

DISABILITY CARE AND SUPPORT INQUIRY

Response to the Productivity Commission's Draft Report

Submitted via email by:

disability-support@pc.gov.au

MND Australia
PO Box 990
Gladesville, NSW 1675

On: 29 April 2011





MND Australia congratulates the Productivity Commission on the breadth and depth of this draft report. Recognition that the current disability support system be totally reformed as it is "underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports" is welcomed.

The proposed framework for a national disability insurance scheme will go a long way in providing an appropriate support structure for people in need of urgent and complex support services following a diagnosis with a rapidly neurodegenerative disease such as motor neurone disease (MND). The draft report has included many of the key characteristics outlined in our original submission which is also welcomed.

People living with MND and their carers are at great risk of falling through the gaps of service provision. The recognition in the report of the need for:

- early intervention for people with progressive degenerative disease
- an assessment process that can anticipate changing need
- effective protocols for timely and smooth referrals to and from the different sectors

is integral in minimising this risk.

The crucial issue in the draft report that must be addressed is eligibility and access to **services based on need not age**. The report states that the needs of those who acquire a disability after age 65 would be best met by the aged care system. This is not the case. MND is not a disease related to ageing but many people are diagnosed when they are over age 65. People diagnosed with MND aged over the pension age will need services from both systems to address their changing and complex needs and to ensure their quality of life.

We estimate that about 30% of people living with MND in Australia are over the age of 65.

Our original submission (no. 264) provides detailed information on motor neurone disease (MND) and the services required to meet the needs of people living with MND and their carer.

In this response to the draft report MND Australia has focused on the draft recommendations that will have a direct impact on the care and support of people living with MND and their carer.

Specific comments

Chapter 3: Who is the NDS for?

- Eligibility and available supports

MND Australia is pleased that the number of people to be supported under a NDIS would increase and that people with degenerative diseases such as MND have been included as an early intervention group. MND Australia asks the commission, however, to ensure that all people with a disability will be eligible to seek support from the new system in response to the needs created by their disability. People must have access to address disability related needs no matter the age they acquire those needs.

The report states that the needs of those who acquire a disability after age 65 would be best met by the aged care system and they would not therefore be eligible for the NDIS. It is not the case that the aged care system can meet the needs of people living with MND. Most people with progressive neurological diseases over the age of 65 will need services from both sectors – to address needs related to their disability and in some cases also needs related to ageing.

The draft report suggests that those who acquire the disability before aged 65 can elect to either stay with NDIS or transition to aged care services when they turn 65. This will mean that NDIS recipients will be able to purchase or acquire the equipment they need, but someone who acquires a disability over 65 will be left to Aged Care for a response.

The Productivity Commission review on Aged Care makes no provision for the supply of the full range of disability aids and equipment for people over 65. This will be a significant gap which must be addressed by the Commission report on Disability Care and Support.

The existing Aged Care funding system does not provide adequate funding to support people who wish to remain living at home assisted by their family and partners – see *examples at the end of this submission*. The existing system provides limited support for people to remain at home and, when that support is inadequate, only offers residential care in high care settings.

To achieve lifetime care and support in their chosen setting people need to be able to access services based on needs related to their disability and their age.

The option for the disability sector to fund services for people up to the pension age and for the aged care system to fund services for people over the pension age is a simplistic approach that denies the complexity of support required by people living with a progressive neurological condition. A bridge of continuity of support service funding is imperative. People must be able to access services from both sectors to meet their needs irrespective of which sector is responsible for funding the package of care.

Access to services based on need must also be irrespective of where a person lives. For many younger people with profound disability and complex needs residential aged care may be the only option. Extra funding to enable them to achieve their personal goals and

dreams is critical. People with MND living in residential aged care facilities – no matter how old they are – will need top up funding to purchase extra services to meet their changing and complex needs and to ensure their quality of life.

In Victoria, the Disability Act makes no exclusion of people based on age. This means that people with disabilities (and MND) can access services based on their assessed needs for service. Disability services then provide support based on need, excluding age. Aged care services can also be accessed by those over 65 with a disability, creating a complementary service system option, and enabling people over the age of 65 to access services that best meet their needs, rather than best meet their age.

Conversely in NSW people are not eligible to be assessed by an aged care assessment team for aged care services until they are 70. People between the ages of 65 and 70 years therefore struggle to access services from either sector.

