Productivity Commission

DISABILITY CARE AND SUPPORT INQUIRY

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Executive Summary

MND Australia believes that any new system or scheme for the provision of disability care and support should have the following characteristics:

1. The support scheme must encompass every person who has a disability, either from birth or acquired via disease or other intervention, with no restrictions based on age of onset
2. It must be a no fault social insurance scheme
3. It should exclude disabilities attributable to the normal process of ageing
4. People who acquire a disability after the age of 65 must be able to access disability services to meet their needs
5. It must be an entitlement model, based on establishing eligibility through simple but clear eligibility criteria, with some diagnoses or disabilities having automatic eligibility without assessment
6. Assessment should be provided by an authorised and funded organisation, independent of the service provision funding bodies, with extensive knowledge and experience of assessment and the person's disability
7. There should be a regular process of reassessment where needs are changing and unmet needs emerging
8. It must encompass the purchasing of services to address unmet needs, created by disability, identified and measured by an assessment process
9. It should be funded by a universal taxation contribution or a social insurance like system akin to Medicare
10. Income to the scheme should be pooled to create a corpus of funding with ongoing investment income and new contributions from taxation.
11. It should not make dividend payments to government but excess capital and income should offset reduced taxation contributions in the future
12. The scheme should make direct payments to or for eligible people with disabilities so that they and or their families, carers or designated support organisations can purchase services to address unmet needs created by their disability
13. Services purchased by those entitled to those services must meet national quality and operational standards established by the scheme

1 Introduction

MND Australia welcomes this once in a lifetime opportunity to change the lives of people living with a disability in Australia. For too long people living with progressive neurological diseases such as motor neurone disease (MND) and their families have not received the support they need to maintain their independence, social inclusion and quality of life. For too long people with MND and their families have had to wait for an assessment, wait for services to commence and then wait for an increase in services to meet their increasing needs. The complexity of the current system has for too long precluded access, equity, self determination, efficiency and coordination.

A National Disability Insurance Scheme represents the opportunity to make reforms and systemic changes to ensure that every person who has a disability, either from birth or acquired via disease or injury, will be entitled to care and support to meet their needs with no restrictions based on the age of onset.

People living with MND and their carers face a spiraling series of losses – loss of speech, swallowing, mobility and breathing - with severe impact on physical, emotional, psychosocial and financial well-being. Rapid progression and the complex care needs in MND are either not met or poorly met by existing statutory services. Currently services are provided based on age, the type of disease or disability, and the availability of funding and services in a particular region. Eligibility is competitive, with no mechanism available to determine prioritisation of funding. Accessing services becomes a lottery. Services are provided based on needs, but not individualised to ensure that the needs of the individual are addressed. The individual, their family and carers have very little choice in the services provided, or the service providers. A whole of government approach to Health, Disability and Aged Care services is needed to promote responsive, coordinated and seamless planning options and services for people with MND and their families and carers.

The rapid progression of MND necessitates a rapid response from service providers who understand the impacts of this disease. The need for rapid and appropriate responses must be anticipated and this means a spectrum of services must be available, with the flexibility to meet the rapidly changing needs. A funding model where the individual is funded to purchase their own services is the only possible mechanism to achieve this.

People with MND and their carers need access to a range of planning options and services to ensure their quality of life (see Appendix A). The services that need to be increased or created nationally include:

1. Effective case management and care coordination
2. Packages of funding to purchase service to address individual needs, including respite care, care in the home, aids and equipment, accommodation and attendant care services.
3. Top up funding to assist ongoing disability and brokerage services to provide responsive needs based care that reflect the rapid progression, change and escalation of needs.
4. Flexible respite, with a wide range of options and opportunities
5. Timely access to aids and equipment and home modifications

A new national care and support scheme provides the opportunity for an entitlement model to be developed with some diagnoses, such as progressive neurological disease, having automatic eligibility. Any new scheme must encompass a regular and responsive assessment process that will identify the changing and emerging unmet needs of people who acquire a progressive neurological disease.

A new scheme must encompass the purchasing of quality services to address unmet needs created by the disability or disease. Case manager support must be available early in the disease for those individuals who may wish to purchase case management services to assist them to identify needs and purchase appropriate services in a timely manner.

Engagement with disease specific not for profit associations in developing a life time model of support that includes automatic eligibility for people with progressive neurological diseases will be imperative to ensure that disability services are available based on the needs and wishes of the person and their family and take into account the rate and impact of progression of the individual.

