



Department of Social Services Consultation on draft lists of NDIS Supports



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Further Information

MND Australia welcomes the opportunity to provide further information in addition to the information contained in this submission. Please contact Clare Sullivan, CEO of MND Australia, on clare.sullivan@mndaustralia.org.au or 0415 265 262.

Introduction

Motor Neurone Disease (MND) Australia is pleased to provide this submission on the Department of Social Services Consultation on draft lists of NDIS supports, on behalf of its members, the State MND Associations, and people living with MND.

MND Australia is the national peak body of state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected. We fund world-class research for better treatments, improved care, and ultimately a cure.

About MND

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate them, people with MND lose their ability to walk, speak, swallow and ultimately breathe. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy is just 27 months from diagnosis, with a third of people dying within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the 15–20% per cent of cases which have a genetic basis. There are no effective treatments and there is no cure.

There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability and a consequent need for a wide range of changing supports based on the person's complex needs.

Overarching Feedback

MND Australia understands the Government's reform agenda regarding the NDIS, however, MND Australia has a range of concerns about the approach and proposed transitional rule for NDIS Supports. Specifically, MND Australia believes greater clarity needs to be provided regarding:

- the timeframe that the transition rule may remain in place as the new rules may take longer than intended
- clarification around existing plans and how/when/if these will be reviewed under the transition rule
- clarification around the discretion and implementation of the 'carve outs', at this stage it is unclear how this will be approached and how these decisions will be made.

NDIS Support Lists

MND Australia has a range of concerns with 'Supports that are not 'NDIS supports' with greater clarity and advice on the need 'carve outs' from supports proposed as 'not included as NDIS supports'. Without these changes, proceeding with the proposed list would significantly impact on the lives and well-being of people living with MND and the associated life limiting disabilities this causes.

Feedback from MND Australia on the Support List is detailed below and is summarised as:

- Early Intervention Supports for adults has been omitted from the draft Lists. Currently Early Intervention Supports can be used for both adults and children
- Additional carve outs be included in the 'Day-to-day living costs' for items that specifically relate to the disabilities associated with MND
- Carve outs being included in 'Mainstream Health' for people living with MND including respiratory specialist services and prescribed ventilation (Bipap etc), as well as equipment such as suction machines and cough assist machines
- Carve outs in 'Mainstream – mental health' including psychiatric, psychology and counselling services to support the many psychological challenges of living with a fast-progressing life-limiting disease
- Carve outs in 'Mainstream – Housing and Community Infrastructure' to ensure access to medium term accommodation is available for people living with MND while the inevitable home modifications are undertaken
- It is critical that as part of 'Mainstream – Housing and Community Infrastructure' delivery fees for NDIS supports, including assistive technology, be included and maintained as carve outs that are included for people living with MND.

Detailed Feedback on 'Supports that are NDIS supports'

Early Intervention Supports For Early Childhood

Early Intervention Supports for adults has been omitted from the Lists and has not been addressed in carve outs. Currently Early Intervention Supports can be for both adults and children. NDIS participants who have MND rely on NDIS early intervention to mitigate the functional impact of their progressive impairments. It is critical that Early Intervention Supports be available for adults as well as children.

Detailed Feedback on 'Supports that are not 'NDIS supports'

MND Australia is providing specific feedback and raising significant concerns within the categories of goods and services that are proposed as not a 'NDIS support'.

Day-to-day living costs

Carve outs that may be considered 'NDIS supports' for certain participants

It is suggested that the following carve outs also be included for people living with MND. These are:

- Internet connectivity and technology relating to augmentative and alternative communication (AAC), smart watches and communication devices. For people with MND these are critical communication supports and often provide their sole means of communication.
- Clothing and footwear that is necessary due to their disability, for example easy slip-on shoes.
- General home maintenance that they would have been able to undertake themselves had they not had a disability.

Mainstream – Health

Carve outs that may be considered 'NDIS supports' for certain participants

- Disability-related health supports where the supports are a regular part of the participant's daily life, and result from the participant's disability. This includes continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care supports.

For people living with MND, respiratory specialist services and prescribed ventilation (Bipap etc) are directly related to their disability and critical to their quality of life. In addition, equipment including suction machines and cough assist is vital. These services and equipment must be included as carve outs for people living with MND.

Mainstream – Mental Health

Carve outs that may be considered 'NDIS supports' for certain participants

- Ongoing psychosocial recovery supports

For people living with MND psychiatric, psychology and counselling services are very much needed and are specific to their life limiting disability need. MND Australia strongly supports NDIS participants being able to access these services as NDIS Supports.

Mainstream – Housing and Community Infrastructure

Carve outs that may be considered 'NDIS supports' for certain participants

- Medium term accommodation if you have a long-term home you will move into after MTA but you can't move into your long term home yet because your disability supports aren't ready and you can't stay in your current accommodation while you wait for your long term home.

Access to medium term accommodation is critical for people living with MND while home modifications are undertaken when it means their home is not habitable. MND Australia acknowledges that State Government housing and community infrastructure is primarily responsible for housing and homelessness services. However, often these properties aren't disability accessible. The lack of SDA and timely access remains the biggest challenge.

- Delivery fees for NDIS supports (e.g. delivery of assistive technology)

It is critical that 'Delivery fees for NDIS supports including assistive technology' be maintained as carve outs that are included as 'NDIS supports' for people living with MND due to the often bulky nature of the equipment required, the speed at which this equipment is required and the frequency with which participant needs for equipment changes. This is especially critical for people living in regional and remote areas.

Mainstream – Aged Care

Description

- Aged care services

Carve outs that may be considered 'NDIS supports' for certain participants

- Supports for an NDIS participant under the age of 65 who chooses to live in residential aged care and purchase support from an aged care provider

MND Australia strongly supports this carve out so that NDIS participants under the aged of 65 that need to live in residential aged care, or wish to purchase support from an aged care provider, are able to do this as part of their NDIS Supports. This is especially important for participants living in regional and remote areas.