The draft report proposes establishing no-fault lifetime care and support for all catastrophic injuries. The scheme established for this purpose would be the national injury insurance scheme (NIIS) which would operate alongside the NDIS. The commissions view for people over the pension age who have a catastrophic accident related injury is that the NIIS would fully fund people's support needs attributable to the injury and that the aged care system would meet any ageing related care and support costs as the person grew older.

A similar approach could also be taken for people over the pension age who acquire a disability that is not a normal part of ageing such as MND.

- **Early Intervention**

MND Australia congratulates the commissioners on their acknowledgement of the importance of early intervention for those newly diagnosed with degenerative diseases. Early intervention is vital for people living with MND. Early access to information and counselling creates a solid base upon which the needs of people diagnosed with degenerative disease can be addressed through appropriate levels of support.

Anecdotal evidence indicates that preventing crisis phases in care delivery is an effective mechanism to address needs and maintain quality of life. Preventing a crisis driven approach to intervention is also cost effective. It reduces the need for services and crisis admissions to acute care hospitals and aged care facilities thereby reducing costs to the disability, medical and aged care systems

For people with progressive degenerative diseases, such as motor neurone disease, early intervention must include immediate access to assessments, initial low care services and assistive technology through the scheme as well as counselling and information.

Varying and increasing levels of service support will ensure that people newly diagnosed with degenerative disease have access to services based on need from diagnosis onwards with the knowledge that the full spectrum of services can be rapidly introduced as needs change. A seamless approach to service provision and better support for the



family carer is the most effective and efficient use of resources for people living with MND.

The imperative for early intervention for people diagnosed with MND is the length of the disease trajectory as the average life expectancy is only 2 to 3 years. Rapid access to services to meet high and complex needs promotes and supports home based care, which is the preferred option for most people. The use of high care supports is usually relatively short.

The Continuous Care pilot conducted at the Bethlehem Hospital in partnership with the MS Society and MND Victoria provides a model for coordinated care for people with neurodegenerative diseases. This pilot, which included people living with MND, has been highlighted in the draft report as evidence to support early intervention and coordinated care for people with progressive neurological conditions.

- **Interfaces with other systems**

- Palliative care***

- MND is a terminal disease – however the rate of progression varies considerably. Ideally referral to palliative care services takes place soon after diagnosis with palliative care services moving in and out alongside disability, aged and health care services to ensure that a person’s needs are met as and when they arise.

The report states that the needs of people with terminal disease would be more appropriately met by the health and palliative care system. For people living with MND this is not the case as the health and palliative care sectors alone are not able to support people with high needs at home. Most people with MND remain at home until they die or until the last few days of life.

Palliative Care in NSW currently varies significantly from one area to another. Eligibility varies but overall they require the person to have complex care needs to receive specialist palliative care services. In some areas this includes a multidisciplinary team and in others this may be a palliative care nurse. It is getting more difficult to access a palliative care multidisciplinary team for people with MND in NSW. There is no consistency across the state or between local health networks. Some services do provide excellent service to our members and assist in people having a peaceful death while other areas have no such involvement and people die in distressing situations. Often people need to be at end of life before referrals are accepted by some services and in many areas a person must be referred by a medical practitioner. With MND it is not easy to know when a person is at the end stage of their disease.

In Victoria, people with MND are eligible to access palliative care services from the time of diagnosis or when they first need a service provided by a palliative care service. This “pre eligibility” facilitates earlier access to support and services, and removes waiting lists.

People with MND need access to a range of services to meet needs related to their disability and the terminal nature of the disease.

Health

Draft recommendation 3.4 acknowledges the need for MOU's with health, mental health, aged and palliative care to ensure that people do not fall through the gaps of the respective schemes and have effective protocols for timely and smooth referrals. Evidence confirms better outcomes for people living with MND who are able to access inter/multidisciplinary care and support. Coordination is therefore critical for people living with MND who consistently fall through the gaps of service provision.

A national pathway of care for people with progressive neurological disease is vital in streamlining referrals to and from the health and disability sectors and palliative care and ensuring swift access to the NDIS. The NDIS should draw on the expertise and experience of the disease specific organisations to develop and fund the development of these pathways.

Swift access for those with rapidly progressing disabilities may be supported by pre approval, as exists in legislation related to access to superannuation.

Chapter 4: Individualised supports funded by the NDIS

A national and timely approach to the provision of aids and equipment will be a long awaited and welcome outcome of the NDIS for people living with MND.

The existing waiting times for the provision of urgently needed aids and equipment must be addressed through effective and timely assessment and approvals for aids and equipment. Maintenance of mobility, independence and communication are essential to support ongoing community engagement and participation.

