MND

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The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

RE: Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement

The Motor Neurone Disease Association of Victoria wishes to make the attached submission to the Senate Committee's Inquiry into the CSTDA.

If you require any further information, or wish to pursue further discussions, please contact me on 03 9830 2122 or 1800 80 6632.

Yours faithfully

Rodney Harris

Rodney Harris
Chief Executive Officer

SUBMISSION TO THE

SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

BY THE

MOTOR NEURONE DISEASE
ASSOCIATION OF VICTORIA

ON BEHALF OF

PEOPLE LIVING WITH
MOTOR NEURONE DISEASE IN VICTORIA

Introduction

MND affects people across a range of ages. This results in people requiring a broad range of support services usually delivered by a number of different organisations. Organisations providing support include those funded through Disability Services (State Government, primarily, via the CSTDA) and Aged Care (Commonwealth, State and local government). Department of Veterans Affairs also provides support for ex-service personnel eligible for DVA assistance.

The needs created by MND require the same response, through information, counselling, aids and equipment provision or other community based services, no matter what the age of the person.

The introduction of the CSDA, and the subsequent CSTDA, has introduced a demarcation between services funded and given oversight by State and Commonwealth Government. This separation, between employment services and accommodation/support, has enabled both State and Commonwealth funded agencies to focus on effective service delivery. However, the division of responsibility between governments has extended to not just between employment and accommodation/support but also to age.

The Commonwealth's responsibility for Aged Care results in people who acquire a disability over the age of 65 not being able to access the same level of support as people who acquire a disability under the age of 65.

People with MND access aged care services via the same access pathways as all people over the age of 65 – assessment via the Aged Care Assessment Service (however named), and referral to appropriate aged care services – they just don't get to access the same level of support that people under the age of 65 can access to remain in the accommodation of their choice.

At the same time as there is on going demarcation, unmet need is continuing to rise, and their appears to be an inability to measure, assess and address unmet needs created by disability in the community.

People with MND access residential aged care services because their care needs exceed the ability of their carers and/or other funded services to meet in their existing accommodation. Some people who do not have family carers have no option other than to seek supported accommodation.

Background to MND and the MND Association of Victoria

In summary:

- ❑ MND is a progressive degenerative neurological disease that causes rapidly increasing levels of disability, and death
- ❑ Average life expectancy in Victoria from diagnosis is about 27 months
- ❑ Average age of onset is 59 years, however, the age range of onset is 40 to 70 years

- ❑ The rapid progression of MND creates high levels of disability and consequent needs for support — feeding, communication, movement, transferring, toileting, day activities etc. MND has a comprehensive impact on all aspects of living
- ❑ While people of working age can remain at work after diagnosis, this is usually for a very short time, often only weeks or a few months
- ❑ The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to those who are involved in providing the highly variable and complex care
- ❑ Over 90% of people with the disease are supported by a spouse or carer in the home (Sach, 1995)
- ❑ Carer stress is a significant cause of hospitalisation, facility-based care/respite and movement to residential aged care facilities
- ❑ People living with MND are not traditional service users, and have rarely had involvement with the disability or community services sector
- ❑ Research by Sach (1995, 1997) indicates that people living with MND **will not access services** unless they have confidence in the provider's knowledge of MND and its impact.

Service Needs

Service needs arising from MND include:

- counselling and support at and following diagnosis
- accurate information
- respite for carers and ongoing support in day activities for client
- accommodation services when people cannot remain at home
- support from volunteers when appropriate
- equipment and activities to maintain independence, including communication
- a focus for supported access to services
- flexible services that respond to changing and increasing disability levels
- coordinated support from a team of professionals
- early intervention which often reduces overall service needs
- urgent response to needs - waiting lists are not appropriate

In addressing service needs, people with MND need recognition that while they have a progressive disability, they have no cognitive deficit, and are aware of themselves and their surroundings at all times. They need to be engaged in service processes.

Association Services

The Association delivers four main services, supported by administration and fundraising.

The services are:

- Equipment Loan
- Case planning, needs assessment and referral (delivered by Regional Advisors)
- Volunteers

- Information

The Association has registered and is supporting 98% of the projected cases of Motor Neurone Disease in Victoria. This market penetration has given the Association a clear understanding of the impact of services and service availability on people diagnosed with MND and their families. It has also made us aware of the gaps in service availability and levels.

The Motor Neurone Disease Association of Victoria was established in 1981 and is a community-based organisation run by an elected State Council.