Background

MND Associations in Australia were formed during the 1980s to meet the complex and changing support, equipment and information needs of people living with MND, their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND).

MND Australia and its six State Association members work together to advance, promote and influence local, state and national efforts to achieve the vision of '*a World Free from MND'.*

Motor neurone disease (MND) is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within three years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS). Currently around 1400 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause (in most cases), no known cure and no effective treatments. Average life expectancy from diagnosis is about 2 years (page 3, Sach 2003). Average age of onset is 59 years; however, the age range of onset is 18 to 90 years. MND is not acquired as part of a natural process of ageing.

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

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

3. Submission

A whole of government approach for the provision of disability services on an entitlement basis is essential in providing equitable access to care and support for people with MND and their carers throughout Australia. A new scheme must be based on no fault entitlement and eligibility for the scheme must be needs-based, not aged-based.

Service delivery should meet each person's needs with the consideration of individual symptoms, perceived needs and rate of disease progression. Care required by individual MND clients is not a fixed quantity; it differs for each person over time. It is important that carers and families are also entitled to the support they require to continue their role in supporting their family member and receive greater focus in the assessment process.

MND Australia believes that a national disability insurance scheme is the most appropriate and equitable approach to future disability funding (see Appendix B). Such a scheme would create entitlement and would support a person centered and individualised approach. The services and supports able to be purchased through the scheme should be broad and diverse, determined by the individual needs and circumstances of the person with MND and their family and carers.

The key questions from issues paper:

- **who should be the key focus of a new scheme and how they may be practically and reliably identified**

Any person born with, or who acquires a disability that requires intervention and services to address their unmet needs and to support their community engagement should be the key focus of the scheme. People should be identified through a simple but clear eligibility assessment process, which incorporates measures of automatic eligibility for defined diseases or disabilities

Some diagnoses or disabilities should have automatic eligibility. MND, for example, has a well known disease trajectory and clarity around the levels of disability that will be created. Automatic eligibility would provide certainty and promote planning ahead with consequent improvement to quality of life for the person diagnosed, their family and carer. It would also be a more cost effective model than the current system that involves multiple assessments, waiting lists and crisis intervention.

People over 65 who have or acquire a disability must not be excluded. Progressive neurological diseases are not acquired as part of the natural process of ageing but many people do acquire these diseases in their 60's and 70's. As people age with a progressive neurological condition, their needs increase 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.

The aged care system already has rigid eligibility and assessment criteria to provide aged care services to people aged over 65. People who acquire a disability aged over 65 must be able to access disability services to address unmet need related to their disability when aged care services cannot address that need.

Assessment should be undertaken regularly where the disability or disease is rapidly progressive, and funding levels modified accordingly. Assessment should be provided by an authorised and funded organisation, independent of the service provision funding bodies. The assessor should have extensive knowledge and experience of assessment and the person's disability

People with progressive neurological disease can be practically and reliably identified and progression monitored by the general practitioner and/ or by disease specific not for profit organisations. MND associations already play a vital role in identifying and monitoring needs and identifying and referring to appropriate services and service providers to address unmet needs.

- **which groups are most in need of additional support and help**

All disability groups need better and faster access to the services that will address their unmet needs and improve their quality of life and community access. It is entitlement and timely acquisition of support that is essential.

People with progressive neurological disease, and rapidly progressive neurological diseases like MND in particular, need additional urgent access to support and help, more often than not, for a relatively short period of time. As needs change, so must funding change, to ensure that new or additional services can be purchased to meet the need as soon as it is identified.

MND Victoria and MND NSW have engaged with government funding bodies over the last few years to highlight the additional and responsive support that people with MND need. This has resulted in the approval of emergency access to packages of care for people with rapidly progressive neurological disease in some regions. This emergency response to identified high unmet need minimises long term negative impacts on families and carers and prevents high cost crisis intervention.

> "*The rapid nature of the debilitating effects of motor neurone disease means that the individual will need an increasing amount of personal assistance as the disease progresses. This task usually falls to a partner, close relative or friend.*"
> (Mockford et al, 2006).

Families and carers need additional help to support them in their caring role. Timely provision of services and flexible and innovative respite options are vital in enhancing their quality of life and in maintaining employment, social inclusion and their physical and emotional health.

- **the kinds of services that particularly need to be increased or created**

It is essential that eligibility and needs assessment services be created to support improved service delivery. It is also essential that variations on existing services be developed to ensure that people with disabilities can access creative options of support to enhance their quality of life, independence and community access. There is also a need to generate new services to meet growth in demand arising from previously unmet need and newly identified needs.

