Response to the NDIS draft definitions:

Eligibility and reasonable and necessary support

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1. Eligibility

Recommendation 1.1

Improve the ageing-disability interface to ensure access to needs based services for people who acquire a disability when over the pension age

Recommendation 1.2

Ensure progression of disability is taken into account so that a person with urgent and changing need for assistance has access to support

Recommendation 1.3

Reinforce and support the health/allied health/palliative care interface

Recommendation 1.4

Ensure assessment is considered when developing the eligibility statement

2. Reasonable and necessary support

Recommendation 2.1

Ensure timely availability of equipment and assistive technology to address all needs created by disability

Recommendation 2.2

Develop service options that are responsive to changing need

1. Eligibility

Recommendation 1.1

Improve the ageing-disability interface to ensure access to needs based services for people who acquire a disability when over the pension age:

The specification of age limits means that people who acquire a disability when over the pension age will not be eligible for the NDIS. 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. 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 1 - the story of two brothers). These diseases are not acquired as part of the natural process of ageing, 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.

The ***Living Better, Living Longer*** reforms to Aged Care specify that more packages of care will be available; however, the focus remains on addressing need related to ageing. Access to disability services and hours of support available will therefore remain limited and the gap between what is available under an NDIS and Aged Care will widen.

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. 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 16 hours per week (see Appendix 2).

The exclusion of people who acquire a disability when over the pension age from the NDIS will lead to the discrimination of older Australians unless provisions are made to ensure equitable access to needs based care. Further discrimination exists with respect to financial burden. Aged Care is a system where people are asset and income tested and expected to contribute to the cost of services if they are able. This will mean that people acquiring a disability over the age of 64 will be contributing to the cost of their services in accordance with income and asset assessments. Conversely people eligible for the NDIS, an insurance model of support, will not be expected to contribute financially.

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 need 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, equipment, specialised therapy and communication aids rarely occurs.

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
- Clear assessment processes and protocols for the interface between the NDIS and the aged care system

Recommendation 1.2

Ensure progression of disability is taken into account so that a person with urgent and changing need for assistance has access to support:

The 'High-level Principles for a National Disability Insurance Scheme' states that an NDIS should be needs based and provide people with disability access to individualised care and support. It also states that an NDIS should provide certainty for people with disability in accessing high quality and effective services and support when they need them.

- Ensure that eligibility encompasses initial low level need for assistance with increased funding under the NDIS available as the disability level escalates and progresses

Recommendation 1.3

Reinforce and support the health/allied health/palliative care interface:

Good interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated multidisciplinary approach to care and support (see Appendix 3). The introduction of the NDIS should entail practical protocols being put in place for how these sectors will work together to best assist people with complex needs.

- Negotiate eligibility protocols between the NDIS and allied sectors—such as health, including palliative care —which ensure that people receive the appropriate support they require as soon as a need arises.

Recommendation 1.4

Ensure assessment is considered when developing the eligibility statement:

The eligibility statement will frame the development of the assessment process. For people with progressive neurodegenerative conditions early intervention with careful and appropriate

ongoing assessment will be key to efficient use of the NDIS and access to needs based care to support quality of life and community participation.

- Include the multidisciplinary team in the assessment process to ensure eligibility for the early intervention groups and to support an anticipatory approach to the re-assessment of people with complex needs and their carer.

2. Reasonable and necessary support

Recommendation 2.1

Ensure timely availability of equipment and assistive technology:

Important to many people with disability is access to equipment and assistive technology, which includes expert assessment, consumer information, support to select the most appropriate item/s of aids and equipment, installation and training, and maintenance and repairs. The delivery of appropriate and timely assistive technology to those who need it has benefits including: improving the quality of life for those with disability and their families; reducing reliance on expensive personal support, lessening the need for accommodation support or residential care admissions; reducing family carer injuries and stress; increasing participation in employment, education and the community; reducing hospital admissions and shortening hospital stays.

Access to equipment and assistive technology under the existing aids and equipment schemes operated by state and territory governments is too slow for people with rapidly progressive disability. It is understood that under the NDIS this will change.

