

# Feedback on the National Disability Advocacy Framework Discussion Paper

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**By:**

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**On behalf of:**

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## **INTRODUCTION:**

MND Australia is the national peak organisation representing all across Australia who share the vision of a world without motor neurone disease. We work collaboratively with our member organisations, the state MND Associations, to influence policies and services at a national level and to advance research to ultimately end motor neurone disease (MND). The state MND Associations provide information, equipment and support services to people diagnosed with MND, their family and friends and the health, aged, disability and community care providers involved in their care. They engage constantly in grass roots advocacy to ensure people living with MND get access to right care, in the right place and at the right time.

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time. In approximately 60% of cases cognition is affected but in the majority of these individuals the impact is mild.

Peak age of onset is 50's and 60's with approximately 50% of people being diagnosed when aged 64 or under.

Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases), no effective treatment and no cure. There are no remissions and progression of MND is usually rapid, creating high levels of disability.

## **THE CHALLENGES**

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses, which pose:

- huge problems of adjustment for people who have MND;
- an escalating burden on carers and families; and
- a challenge to health, aged, disability and community care professionals involved in meeting the variable and complex care needs, particularly in regional, rural and remote Australia.

MND care must be addressed through a coordinated multi/interdisciplinary team approach with timely referrals to services that will address identified needs. Information and education for providers on the specific impacts of MND are vital.

Due to rapid progression, escalating complex needs and, in many cases loss of speech, specialist, disease specific advocacy is vital for people living with MND at every level of service provision and government.

## **Responses to terms of reference:**

Please use the questions below as a guide when developing your submission:

### **1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?**

Whilst the framework addresses the issues in relation to organisations whose sole purpose is advocacy and people living with a disability in general, it does not address the advocacy needs of people with progressive terminal conditions such as motor neurone disease (MND). People living with progressive complex neurological conditions need specialist advocacy from organisations with an understanding of the needs of people living with that specific condition.

The framework does not encompass the individual advocacy that is done every day in encouraging and supporting people with disabilities to gain access to services, and the ongoing systemic advocacy to ensure that services meet the needs of clients.

### **2. Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?**

Experience in the launch sites to date indicates that the introduction of the NDIS will necessitate ongoing individual advocacy to ensure that the changing needs of people living with conditions such as MND are met. This advocacy often entails significant and lengthy one on one discussion to help service providers understand the funded services required to meet the progressing needs of the individual, and to advocate for a person to be able to access those services. Person specific support to ensure that a person can access the appropriate service to meet their individual preferences, goals and needs through training, advocacy and support for individual workers within the service will be vital.

The framework needs to acknowledge the need for condition specific and expert advocacy to support people with progressing and complex conditions to access services to meet their needs. The role of these organisations in supporting and educating the service providers entering the market also needs to be incorporated as a vital component of grass roots advocacy in the context of the NDIS.

### **3. Are the outcomes of the Framework still relevant or should different ones be included? If so, what should be included?**

Although outcome (f) refers to people with disability experiencing multiple disadvantage it does not encompass the needs of people with disability who have complex progressing needs that require input across all sectors including health, aged, respite, carer support and palliative care.

As an example, MND Victoria fought a ten year advocacy battle to have people living with MND eligible to access palliative care, removal of the “last three months of life” eligibility rule, remove the “cancer only” label that palliative care in Victoria had assumed, and gain access to a service that improves quality of life.

**4. Are the outputs of the Framework still relevant or should different outputs be included?**

Our concern is with the generic nature of the outputs that focus on the roles and responsibilities of funded advocacy organisations. The outputs do not encompass advocacy that promotes information and education for service providers to assist them to meet the individual needs of people with a disability. Condition specific advocacy is vital and this needs to be acknowledged.

**5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?**

Ongoing, coordinated systemic advocacy is required to ensure that people with a disability are able to access services to meet their individual needs. Funded advocacy organisations rarely advocate systemically or at the grass roots level for a specific group.

The role of intensive advocacy from a specialist agency to address deficiencies in access to disability support should be acknowledged.

As a current example, MND Australia is advocating strongly for people with MND who are diagnosed when over the pension age for access to services to meet needs related to their disability not their age. This is not an issue being pursued by generic advocacy organisations.

**6. Do you have any other comments, thoughts or ideas about the Framework?**

The framework for advocacy needs to be extended beyond its current focus on advocacy only organisations to organisations that do advocacy on the ground and systemically, every day, to get people access to the services they need and want.

Thank you for the opportunity to provide feedback on this discussion paper. We would be happy to discuss further the requirements of this group at any time.

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