People with MND and their carers need access to a range of planning options and services to ensure their quality of life. The following kinds of services need to be increased or translated nationally to meet the needs of people with MND and their families:

1. Effective case management and care coordination
2. Packages of funding to purchase service to address individual needs, including respite care, care in the home, aids and equipment and attendant care services.
3. Top up funding to assist ongoing disability and brokerage services to provide responsive needs based care that reflect the rapid progression, change and escalation of needs.
4. Flexible respite, with a wide range of options and opportunities
5. Timely access to aids and equipment and home modifications

Existing state based models for targeted funding include dedicated funding packages for rapidly progressive diseases or ‘top-up’ funding to address timely access to existing services and high level need. Life expectancy in MND limits the length of time that individuals are likely to need funding and services, therefore funding commitments have the potential to assist a number of individual clients within a relatively short time frame.

Direct payments to the individual so that they and or their families, carers or designated support organisation can purchase targeted packages of care for rapidly progressive disabilities is essential to address rapidly changing and emerging needs, and facilitate timely access to services.

> “We were asked to make decisions as to what list we wanted our names to wait on….how many hours we thought we would need… for what and why and what did any of this mean, It meant nothing to us, and we both found it incredibly difficult to get our heads around this new language, let alone apply it to ourselves.” (Lisa Morgan, 2008)

Care coordination is vital to assist people with disability and their families to navigate the system and identify and evaluate services available. Families require assistance and support to understand the services that are available and what they will mean for the person with MND. Case manager support needs to be purchased and allocated early in the disease to enable the case manager to work with the client to identify needs and purchase services in a timely manner. Care coordination enhances quality of life and is vital in minimizing duplication of services across health, disability and aged care services.

The ability to self manage the acquisition and purchase of services, with the support of case managers, builds independence and resilience, and assists people to retain control over their lives with a disease which is uncontrollable.

- **ways of achieving early intervention**

Early assessment of eligibility for a no fault entitlement funding scheme, with rapid evaluation of unmet needs, will facilitate earlier access to targeted services. Identifying those diagnoses, such as progressive neurological diseases, which should be entitled to automatic eligibility, will be instrumental in achieving early and timely intervention.

Most people diagnosed with MND join the state MND associations soon after diagnosis and are linked in with a MND association Regional Advisor. The Regional Advisor stays in regular contact with the person living with MND and their family and as the disease progresses links them into services and providers to meet identified needs.

Early intervention is dependent upon early diagnosis. Australia has a good rate of referral from GPs to Neurologists for diagnosis. Neurologists have prioritised possible MND clients for diagnosis. Research indicates that 70% of people diagnosed with MND register with the MND Association within three months of diagnosis (Sach, 2003)

Case management models of care in Victoria and NSW have demonstrated the value of partnerships between case management services and MND associations in monitoring need and planning responsive service provision based on the needs and wishes of the person with MND and their family. For many people knowing that services to meet their need will be available when and if they need them enables them to remain as independent as possible for as long as possible.

Automatic eligibility and early referral to disease specific not for profit organisations will enhance early and timely intervention and ongoing monitoring of need for people with progressive neurological diseases.

Investment in early intervention and the timely and appropriate provision of home modifications and aids and equipment, including communication devices and non invasive ventilation, is vital in maximising independence and quality of life. This investment would ultimately reduce long term costs associated with crisis interventions, inappropriate residential aged care placement and negative impacts on family and carer health and well being.

- **how a new scheme could encourage the full participation by people with disability and their carers in the community and work**

Effective funding and service delivery to address unmet needs would facilitate return to work for carers and people with disabilities, prompting contribution to the economy.

MND carers are not able to remain in work unless there are effective and appropriate services to support their family member at home. Service provision for MND carers must include adequate levels of emergency and planned in home and residential respite care from appropriately trained staff in a variety of locations. Timely and flexible respite options are essential to support carer wellbeing and continued participation in the community and in the workforce for as long as possible.

A recent partnership initiative in NSW is the flexible respite program - FlexiRest - which provides a model that has the potential to be translated nationally. MND NSW has established a consortium with Multiple Sclerosis Limited and the Muscular Dystrophy Association of NSW. This consortium has been successful in obtaining funding from ADHC to provide flexible and innovative respite options for people with these progressive neurological conditions to support the carers to maintain their caring role. Investigating the potential to extend the FlexiRest concept nationally would provide a practical measure to support carers and encourage their continued participation in the community and work force.