Membership of the Association is currently over 900, comprising patients, carers, former carers and interested people. The Association, as at 30 June 2006, was supporting 238 people with the diagnosis of MND. They receive a variety of services provided by the Association, including case planning, assessment and referral by Regional Advisors, information, aids and equipment, and volunteers. In 2005/2006 378 people diagnosed with MND received support from the Association. The Association also supported their families, friends and work colleagues.

The Association moves in and out of the lives of people with MND as their needs demand. Given the relatively short life expectancy of people diagnosed with MND (27 months from time of diagnosis), the monitoring and reassessment of needs is an essential element in ensuring that they are able to appropriately access quality services when they need them. Our aim is to assist people to live as well as possible while living with MND. Transition management and facilitation is an effective mechanism to achieve this.

This transition process, or the role of being an interface between people with the disease and the service sector, is fundamental to effective service delivery for people with progressive degenerative diseases, and particularly MND.

Case Studies

CASE STUDY 1
Joe W is aged 68 and has motor neurone disease. He has a carer who is fit and well, but needs assistance to support him safely at home. Joe lives in the home he has lived in for the past 28 years, where he and his wife raised their children.

Joe is unable to get out of bed and use the bathroom for toileting and showering without assistance. His carer needs assistance to manage this, but once he is showered and dressed she can manage him in his electric tilt in space wheelchair. His carer then needs assistance to undress him and transfer him to bed. He has appropriate aids and equipment – a hoist, electric wheelchair, toilet and shower commode etc, which could be used by his carer. The aids were provided by the MND Association’s equipment library, following assessment by an Occupational Therapist. Some support has been provided through “Linkages”, but only 6 hours per week. However, his carer is now at risk of injury and needs additional assistance.

His support levels have been further compromised by occupational health requirements that insist on two person transfers using hoists. This has cut his effective hours of support from 6 to 4.

Assessment by the MND Association's Regional Advisor indicates that Joe and his carer need 30 hours of support per week. This level of support is available from the "Home First" packages provided by the Victorian Department of Human Services, but Joe is not eligible because he is over the age of 65. "Home First" can provide up to 34 hours of support per week.

The alternative for Joe is assessment and admission to a residential aged care facility, where services will be delivered based on his age, and not his disability. He will not be able to access the specialist disability aids and equipment to address his rapidly changing and unique needs as the Association's Equipment Library is linked to the Victorian Aids and Equipment Program and is not available to people receiving aged care services funded by the Commonwealth. He will move away from his life long partner and carer, and away from his community where he has a well-established social support network.

CASE STUDY 2

Simon W is aged 47, is married and lives with his partner and two children. His partner works part time. He has motor neurone disease. He receives 34 hours of support per week from the Victorian Government's "Home First" program. This provides assistance for him to get up and showered in the morning, dressed and able to participate in breakfast with his partner and children.

His partner wishes to continue working as she will need ongoing employment after his death, and is fearful that she will not be able to re-enter the workforce if she leaves to provide full time care to Simon. They also need the money, as Simon has not been able to access his superannuation as yet.

Once in his electric wheelchair, he is able to get out and about, and is a regular user of the local library and other community facilities.

He is maintaining his engagement with his local community, and participates in his children's schooling.

He and his family have accessed respite weekends away funded through the Commonwealth's Carers Program, and these breaks have assisted his partner to remain healthy and at work.

All his disability equipment, including electric bed and hoist, pressure care mattress, electric wheelchair, commode and shower chair, have been provided through the MND Association's Equipment Library.

Summary of Case Studies

Same disease, similar needs and different ages of onset result in different levels of support to address the same unmet needs.

CSTDA – Key Issues

In relation to the CSTDA, we would like to highlight the following issues:

Respond to unmet needs – services funded via the CSTDA should be delivered to address unmet needs of people living with a disability. There must be a clear distinction between the "need for support" created by disability and the "unmet needs" that exist and should be addressed through service delivery and funding.

Eligibility based on unmet need – eligibility for people living with disabilities to access services funded by the CSTDA should be based on "unmet needs", not on their age.

COAG has agreed that aged care residential services are not an appropriate place for people living with disabilities to live, and have made a funding commitment to better address the accommodation needs of younger people who are living in aged care residential facilities, and to look at systemic issues that can keep people with disabilities out of residential aged care.

The CSTDA needs to ensure that a person over the age of 65 who acquires a disability is able to access the same services, service standards and service levels as a person aged under 65 who acquires a disability.