The inclusion of PEG feeds in the NDIS is also welcomed. However, MND Australia is concerned that there is no mention of respiratory support equipment such as non invasive ventilation and masks. Evidence supports the use of non invasive ventilation as a vital quality of life intervention for people with MND who have respiratory involvement. In most states and territories people with MND requiring non invasive ventilation are required to cover all costs themselves and this deters many people from using this evidence based intervention in Australia. The health system in most states does not fund respiratory support for people with MND. Funding for non invasive ventilation machines and masks must be addressed within the NDIS.

A range of respite options has been recommended – it is vital that these options are flexible and include a full range of options. Ultimately, it should be up to the individual to identify the respite services or options they want and be able to authorise payment for them. It is also vital that there is access to equitable respite options nationally. Current flexible respite programs accessed through MND NSW and Victoria confirms that people will chose a wide range of respite options.

From a recent MND flexirest recipient:

'I'm 28 years old and was diagnosed 2 years ago. I'm currently traveling around Australia with my wife. Through flexirest we obtained \$1000 to go towards our petrol. And Petrol is not cheap on the Nullarbor.... There have been many changes in my life, going from



being a footballer and electrician to not being able to do anything with my hands or feet. Relying on others to do things for me and just getting around doing day to day things is hard. I'm traveling around Australia and enjoying life and refuse to get in a wheelchair. I'm always happy and still go fishing and enjoy life as much as I can'

(Flexirest - NSW State Government provides funding to a consortium of progressive neurological disease organisations to fund flexible respite options).

Chapter 5: Assessing care and support needs

We congratulate the commissioners on acknowledging the need for the assessment process to anticipate changing need. MND is generally a rapidly progressive disease for which prompt (if not immediate) approvals for support services are required as needs change. A fast track process that eliminates the need for reassessment as needs change for people with rapidly changing needs is imperative.

It is proposed that the NDIA will employ trained assessors. The commissioners will need to consider how these assessors will build on the experience and expertise of existing aged care assessment teams and disability service assessors.

Assessment for carers is a welcome inclusion - MND carers are integral to the care and support of people living with MND and invariably provide a large share of the care. Assessment and funding of their needs will enhance the support of people with disabilities and will assist families and carers to continue to be active in the life of the person with MND.

The NDIA assessors and case managers will need to understand MND and the impact of progression and rapidly changing needs. Disease specific organisations can play a vital role within the proposed NDIA in the provision of tailored education and information to stake holders, as well as effective case management and care coordination. In addition consideration should be given to the NDIA engaging agencies that are currently providing case coordination and case management to ensure that specialist knowledge, expertise and experience related to lower incidence diseases and disabilities is not lost.

MND Victoria and MND NSW have close partnerships with the case management services in their respective states to promote fast access and ongoing monitoring of changing needs. The MND association regional advisors play a pivotal role in maintaining ongoing contact with people living with MND and in monitoring progression and changing need. Community Options NSW (COPS) has been funded by the NSW state government to provide MNDPacks to people with rapidly progressive neurological diseases. These packs provide additional brokerage funding to meet rapidly changing care and support needs.

Chapter 6: Who has the decision making power?

MND Australia supports the recommendation that people should be given more power and choice in a new system with the objective of giving people greater flexibility and control over their lives. For many people with MND, however, the rapid progression and adjustment to rapidly changing needs will negate their ability to manage self directed



funding. The role of the proposed disability support organisations will therefore be crucial for many people with MND and their carers and families.

- **Disability support organisations**

Role of specialist disease specific organisations and whether the Disability Support Organisations would include existing specialist disease specific organisations such as MND associations is unclear in the report.

It is essential that the NDIA utilise the existing knowledge, expertise and experience of specialist disability agencies to ensure that the unique issues related to progressing and escalating needs in low incidence diagnoses and disabilities is not lost.

Specialist disease specific organisations, such as MND associations, are ideally positioned to be DSO's. They are very often the trusted advisor to their clients, have strong relationships with them, understand their challenges and have expert disease specific knowledge. To create another entity would be to duplicate and introduce another layer for clients and create confusion.

For instance it is proposed that the NDIA as part of its public education strategy could fund DSO's to provide early information sessions. MND Associations have well established information sessions for people recently diagnosed with MND, their family and friends which could easily be expanded to include information about the NDIS.

There will need to be clear definitions related to service provision and DSO's to allow some flexibility so that existing quality programs and services can be utilised by the NDIA. In addition recurrent funding will need to be available through the NDIS to support the DSO's.