As MND is a progressive illness, the support of people diagnosed to remain at work must focus on addressing unmet needs in the workplace by purchasing care and support services, minor workplace modifications, and appropriate withdrawal strategies.

- **how to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong**)

Empowerment comes from control over funds and purchasing decisions. People with disabilities must be able to control and manage service purchasing decisions, or be able to purchase support services that allow them effective control. They must also be able to access effective advocacy support that can assist them in managing and controlling their resources.

People with MND can deteriorate rapidly from being active, independent individuals to a level of dependence that they or their carer could never have anticipated. The speed of this process severely impairs the capacity to plan ahead and to make decisions regarding service need. There is often a failure to come to terms with and face the personal level of need. Accessing adequate levels of support to maintain home based care, if that is the preferred option, can be challenging. Purchase of the services of a case manager and packages of care from early on in the disease process assists people with progressive neurological disease and their carers to plan their care needs, make decisions, and retain control.

- **how to improve service delivery — including coordination, costs, timeliness and innovation**

Improvements to service delivery will come from competitive purchasing and control of purchase decisions by the users of the service. Competition will ensure that service quality is maintained and improved, options increased, innovation encouraged and individualisation the norm.

In a number of regions the complexity of MND care has encouraged local health, palliative, community and disability services to initiate MND care coordination meetings on a regular basis. These models have proved effective in developing a coordinated inter-disciplinary approach to MND care management minimising duplication of services and unnecessary visits to the client's home. These models of care are not formalised within the system and rely solely on the goodwill of the providers involved. Support for innovative care coordination initiatives, controlled and purchased by users, would improve timely service delivery and save costs overall. Coordination of care is vital to quality of life and the prevention of duplication and high cost crisis intervention.

- **the factors that affect how much support people get and who decides this**

The level of unmet need should be assessed using a common assessment tool and funding applied to address those needs in the circumstances and environment in which they arise. Specialist agencies, authorised by but independent of the funding body , should undertake assessment and preliminary planning to determine an appropriate level of introductory funding, with adjustment to funding levels on an ongoing basis or when needs change.

The impact of rapidly progressive disease must be taken into account. As needs change, funding levels must change to support purchase of need appropriate services. Funding must represent the cost of purchase of the service and where it is to be delivered. Funding must recognise the additional costs to be incurred in rural and remote areas.

The UK MND Association has produced an MND Year of Care Pathway to help the NHS and Social Services improve the provision of services for people with MND. The MND Year of Care pathway lists all the possible care and equipment needs that a person with MND may have over a 12 month period. By attaching a cost to each element, commissioners of services in the NHS will be able to plan and deliver services more effectively for the benefit of people with MND. http://www.mndassociation.org/for_professionals/sharing_good_practice/mnd_year_of_care.html This initiative could be adapted for Australia and for other conditions.

> *The months of Deb's illness were marked by a game of chasing our tails. I was about to learn something that you know only too well: being a carer is very hard. Physically caring for Deb got hard very quickly. We had to learn new skills of lifting, showering, dressing and feeding. We learned on the run, for virtually every day presented a new challenge.* (Armstrong. D, 2002)

Disease and disability specific information and education for service providers is vital to assist them to deliver needs focused services for their clients.

- **how to ensure that any good aspects of current approaches are preserved**

Client focussed funding will ensure that good services are supported and poor services either improve or disappear. Innovation will be encouraged as people with disabilities individualise the services they purchase to meet their needs.

There are many current approaches that work well for people living with MND – some of which have been outlined in this submission. These innovations are currently confined to one state or even just one region within a state. A national approach to disability service provision is vital in order to address this inequity.

"For what turned out to be Richard's last ten days, we received funding from DHS for an overnight carer - the package that had been discussed with us so early on in our journey finally came to fruition. This carer was a young fellow, but with enormous compassion, kindness & respect and Richard trusted him to care for him competently over night, which meant I could get some sleep" (Lisa Morgan, 2008).

Another problem with current approaches is that there is often a long wait for services that if introduced early would make a vital difference to the quality of life of the individual and their carer. Client focused funding would enable people to purchase the services they need when they need it thereby improving quality of life and control. This approach would also encourage the further development of current services that work well for individuals.

- **what to do in rural and remote areas where it is harder to get services**

Demand and price must drive service availability.

Although services in rural and remote Australia are often few and far between the community itself is usually more involved in supporting their community members living with disability.

