

MND Australia

**Response from MND Australia to the Senate standing committee
on the NDIS on the top priority for change**

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MND Australia

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Working towards a world without motor neurone disease



Specialist planning and people living with motor neurone disease

Recommendation

MND Australia recommends that:

- A pilot program of specialty agency planning be conducted with people with MND who are participants
- MND Australia and its State Association members undertake pre-planning for participants living with MND for submission to Planners for approval
- The location of the pilot to be agreed
- On successful completion of the pilot, the engagement of State MND Associations as pre-planners and planners for participants living with MND be confirmed, and
- NDIS Planners remain the final authority for the approval of participant plans.

Background

The average lifespan for a person diagnosed with MND is 3-5 years. Time is of the essence in initiating effective services and supports as rapid paralysis and increasing disability are hallmarks of MND. Experience has shown when the Planner lacks knowledge of MND, poor plans and multiple plan reviews are generally the outcomes, with some proceeding to judicial review. For a person with a life limiting disease delays impact not only the person with MND but also their carers, family and the broader community, and dramatically increase the cost of supports.

The Independent Assessment Pilot currently underway with the Benevolent Society and The Early Childhood Early Intervention service are examples of independent planning processes, and can be replicated by specialist organisations.

Further, the Productivity Commission review of planning indicated that NDIS should consider the use of specialist skills and knowledge of disability agencies to undertake planning for small and unique disability groups.

We believe that a model where pre planning by experts to be endorsed by NDIS Planners would work well for people with complex, progressing and life limiting conditions such as MND and reduce the level of re-planning and avoid legal challenges.

MND Australia estimates that of the 2000 people diagnosed with MND nationally approximately 900 are currently eligible to be NDIS participants. In 2017/18 MND Associations registered 894 people newly diagnosed with MND, of whom it is estimated that 50%, or 450 became eligible to be participants of the NDIS.

During 2017/18 State MND Association support services provided:

- care, information and support to over 2,000 people living with MND
- support and information for over 865 people newly diagnosed with MND
- support for the families of the 560 people registered with an MND association who died
- over 5,512 items of equipment provided to people living with MND
- 4,464 home visits and over 31,000 contacts electronically
- education to over 2,000 health, disability and aged care providers

Motor Neurone Disease Associations across Australia are professional organisations that have been in business for over 35 years. Each Association employs professionals with a background in health



and/or disability as MND Advisors who are expert and experienced in MND and its trajectory and who work closely with neurologists, MND clinics and broader health, disability and aged care services.

Independent Assessment Pilot

MND Associations across Australia have worked with the NDIS since its inception, offering pre planning support and information and, where requested, attendance at Planning meetings. For the past 5 years MND Advisors have witnessed the broad spectrum of quality of NDIA Plans. For the year to January 2017, in NSW, 100% of all Plans for people with MND were inadequate and were referred for Plan Review.

The NDIA and MND Associations have recently worked together to update the MND Practice Guide and the NDIA has undertaken to more effectively disseminate and promote this resource. The Planning process has since improved dramatically but now, with an increased imperative for the NDIA to bring people on to the Scheme the process is at risk and of, once again becoming a box ticking exercise.

In most states and territories 80 to 100% of all people with MND become members of the MND Association. People with MND turn to the Associations for expert advice and education which places MND Associations in an ideal position to become pre planners/specialty agency planning. The projected numbers of people with MND eligible for the NDIS (900) make this target group an ideal pilot cohort for expert pre planning intervention. In NSW/ACT and Victoria there is a cohort of approximately 460 NDIS participants.

Projected cost:

At present almost every plan prepared for a person with MND by NDIA planners is referred for an unscheduled plan review with a number being referred to the tribunal. Specialist planning for people with progressing complex neurological conditions will drastically reduce the need for plan reviews and thereby cost to the NDIS.

Projected number of people with MND entering the scheme each year = 300
10 hours of pre-planning per person per year @ \$196 an hour = \$1,960
4 hours of planning per person per year @ \$196 an hour = \$784
4 hours for plan review per person per year @\$196 an hour = \$784
Total per person cost to the NDIS = \$3,528

Projected Outcomes

The benefit of a single pre planning and planning referral resource such as the MND Associations would:

- Deliver better realistic plans for people with MND
- Dramatically streamline the Planning process
- Reduce times for plan approval
- NDIA to maintain its legislated role to sign off as Planners
- Reduce the time and cost of planning and reduce the incidence of re-planning requests in the first 12 months
- Reduce use of the appeal process
- Retain NDIA oversight and audit.



Potential Conflict of Interest Concerns

MND Australia and the State Associations will put in place structures that prevent conflict of interest concerns.

Recommendation

MND Australia recommends that:

Stage 1:

- A pilot program of specialty agency planning be conducted using people with MND who are participants
- MND Australia and its State Association members undertake preplanning for participants living with MND to develop a draft plan for submission to Planners for approval
- The location of the pilot to be agreed.

Stage 2:

- On successful completion of the pilot, the engagement of State MND Associations as pre-planners and planners for participants living with MND be confirmed, and
- NDIS planners remain the final authority for the approval of participant plans