages under My Aged Care. These packages are means tested. Therefore a person on the NDIS gains a package based on need and a person ineligible for the NDIS faces a rationed system.

(k) any other related matter.

Inconsistency in approach by the NDIA has resulted in different levels of supports being provided in plans for people with very similar needs. This has resulted in the need to continually go back to the NDIA for plan reviews to ensure enough supports are in place as a person with MND deteriorates and requires more supports. This process can take up to 4 – 6 weeks. This causes great stress and confusion for participants and their family and carers due to a sense of uncertainty as to whether they will be able to continue to be cared for at home. Dealing with a life limiting progressive disease is difficult enough. The inconsistent and bureaucratic process of the NDIA continues to add additional stress on those whose lives are affected by MND.