"*The role of advocacy for rural people living with MND cannot be underestimated. There are some wonderful rural people doing some wonderful work and some communities that really seem to get it all together better than others. The difference seems to be that these communities have positive community members who are willing to lead. Quality leadership is a common ingredient to quality programs".* (Eric Kelly, 2009)

Providing mechanisms to mentor lone practitioners and service providers through the use of information technology innovations would help support them to work with and lead their community.

- **reducing unfairness, so that people with similar levels of need get similar support**

Effective eligibility and needs assessment, combined with an entitlement model of funding, will remove inequity of funding and support, and the purchase and delivery of individualised services. No longer will it be necessary to compare one diagnosis or disability to another – we will compare unmet needs.

People with similar unmet needs may not want similar levels of support from statutory services. Support will be purchased to address the needs of the individual and their family. The purchasing of case management support will assist individuals to identify the services that will appropriately meet their needs.

- **getting rid of wasteful paper burdens, overlapping assessments (the 'run around') and reducing duplication in the system**

A centralised assessment process, combining some automatic eligibility criteria, will determine eligibility for an entitlement system. Initial funding would be used to identify, assess and measure initial unmet needs and funding needs. It could also identify the capacity of the individual, family or carers to manage the funding and service purchase decisions and/or engage an appropriate provider where necessary.

The assessment process needs to be streamlined. Eligibility for an entitlement system should be a simple exercise, followed by needs analysis and scoping undertaken with the person with a disability and their family/carers and significant others.

Assessment should be provided by an authorised and funded organisation, with extensive knowledge and experience of assessment and the person's disability. One assessment tool needs to be developed for use nationally and there should be a regular process of reassessment where needs are changing and unmet needs emerging. This assessment tool could be developed in a similar way to the personal e-health record held by the client and updated online following review as necessary. Following assessment quality services must be available to meet identified needs.

- **how to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future**

A universal Medicare type social insurance scheme is the preferred option, combined with a user pays component for those people able to afford a co-payment.

Attention must be paid to long term outcomes. Initial funding would be a combination of existing tax funded disability funding through state departments, supplemented by income from a universal contribution scheme funded through a Medicare style levy. As the corpus of invested funds grows and once unmet need is addressed and the new scheme established, the level of funds from existing disability sources would decline. Ultimately there would be an invested pool of funds, supplemented by the Medicare type levy.

The scheme should not make dividend payments to government but excess capital and income should offset reduced taxation contributions in the future.

The scheme should provide an entitlement to services over time rather than a lump sum payment from which the individual should pay for the service they require. In this way the scheme would automatically balance the risks that some people will live longer than expected and others shorter, while some will have higher need than expected and others their needs may be less than anticipated. This approach would maximize efficiency and effectiveness and better meet the needs of the MND population.

- **the practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services**

Individualised funding options need to be explored to investigate risks and costs associated with this type of approach.

Existing service funding and delivery arrangements should remain in place, with a gradual extension and takeover of government funded services by the National Disability Insurance Scheme. The transfer could be undertaken by transferring funds from the Scheme to the government funded provider, with transition to direct client funding, with the agreement of the individual.

More people would be attracted to work in disability services if the services were well funded and more highly valued as a career option. People living with MND in other countries particularly the Scandinavian countries are provided with a team of full time carers. These carers are often young educated people who have chosen a career supporting people who are very disabled and their work is highly valued by the family and the community.

Working in this industry means there are no established career paths and no way to earn reasonable incomes. Remuneration in this field is low, and hence retention is difficult, particularly at the direct care level. Services and the workforce will need to be enhanced to meet increased demand. Remuneration, training, support and development opportunities must be addressed to improve recruitment, retention and the quality of services available. These enhancements must be included in the price of service delivery.

National quality service frameworks and operational standards will need to be developed and monitored.

4. Conclusion

A whole of government approach and investment in disability services is vital if we are to address unmet need in Australia. The current review process and seemingly bi-partisan support for disability care and support reform is a once in a generation opportunity to transform the delivery of disability services. It is a unique opportunity to develop a long term vision for a no fault social insurance approach that encompasses every person with a disability in Australia.

Major changes will need to be made in order to fund a new national disability care and support scheme. Additional funding may be required in the short term but in the long term the scheme will not only deliver better outcomes for people with disability, their families and carers but also savings to the community as a whole.

People with MND their families and carers continue to wait for change. Many models of care and initiatives have been introduced which have made a difference to their lives. But access has been limited by their age or location.