Under the present NDIS recommendations and proposed aged care reforms access to equipment and assistive technology for people who acquire a disability when aged over 64, however, will remain problematic.

- Ensure that the equipment to support communication, mobility, independence and breathing is available as a reasonable and necessary support under the NDIS and regularly update notions of 'eligible equipment' to reflect technological advances

- Investigate the optimal and most cost effective way to fund the provision of equipment and assistive technology during the design of the NDIS, including rental and purchase. This investigation should include the equipment service models some organisations lend to people with rapidly progressive conditions such as motor neurone disease

- Work with the Aged Care sector to ensure equitable and cost effective access to equipment and assistive technology for people is based on need not age - see recommendation 1.1

Recommendation 2.2

Develop support options that are responsive to changing need:

In order for the NDIS to meet the reasonable and necessary support needs of people with progressive disability support options and assessment processes must be developed that are responsive to changing need. Disease and disability specific information and education for assessors will be imperative to ensure that they understand the impact of specific diseases on the individual and their family and the progression of associated disability. The development of an inter/multidisciplinary care plan will help to reduce duplication and enable services not funded through the NDIS to be involved as and when required to meet identified need (see Appendix 3).

- Develop National Guidelines for the management of people with rapidly progressive neurological conditions to assist with establishing interfaces between different sectors, minimise duplication and help to ensure timely and responsive access to reasonable and necessary supports to meet identified need

APPENDIX 1

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.

APPENDIX 2

MND Vic case studies summary

Case Study 1: Andrew had diagnosis of MND in March 2009. Andrew lives alone. Only one relative, nominated as next of kin. No other relatives or close friends who were able to provide support. Pensioner in rental accommodation. Andrew organised a builder to give advice regarding the installation of a ramp, has made application for a personal alarm, the local GP visits fortnightly. His predominant difficulty is his mobility. He prefers at this stage to struggle on with a wheeled walker rather than considering a scooter or power wheelchair.	Home visits by MND RA for case management • **Case management** 2 hrs pw **($98.88pw)** package and also at **CHCB (free)** • **Personal Support** 16 hrs ($568.80)pw • **Nursing assessment** – RDNS • **Nursing support** – 4 hrs pw **Allied Health x 2 hrs pw ($137.28)** **ACAS** • Counsellor • Volunteer support • Massage • Night respite **Advanced care planning - Palliative care** **Equipment** • Commode • Ramp • Personal alarm. • Roho cushion • Air pressure mattress	• **Individual Support Package (ISP)** - variable package can provide: • Case management • Allied health • Personal support • RDNS – nursing • Equipment • Respite **ACAS –** if supported by DHS	• **EACH** package = **$470pw (max. client contribution $58pw)** **ACAS** **Case management** – included in some packages and others not available – this is variable across regions. **Nursing** – full cost recovery if client has EACH package **HACC** – (often) full cost recovery or not available if EACH package **Equipment** – No **Respite –** NO except in nursing home	• No access to equipment • Nursing care costs at full cost recovery $70 per ½ hr) • Personal Support – Gap 1-6 hours pw and above limits of EACH package may need to be paid at full cost (if available) • **Allied Health** through EACH agency costs take from overall capacity of package often charge full cost recovery & lessens $s available for hours of personal support **Andrew requires per week:** Case Mgt 2 hrs 98.88 Personal support 568.80 Nursing 560.00 Allied Health 137.28 **Total Support $1,266.08 pw** **Plus Equipment $29,090.00**

	• Hoist • Hospital bed • Electric riser chair • Manual wheelchair • Lambswool • Roller chair • Communication device/laser pointer • Turning disc for car **Modification for bathroom/shower**			**GAP with EACH package = $796.08pw ($41,396.16pa) or 21.34 hrs personal support plus cost of equipment:** **Total Annual Gap** **Care - $41,396** **Equip - $29,090** (includes annual weekly support plus one-off cost of equipment) **N.B.** This does not cover any additional nursing, allied health or equipment new, replacement or repairs as condition deteriorates.

