



RESPONSE TO THE
**Review of the
Disability
Services Act (1986)**

February 2023



About MND Australia

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.

The six state MND associations provide direct support and services to people living with MND, their carers and families and the health professionals and service providers involved in their care in all states and territories.

Together we are committed to ensuring people living with MND, their carers and family have timely access to:

- care and support to meet their individual needs to enable them to live better, for longer, no matter their age or postcode
- diagnosis, clinical trials, technologies, and therapies.

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, to speak, to swallow and to 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 10 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 disability and a consequent need for a wide range of changing supports based on the person's complex needs.

Consultation questions

QUESTION 1: Do you agree with the proposed objects for the new Act?

MND Australia agrees with the proposed objects of the new Act, noting that Australian disability legislation and policy is well overdue in harmonizing with the UN Convention on the Rights of Persons with Disabilities (CRPD). Additionally, we agree that the new legislation should support and empower the Australian Disability Strategy (and future iterations) to ensure that all Australians who have or acquire disability are able to access supports and services regardless of age, location or socioeconomic status.

QUESTION 2: Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

MND Australia agrees that the target cohort should cover people with disability who experience attitudinal, environmental, institutional and communication barriers as per the social model of disability and the CRPD. However, we would also strongly suggest that the target cohort include anyone who may acquire a disability from a range of life course experiences including diseases, such as neurodegenerative diseases like motor neurone disease.

QUESTION 3: Do you agree with our suggested principles for avoiding duplication and requiring coordination?

MND Australia tacitly agrees to the principles regarding avoidance of service duplication with the proviso that the Australian Disability Strategy be utilized appropriately across all levels of government. Additionally, we wish to emphasize that where a person is eligible for services and supports under more than one piece of legislation, that the person is not denied multiple supports due to age or complexity of need.

Currently, the NDIS is capped at age 65 and older, this leaves a great number of people who acquire disability later in life in a precarious situation, and often unable to access support and services in a timely manner. Thus, the new Disability Services Act must clearly articulate how the gaps will be filled and that these gaps must be filled in a timely manner. This will ensure that the right to services and supports for people who acquire

Consultation questions (continued)

disability later in life is upheld in accordance with the CRPD. MND Australia would be open to further discussion and consultation on these principles.

QUESTION 4: Do you think the new Act should include a definition for disability?

Article 1 of the CRPD states:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

It must also be noted that the Convention does not restrict coverage to particular persons; rather, the Convention identifies persons with long-term physical, mental, intellectual and sensory disabilities as beneficiaries under the Convention. The reference to “includes” assures that this need not restrict the application of the Convention and States parties could also ensure protection to others.

MND Australia wishes to see a clear acknowledgement of acquisition of disability at any point in a person’s life course and that the definition is broadly similar to (but using updated language) the *The Disability Discrimination Act 1992* which defines 'disability' as:

- total or partial loss of the person's bodily or mental functions; or
- total or partial loss of a part of the body; or
- the presence in the body of organisms causing disease or illness; or
- the presence in the body of organisms capable of causing disease or illness.
- the malfunction, malformation, or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions, or judgment or that results in disturbed behaviour.

and includes a disability that:

- presently exists; or
- previously existed but no longer exists; or

Consultation questions (continued)

- may exist in the future (including because of a genetic predisposition to that disability)
- is imputed to a person.

QUESTION 5: How do you think that quality and safeguarding arrangements should be managed by the new Act?

MND Australia supports the creation of an independent disability commission that would have oversight of all quality and safeguarding arrangements pertaining to this new legislation. Similar bodies exist internationally, including the National Disability Authority in Ireland[1]. An independent commission, sitting aside from government, is a more appropriate and objective mechanism to ensure the rights of people with disability are upheld and not compromised by any conflicts of interest.

QUESTION 6: Do you agree with the supports and services suggested?

MND Australia agrees with the supports and service suggested:

- accessibility
- accommodation support
- advocacy
- employment and training
- independent living
- information and education
- recreation
- respite care
- research, development and data collection

MND Australia would also like to see Assistive Technology in all its forms and equipment included in the supports and services covered by the new Act.

[1] <https://nda.ie/>

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