MND Australia believes it is time to change the way services for people with disabilities are funded and structured in Australia. We believe that current funding arrangements are inadequate and that a National Disability Insurance Scheme offers the only solution to the chronic unmet need for lifetime care services. A NDIS would give people diagnosed with MND the peace of mind that optimal care will be available to address their needs to help them live better for longer

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

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APPENDIX A

THE INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS STATEMENT OF GOOD PRACTICE FOR THE MANAGEMENT OF ALS/ MND

Support and care management for people living with ALS/MND is underpinned by five basic principles:

1. Management of the disease determined by the needs and wishes of the person living with ALS/MND, treating the person with ALS/MND with care, respect and dignity
2. Timely response to identified needs
3. Access to a coordinated and integrated care plan
4. Regular monitoring and review of the person's condition, and appropriateness of the care plan
5. Information about the person's medical condition held in confidence

The International Alliance of ALS/MND Associations recommends the following good practice that will result in effective management of the diagnosis and care of people living with ALS/MND.

Before Diagnosis…

Early recognition of symptoms and access to a physician competent to diagnose complex neurological diseases

At Diagnosis…

Diagnosis given by a physician who is informed about ALS/MND, in a sensitive way appropriate to the person with ALS/MND and, in an appropriate setting with family and/or friend(s) present

Information provided in verbal and written forms about the disease, including its impact, sources of help and support, and referral to the ALS/MND Association as appropriate to the needs of the individual

Information sent to the patient's principal health practitioner about the disease, management implications, and the ALS/MND Association

The opportunity to return to the diagnosing physician for further information, care and follow up

After Diagnosis…

Access to:

- information and support services
- planning and coordination of support and care

These include:

- advice about personal care and equipment, clinical interventions, treatments and therapies, palliative care
- support for caregivers and families eg: respite care, bereavement support
- health and financial benefits
- research and clinical trials
- access to support from the ALS/MND Association

In summary, it is essential that people living with ALS/MND are enabled to make informed decisions about living with ALS/MND so as to achieve quality of life, and dignity in living and dying. Adopting a proactive approach to disease management and respecting the needs and wishes of the individual and their caregivers is imperative.

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Appendix B

National Disability Insurance Scheme

POSITION STATEMENT

Background:

The rapid progression of MND results in increasing support needs and reliance on a range of services and aids and equipment to maintain quality of life and social inclusion. The rapid progression also means that people have little opportunity to plan ahead or adjust to increasing disability. A rapid response to service provision is therefore imperative.

MND Australia believes:

- It is time to change the way services for people with disabilities are funded and structured in Australia
- People diagnosed with MND must be able to access disability services based on need no matter where they live or how old they are
- Waiting lists are not an option for people living with MND and their families

.

- A national funding methodology based on need has many benefits for people living with MND and their families to ensure a rapid response to need
- Such a scheme should be funded by all taxpayers through general revenue or through a Medicare-type levy
- Funding for essential care, support, case management, respite, therapy, aids, equipment and training should be drawn from this pool of funds so that people born with a disability or who acquire a disability through accident, injury or a medical condition such as MND would all be eligible for assistance based on need
- A NDIS offers a solution to the chronic unmet need for lifetime care services
- A NDIS would give people diagnosed with MND the peace of mind that optimal care will be available to help them live better for longer

MND Australia calls for:

- A major feasibility study to be conducted to explore cost and design options as soon as possible
- The MND community to support this scheme and to take action to spread the word in their community and to their government representatives
- A bipartisan government response to the outcomes of the *Productivity Commission inquiry into a National Long Term Care and Support Scheme for people with a disability and their families* so that this significant social change can take place to benefit all Australians in the future

At present most people living with MND have to wait for access to disability services. For many they are deemed eligible for a service but are placed on a waiting list often for long periods of time. Case management is not always available and packages of care often scarce.

For many people the wait for equipment may be many months or be very costly. In some states people over 65 are unable to access the disability services they need and people under 65 are unable to access residential care if needed.

The concept of a National Disability Insurance Scheme (NDIS) is receiving increasing support from a range of disability advocacy groups and the wider community. Current funding arrangements are inadequate and a NDIS would provide a more sustainable funding structure for the government and the community as demand increases over time.

Considered by the Executive Management Group I April 2010

Considered and endorsed by MND Australia board 21 June 2010

Signed:

Ralph Warren (President)

Acknowledgement: Background to NDIS taken from the NDIS website and Toolkit: http://www.ndis.org.au/.