Chapter 8: Delivering disability services

The delivery of a high quality and sustainable disability service system is essential and must be the focus for the proposed NDIS. MND Australia welcomes the recognition of the need for a single point of entry and assessment and the need to effectively use information technology to streamline access to information and to improve outcomes.

The report has recommended a centralised internet database of disability services and service providers. The Commonwealth Respite Carelink Centre database has been developed over many years in an effort to assist people to navigate the service system maze and to put people in touch with local services. The NDIS proposal would hopefully provide an opportunity to further enhance this database to better meet the needs of people with a disability.

The report recommends the funding and development of a shared electronic record of relevant details of NDIA clients. The issues related to integrating NDIA electronic records with the personal e-health records are acknowledged. However, it is important that this development is able to be linked at some level with the electronic health records, with appropriate permissions, to support a seamless approach to care across the disability and health sectors.

Services for people with MND following the introduction of the NDIS

Person diagnosed with MND aged 63 - eligible for disability support through the NDIS

- Person diagnosed by Neurologist
- Referred to NDIA for early intervention services
 - MND association information and support
 - MND clinic ongoing health care and disease monitoring
 - Allied health/palliative care
 - NDIA assessor - assessment of needs
- Case manager/care coordinator appointed and care plan developed
- Person with MND and their carer provided with funding package to buy services to meet their assessed needs as the disease progresses.
- MND association act as their DSO and assist with planning and assembly of package of supports and provides information and support to service providers. MND association monitors progression and facilitates access to more services and extra supports funded through the NDIS package as required:
 - Aids and equipment
 - Home and vehicle modifications
 - Attendant care
 - Respite
 - PEG feeds
 - Community and family supports
- Carer well supported in their caring role with all aids and equipment to minimise risk and regular respite in place – supported to care for person with MND at home up until end of life
- Case manager liaises with MND Association, MND clinic, allied, primary, palliative care to promote a multidisciplinary coordinated approach

Person diagnosed with MND aged 66 – not eligible for disability support through the NDIS - services provided by the aged care sector:

- Person diagnosed by Neurologist
- Referred to:
 - MND association information and support
 - MND clinic ongoing health care and disease monitoring
- MND Association assists with case management and referrals
- Referred to aged care or palliative care allied health services
 - the conflict between the rehabilitation and maintenance approaches to care and therapy leads to admission and discharge and readmissions to hospital
- Needs aids and equipment and home modifications - Referral made to occupational therapist
 - assessment and refers to home modification service - wait for service
 - aids and equipment not available through the aged care sector
 - Some state MND Associations able to provide equipment
- Needs respite care - may be provided by aged care sector but may not be flexible to meet the needs of the individual



- Needs personal care and support at home - Referral to aged care assessment team
 - Assessment takes place - eligible for Community Aged Care package of 5 hours a week but no package available
 - Disease continues to progress – reassessed
 - Re-assessed - eligible for EACH package
 - long wait for package to become available
 - EACH package provides up to 17 hours per week of aged care in-home support
 - Person needs two people for personal care which halves their weekly allocation of hours to 8.5 hours of personal care per week
 - *Currently hours available to people under 65 through attendant care is 34 hours per week but can be higher based on assessed need i.e twice the number of hours available through the aged care system*
 - Disease continues to progress – crisis admission to hospital
 - high needs not met by EACH package
 - Admitted to residential aged care facility for nursing home care
 - NH staff unable to provide care and support to meet complex needs and family fund extra support

NB if the person lives in NSW they are not eligible to be assessed for aged care services until they are 70 years old. This person would therefore potentially not receive any personal care services.

Motor neurone disease (MND) which is known as Amyotrophic Lateral Sclerosis (ALS) in many other parts of the world, and as Lou Gehrig's disease in the USA, is a progressive neurological disease. MND affects approximately 1400 people in Australia and thousands more - their carers, families and friends - live daily with its impact. On average every day in Australia at least one person dies from MND and another is diagnosed.

MND Australia is the national peak body for MND care and research in Australia. The MND Australia network comprises of six state Associations, representing all states and territories, and the research arm of MND Australia - the MND Research Institute of Australia (MNDRIA). MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a ***World Free from MND.***

MND Australia welcomes this draft report and is available to provide further information if required.

Carol Birks National Executive Director, MND Australia, carolb@mndaust.asn.au
www.mndaust.asn.au Phone: 02 9816 5322 Mobile: 0408 416 932