

Response to the National Disability Insurance Scheme Bill 2012

Submitted on:
25 January 2013

By:
Carol Birks
National Executive Director

On behalf of:
MND Australia
PO Box 990
Gladesville, NSW 1675

carolb@mndaust.asn.au
www.mndaust.asn.au
Phone: 02 9816 5322





MND Australia congratulates the government on its commitment to the introduction of a National Disability Insurance Scheme (NDIS) and would like to take the opportunity to comment on the National Disability Insurance Scheme Bill 2012.

MND Australia is gratified that people with neurological conditions will meet the disability and the early intervention requirements as specified in Section 24 and 25 of the Act.

Motor neurone diseases (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. Average life expectancy is 2 to 3 years. There are no remissions and progression of MND is usually rapid, creating high levels of disability and a consequent need for a wide range of progressively changing supports.

Although early intervention will not slow down the disease process in MND it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing. It will also assist people diagnosed with MND to maintain their independence for as long as possible and help them to plan ahead to prevent crisis and hospital admissions.

Section 47 states that a participant may change their statement of goals and aspirations at any time and a new plan developed. This is imperative for people living with rapidly progressive neurological disease where goals, aspirations and needs will change as the disease progresses. It is important that the process for developing a new plan is simple, timely and responsive to the persons changing needs.

The age requirement as specified in Section 22 remains an issue for the MND community (see Appendix 1 Position Statement – Aged Care). Whilst we understand that the NDIS is not designed to support the needs of people who are ageing, we are also acutely aware that the aged care system is unable to meet the disability needs of people diagnosed with rapidly progressive neurological disease when over the age of 65 (pension age).

MND Australia strongly believes that the NDIS will better respond to the disability needs of Australians, as opposed to needs related to ageing, if it includes those who acquire their disability having attained the pension age and whose needs cannot be met through the aged care system. This is particularly true for people who acquire a disability when they are over pension age.

The aged care system is designed to address needs related to ageing not disability and there are currently major gaps with respect to the range and level of services available. These gaps are particularly apparent for people with progressive neurological diseases (see Appendix 2 - the story of two brothers). These diseases are not acquired as part of the natural ageing process, however, many people do acquire these diseases in their 60's and 70's. As people age with a progressive neurological condition their needs increase, mostly because of the progression of the disease, not because of ageing. Currently it is only in Victoria that people over 65 are eligible to access State Government funded disability services.

To close the gap, and to prevent the gap widening following the introduction of an NDIS, specialist disability services need to be available to support older people with complex needs created by disability.

Options to ensure access to needs based services for people who acquire a disability when over the pension age:

- Aged Care make provisions to provide the full range of services
- If Aged Care is unable to meet the **disability needs** of older people, the NDIS should develop a safety net model that provides for top up funding through the NDIS to address needs not met by Aged Care
- Special eligibility for the NDIS, on application and argument to the NDIA, in the event that Aged Care cannot provide the appropriate levels of care, support and services and the NDIS is not able to top up Aged Care, including a rapid review and decision making process.
- Clear assessment processes and protocols for the interface between the NDIS and the aged care system
- Ensure that eligibility encompasses initial low level need for assistance with increased funding under the NDIS available as the disability level escalates and progresses

Section 22 states that a person meets the age requirements if the person was aged under 65 when the access request in relation to the person was made. It is imperative that people with progressive neurological disease, as part of the early intervention group, are able to request access to the scheme at diagnosis. This should be irrespective of their needs at that time.



Appendix 1

MND AUSTRALIA POSITION STATEMENT

Aged Care and people diagnosed with MND

Background:

The needs of people living with rapidly progressive neurological diseases, such as motor neurone disease (MND), cannot be met by existing or traditional aged care services or facilities.

The introduction of a national disability insurance scheme (NDIS) has the potential to transform the lives of people living with MND who are diagnosed when aged 64 or younger. However it has been proposed that the needs of those people who acquire a disability after pension age would be best met by the aged care system. The crucial issue is then how do people acquiring a disability over age 64 (pension age) access services based on need.

Responding to this concern requires considering not just the design of the NDIS but also the reforms proposed for the aged care system under the Living Better for Longer aged care reform package. The aged care system is designed to address needs related to ageing not disability and there are currently major gaps with respect to choice and the range, level, and hours of services available.

MND is not a disease related to ageing but approximately 50% of people are diagnosed when they are over the pension age. People over pension age diagnosed with MND need the same services and supports that a person under pension age requires. Both need services from the disability and aged care systems to address changing and complex needs related to their disability and ageing to ensure their quality of life.