Case Study 2: Mr. X. Lives at home with his elderly wife who has significant health issues. No longer has use of lower limbs, upper limbs, has trunk weakness, respiratory weakness, a catheter and some throat weakness. Late diagnosis of MND and could not walk when MND Vic first became involved so had been high care for at	Home visits by MND RA • **Complex Case Management** 2hrs pw x **$49.44 ph = $98.88pw)** • **Personal Support 13- 15 hours @ $37.30ph = $559.50** • **Nursing (RDNS) assessment $1.5hrs x $70 (30 minutes) = $210 one-off** • **Nursing care** – Pressure sore - checks and catheter bag changes x **6hrs pw** ($70	**Individual Support Package (ISP)**- variable package can provide: • Case Management • Allied Health • HACC-funded services and costing for personal support • Nursing (RDNS) twice per week • Equipment • **In-home Respite care** • **Respite** under various programs – National & other Carer Respite Programs • **Bathroom modification**	• **EACH** package = **$470pw (max. client contribution $58pw)** **ACAS** **Case management** – included in some packages and others not available – this is variable across regions. **Nursing** – full cost recovery if client has EACH package **HACC** – (often) full cost recovery or not available if EACH package	**Once EACH allocated:** • **RDNS** charge full fee for nursing **($70per ½ hr**) • **HACC/LGA disability service** – full fee service (rarely available on top of EACH package and access variable in regions) • **ISP/NDIS** – not available but can be requested with support from Aged Care/DHS

least 6 months prior.	per 30 minutes x 12 = **$840pw)** • **Allied Health x 2 sessions pw @ $68.64per hr = $137.28pw** **In home Respite care –** approx. 12 hours per month **= $447.60per mth** **Equipment** • Manual wheelchair (std) • Electric lift recliner chair • Electric bed • Hoist • Commode chair **Bathroom modification**		**Equipment** – No **Respite –** NO except in nursing home	• **Allied Health - EACH/EACHD -** if contract full cost recovery is charged diminishes $s available for personal support, nursing, etc. • **Equipment** **Mr. X requires per week:** Personal support 559.50 Nursing care 840.00 Allied health 137.28 In home Respite 111.90 Total Support $1,648.68 pw **Plus Equipment 10,550.00** **GAP with EACH package = $1,178.68pw or 31.6 hrs personal support & equipment:** **Annual Gap Care - $61,291 Equip - $10,550** (includes annual weekly support plus one-off cost of equipment) **N.B.** This does not cover any additional nursing, allied health or equipment new, replacement or repairs as condition deteriorates.##

Case Study 3: Mrs JB diagnosed with MND in February 2011. Lives with her husband who is her primary carer. **JB main symptoms** – no speech, no mobility, no upper limb movement, no swallow and has PEG. Completely dependent on others for daily needs. Requires hoist transfer. Progression was rapid. Client's needs were unable to be met by her husband and current level of care in the home and there was no further extension of the level of care she was receiving available. Client was placed in a Nursing Home in February 2012. Client took MND roho mattress with her to the facility. Client uses a Princess chair in the facility and does not experience the same level of comfort that was provided by the electric lift recliner she was using at home through MND.	Home visits by MND RA • **Complex case management** 2hrs pw = **(98.88pw)** • **Personal support** (34 hrs pw) = **(**$1,268.20pw) • **In home respite** (8 hrs pw **=** $298.40pw) **Equipment** • Electric wheelchair (tilt) • Communication aid - laser • Hoist/hoist transfer • Recliner/lifter chair • Roho mattress **Bathroom modification**	**Individual Support Package (ISP)**- variable package can provide: • **Complex case management** – Linkages • **Personal Support** - HACC services and costing • **Equipment** • **Bathroom modification**	• **EACH** package = **$470pw (max. client contribution $58pw)** **ACAS** **Case management** – included in some packages and others not available – this is variable across regions. **Nursing** – full cost recovery if client has EACH package **HACC** – (often) full cost recovery or not available if EACH package **Equipment** – No **Respite –** NO except in nursing home **In nursing home:** **Personal support** **Nursing**	**Mrs. JB requires per week:** Personal support 1,268.20 & Inhome respite 298.40 Total Support 1,566.60 Plus Equipment 25,550.00 Total Required: $**27,116.60** **GAP with EACH package =** **$857.90pw or 23hrs personal support** **Total Gap** **Care - $44, 610** **Equip - $25,550** (includes annual weekly support plus one-off cost of equipment) **N.B.** This does not cover any additional nursing, allied health or equipment new, replacement or repairs as condition deteriorates.## *Quantum of personal support required not able to be provided out of EACH package necessitating transfer to nursing home.*