Funding must be increased to meet the known unmet need – there is insufficient funding in both State and Commonwealth contributions to address the existing known unmet need. For example, there are significant waiting lists for access to disability aids and equipment, insufficient funding for services to provide adequate hours of personal care to support a person living with a disability, and inadequate numbers of hours of support to enable a person with a disability to remain in the accommodation of their choice.

There must be systemic recognition and measurement of unmet need – the CSTDA negotiations must incorporate a plan to measure or assess unmet need and a commitment of all governments to move towards funding CSTDA activities so that no person with a disability has to live with a high level of unmet needs in our community.

Currently, significant numbers of people with disabilities whose unmet needs should be addressed by CSTDA funds do not apply or register for support and services because they know that it is unlikely that they will ever get into a priority position on the waiting list. Similarly, health and social care professionals are reluctant to add people to the waiting list due to the heightened expectations created that are mostly unmet.

In Victoria, the extensive and comprehensive application forms act as a disincentive to health care professionals to make referrals for services. Significant time can be spent completing a multi-page application form, and then providing regular updates of the application as the disability changes or circumstances alter, while the health professional is aware that it is highly unlikely that the person will ever receive a service.

Recognition of the needs of people who acquire a disability later in life – the CSTDA must recognise that disability is acquired throughout life, and that it is the unmet needs created by disability, no matter what age the disability is acquired, that need to be addressed. CSTDA should encompass a commitment and appropriate funding to ensure that people who acquire a disability over the age of 65 can access the same levels and quality of services as those who acquire a disability under 65 years of age.

Disability Aids and Equipment – the CSTDA must require that disability aids and equipment be provided to people living with the impact of disability wherever they choose to live. Aids and equipment should be provided on the basis of addressing disability, and to facilitate safety, mobility, and community participation. Aids and equipment supply should not be affected by the age of the recipient or their place of residence.

Adequacy of Support – some younger people with MND need the level of care and support that can currently only be provided in a residential care facility. However, this support is only made available in a dementia or aged care framework which does not recognise the needs of a younger person with a disability.

Within the residential care and aged care residential models, inadequate funding is available to provide anything more than basic care. This does not address the aspirations of younger people with MND. They want to be able to maintain and develop community interests and activity, participate in community and social activities, and receive support that respects them as a person with high physical needs. This support does not take account of their existing family and social relationships, nor address their disability. They do not have dementia, and are fully aware of their surroundings. They need to be active players in their care.

Support at this level must be provided in a setting that does not focus on age, but on the unmet needs of the individual. It must recognise and respect their disability, and deliver services that allow them to optimise their quality of life and fulfil their ambitions.

We recognise the important steps that the COAG decision on younger people in nursing homes has taken in this regard, however, there must be an additional emphasis on funding to keep people out of residential facilities where their needs are better met in the accommodation of their choice.

Need for disability focussed support – people with MND need a service that focuses on their disability, and is not based on age. Services must understand the disability and provide support and services that address disability and complement ability.

Funding must be available that allows disability focussed care and support in an environment of the person's choosing and which supports their needs, desires and aspirations. The service should address disability issues, and create an environment which supports and enhances quality of life, creates opportunities for action and interaction, and which promotes interaction with the community.

Home based care must be adequately supported by trained and well remunerated staff – CSTDA negotiations must include commitment to ensure that there are a sufficient number of appropriately trained and skilled staff available to provide high quality home based personal care services.

Currently, a shortage of staff exists which results in paid carers not being available to fill rosters. Staff not turning up to work further complicates this.

People living with disability and particularly those living alone, are dependant on their carers for most aspects of daily living. They need reliable and knowledgeable staff. CSTDA discussions need to encompass workforce issues as a whole, and salary and training in particular, to ensure that quality staff delivers this vital service, and that people living with disabilities are not at risk or abandoned.

Conclusion

Services for people with disabilities must be provided based on needs, and not on the basis of age. Services must be available for people to address their unmet needs.

It is clear that people who acquire disabilities when they are over the age of 65 need services that are currently provided through disability services but only for people under the age of 65. This barrier or division of responsibility, currently in place between Commonwealth and State funded services, must be removed.

Where services are provided, they must be holistic and effectively address the unmet needs created by disability. Support must reflect the disability and the needs it creates. We must move away from only supporting a generic service model, and move to a model of service which has some basic components which most people require and other components that only some people require.

People with MND have a short life expectancy, and deserve the opportunity to access the broad range of services that the community has available. Those services need to address the needs created by MND, maintain quality of life, and support intellectual and social stimulation and community participation.

Motor Neurone Disease
Association of Victoria
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