The Living Better, Living Longer reforms to aged care specify that more packages of care will be available and that four levels of home care packages will be established to provide a continuum of home care options covering basic home care support through to complex home care. However, the focus remains on addressing needs related to ageing. Access to disability services and hours of support available will therefore remain limited and the gap between what is available under NDIS and Aged Care will widen.

A person diagnosed with MND aged 66 must be able to access the same range and level of service to meet their assessed needs as those diagnosed aged 64 no matter which system funds or delivers the services. A rapid response to service provision from a range of services based on the needs of the individual not their age is imperative.

To close the gap, and to prevent the gap widening following the introduction of NDIS, specialist disability services need to be available to support older people with complex needs created by disability. These services must include aids and equipment, flexible respite options, case management, therapy and hours of support to remain at home via packages of care in excess of the current 12 - 15 hours per week.

The exclusion of people who acquire a disability when over the pension age from the NDIS will lead to discrimination against older Australians unless provisions are made to ensure equitable access to needs based care.

People with rapidly progressive neurological disease living in residential aged care have changing and complex care needs which very often cannot be met by aged care staff. In some cases people living with MND have been refused access to residential aged care due to the high level of care required.

Needs based support hinges on careful and appropriate assessment. Currently, Aged Care Assessment Teams are the gateway to aged care services but extensive anecdotal evidence indicates that they frequently refuse to assess older people with complex needs or, when they do, that they

have difficulty in determining what level and types of support the individual needs. Under current aged care assessment processes consideration of whether a person would benefit from a specialist disability service such as case management, flexible respite, aids and equipment, specialised therapy and communication aids rarely occurs.

MND Australia believes:

- People diagnosed with rapidly progressive neurological disease must have access to early intervention, ongoing expert assessment and a range of services to meet their assessed needs irrespective of where they live, their age or which sector funds the service
- MND associations will play a vital role within the NDIS and aged care sectors to deliver specialist MND information, training and education and expert individualised and personalised support and services

MND Australia calls for:

- 1. Improvements to the ageing-disability interface to ensure access to needs based services for people who acquire a disability when over the pension age for example:**
 - a. Aged Care make provisions to provide the full range of services
 - i. Introduce a rapidly progressive neurological disease supplement similar to the dementia/behaviour/veterans supplement to supplement both home care and residential care and to meet complex and changing needs
 - ii. Extend the provision of Aids and Equipment to ensure that older people diagnosed with MND and needing aids and equipment to maintain their independence and community access can get that equipment
 - b. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top up funding through the NDIS to address needs not met by Aged Care
 - c. Special eligibility for the NDIS, on application and argument to the NDIA, in the event that Aged Care cannot provide the appropriate levels of care, support and services and the NDIS is not able to top up Aged Care
 - d. Clear assessment processes and protocols for the interface between the NDIS and the aged care system
- 2. Improvements to the health/allied health/palliative and aged care interface:**
 - a. Good interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care
- 3. Timely availability of equipment and assistive technology:**
 - a. Aged Care sector to ensure equitable and cost effective access to equipment and assistive technology for people at home and in residential aged care to support their independence and community access
- 4. The development of National Guidelines for the management of people with rapidly progressive neurological conditions:**
 - a. to assist with establishing and maintaining interfaces between different sectors, to minimise duplication and to ensure timely and responsive access to reasonable and necessary supports to meet identified needs

Appendix 2

The story of two brothers

Two brothers were diagnosed with MND.

One brother was unlucky/lucky. Unlucky to have been diagnosed with MND and acquire a disability, but lucky that at age 64, he was entitled to support under the NDIS, the no fault scheme that funded the needs created by the disability acquired because of the disease. He had funds to purchase fast track rehabilitation to overcome some of his disabilities, and slow track to ensure sustained outcomes. He was able to purchase the wheelchair he needed, and for that to be replaced when he needed an electric wheelchair. The maintenance was provided and replacements when they wore out. He received funding to purchase support services to enable him to remain at home with his wife, to purchase respite care when she needed a break, and for modifications to his home to ensure he could remain there, living with his wife, for as long as he wanted. He was unlucky/lucky.

The other brother was unlucky/unlucky. Unlucky to have been diagnosed with MND and acquire a disability and unlucky that at age 66 he was not entitled to the NDIS. He had the same needs as his brother but he couldn't purchase aids and equipment he needed because Aged Care does not provide a comprehensive equipment program. He only received public health support for his rehabilitation - not enough, for not long enough. His only service options were aged care. He could access up to 11 hours of support per week to remain at home, but he needed more. His only option was a nursing home.

The story of two brothers highlights the inequity that arises when age is used to place boundaries around programs, or manage budgetary impact. Is this what we want for people over the age of 65 who acquire a disability? To only have very limited access to support to remain at home, or a nursing home bed? And not enough support to meet their needs?

We must retain our focus on needs to determine eligibility, not on age