Placement was not planned but decided upon as a reaction to the care situation not being sustainable in the home and it was to avoid complete breakdown of the care situation.				**In nursing home:** • Allied health – limited access w/o paying for private providers • **Equipment** e.g. electric wheelchair, not available

N.B. ASSUMPTIONS:

1. All clients, regardless of age, are able to receive Palliative care and associated services so long as they are registered as eligible for palliative care.

2. In all examples of the GAP it has been assumed that the cost of personal support is at the approx. rate of Disability Services Unit Prices – if out of hours support is required this can be at substantially higher amounts.

3. In all examples of the GAP is has been assumed that the cost of case management is either provided outside of the EACH package. IF this is not the case then the GAP is actually larger and thus the amount of support hours/$s available for personal support/allied health, etc. is significantly less than illustrated.

4. In examples where nursing care is not currently required, it can be assumed that it will be required at a cost of $70per ½ for district nursing.

5. EACH packages assess for CURRENT AND NOT FUTURE needs as the condition deteriorates. In the case of MND, this can occur quickly and require re-assessment and thus delays in accessing packages.

6. Access to EACH/D packages can have a waiting period of 1-2 YEARS.

7. ##This does not cover any additional nursing, allied health or equipment new, replacement or repairs as condition deteriorates.

8. Bathroom modification costs are not included – not provided >65.

9. GAP is calculated on total weekly requirement - EACH package max. of $470pw x 52 weeks p.a. plus cost of equipment

APPENDIX 3

What is different about MND?

The proposed National Disability Insurance Scheme (NDIS) is welcomed by a vast majority of the Australian community. However, some people with rapidly progressive neurological diseases such as motor neurone disease (MND), and the organisations that support them, are concerned that not all people diagnosed with MND will be eligible for support under an NDIS. There are features of MND which distinguish it from other diseases which help explain these concerns.

MND is the name given to a group of 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. 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. Care provision for people with MND crosses traditional funding silos including: health, disability, equipment, respite, chronic disease, and aged and palliative care. It also involves a combination of state and federal funding. This system is currently a major barrier to equitable access to quality needs-based care for people living with MND and their families.

The average age of onset for MND is 60 years and average life expectancy is only two to three years. The age range of onset is 18 to 90 years. Of the estimated 1500 people living with MND in Australia today approximately 600 (40%) were diagnosed with MND when aged over 64.

Under the current draft eligibility statement people diagnosed with MND, assuming Australian citizenship or residency, would be eligible to receive support funded under an NDIS. Excluded would be those aged 65 or over at diagnosis which means that 60% of people with MND would eligible for the scheme and 40% would not.

We acknowledge that a significant number of people diagnosed with MND when aged over 64 will be able to access services to meet their needs through the aged care system. It is imperative, however, that their needs are assessed in the same way as those aged 64 or under and that services are available to meet their assessed needs no matter which system funds them.

The needs assessment process will be inextricably linked to eligibility it is therefore important that the eligibility statement encompasses diseases that progress rapidly so that a person with an urgent need for support will be able to access that support. An assessment process must be developed that takes into account the need for early intervention for progressive neurological conditions with access to increasing and changing support from a range of service providers as the disease progresses.

Disease specific information and education for assessors will be imperative to ensure that they understand the disease and its impact on the individual and their family. The development of an inter/multidisciplinary care plan will help to reduce duplication and enable services not funded through the NDIS to be involved as and when required to meet identified need.