The Multiple Sclerosis Society of South Australia & Northern Territory Incorporated

Submission to the Productivity Commission on its draft Report into Disability Care and Support – February 2011

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The following submission on some aspects of the draft report of the Commission is from the Multiple Sclerosis Society of SA and NT Inc. (Society). The Society is a member and shareholder of the federal national body, Multiple Sclerosis Australia (MSA), which is a member of the Neurological Alliance of Australia (NAA). Both of these organisations have made or will make submissions to the Commission about the draft report and the topic generally, however there are a number of key points that our organisation would like to raise as it impacts directly on the clients that we serve.

The Society strongly supports the recommendation for increased funding in the disability sector. The Society welcomes the Productivity Commission's draft report and is supportive of the directions it proposes. As identified by the commission, the current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty that they will be able to access appropriate services that ensure that they can remain active and contribute to the wider community.

In addition to considerations of social justice and equity, increased funding for people with Neurological diseases like MS and other neurological conditions with which the Society also deals with is likely to produce a considerable economic benefit to the nation, from increased productivity of a section of the community whose talents, experiences and training acquired before they contracted the disabling condition are not presently being efficiently utilised. Further, there is an even more critical need to boost funding for people with disability in South Australia, which has for decades been, by some margin, the least generous funder per head of the disabled community among the Australian States.

What is Multiple Sclerosis and how does it impact on the lives of people with the condition

Multiple sclerosis (MS) is a progressive, chronic disease of the central nervous system (brain and spinal cord). It is the most frequent neurological disease in young and middle-aged adults in developed countries and has a lifelong impact. Because MS involves multiple areas of the central nervous system, it is characterised by a variable and complex range of symptoms, including visual disturbance, fatigue, pain, reduced mobility and coordination, cognitive impairment, and mood changes. Average age at onset is between 20 and 40, and 75% of people with MS are women. Thus, MS tends to strike people in their most productive years. It affects ability to fulfil expected life roles at a stage when careers, relationships, and adult life in the community are consolidating, with resulting impact on work, family, and social life.

The typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation.

There are significant personal and family costs associated with having MS that could be included in the benefits schedule of a no fault scheme. People living with MS face lower than average incomes combined with significant disease costs. In addition to the range of clinical and social impacts of the disease, financial insecurity is a major issue that can limit life options.

CHAPTER 3 WHO IS THE NDIS FOR?

Recommendation 3.2

Although MS is a long term chronic condition, there is demonstrated benefit of early intervention to reduce the progress of the disease, limit the disease burden and manage risks over the life course.

Early intervention needs to be comprehensive and inclusive of individuals and families. The early management of MS is dynamic, as people need to integrate their disease into their work, study or family life, and service responses need to be respectful of choices that people need to make. Information provision and counselling are critical first responses. Disclosure of disease status is a vexed issue for people with MS, and the input into decisions about disclosure to employers, friends and family needs to be supported. A range of services can still be provided to people (such as medical, pharmaceutical, allied health and employment supports) without full community disclosure and under a no-fault scheme, eligibility would be on proof of diagnosis only, and would not require full disclosure.

A range of services are needed at the point of diagnosis and are often provided through MS clinics in public hospitals and through MS Societies. A number of interventions are indicated to occur early in the disease process, however due to professional practice, service program limitations or naivety about the disease these do not occur. They include early referral for employment support and early access to MS immunotherapy treatments.

We thank the commission for their recognition of Multiple Sclerosis under the category of the early intervention group, however issues re the early diagnosis and understanding of the condition can be a barrier to the early intervention strategies. Education and information provision to assessors, disability support organisations and to clients are essential to the success of the program.

Recommendation 3.4

Collaboration between disability, mental health services and the health sector will be paramount to the success of the program and to close the current gaps which allow individuals to fall through the cracks. In particular for people with MS all three areas of service provision can come into play in order to achieve sustainable outcomes for clients.

Recommendation 3.5

Experience has shown that the aged care sector is unable to sufficiently meet the specialised and often high needs of care for those people who have a lifelong disability and cross the age of 65. Although many people also experience disability in their old age, this disability is often associated with the ageing process.

The Society believes that the choice of funding either through the NDIS or transfer to the aged sector is an admirable one but problematic from an operational perspective and could potentially allow for a reduction in the quality of care for complex support needs or transfer the burden of further aged related disability to the NDIS system.

A significant review of a person’s support needs should be undertaken with these views in mind.

CHAPTER 4 WHAT INDIVIDUALISED SUPPORT WILL THE NDIS FUND?

Recommendation 4.3

A modest upfront contribution will be difficult to introduce if the scheme is not means tested as not everyone will have capacity to pay.

Recommendation 4.4

Evidence is not always available for all therapies and different professional groups view various therapies in differing ways depending on the research, or lack of research conducted

The Society recommends an approach that only excludes therapies known to cause harm and those that make extraordinary claims for cure and prevention be excluded, where possible.

CHAPTER 5 ASSESSING CARE AND SUPPORT NEEDS

Recommendation 5.1

The Society currently operates both a Disability Employment Services tender and a Job Capacity Assessment tender for the Department of Employment, Education and Workplace Relations. From the experience we have developed through this process a number of key points are raised:

- The qualifications of the assessors is not the only important factor;
- The assessors ability to understand all disability types and the varying conditions that apply to each makes it an extremely challenging process;
- If the provision of the assessment process shifts to a tender environment, which allows for “for profit” assessors taking part, a definite drop in the above factors results, which potentially puts clients at risk of miss-assessment and therefore the wrong services being available;
- The process needs to be transparent and timely to ensure that the client understands the process and to ensure that it is not a drawn out experience due to bureaucracy and red tape;
- The client needs to be part of the process and not just be assessed;
- Reducing the number of assessment tools used across the sector, if possible, would provide for a more streamlined assessment process and a more concise range of services. However, taking into account the differences between each disability type, and the inclusion of mental health as well as other health factors that are common to a number of clients, will make the tool difficult to develop without the support of existing disability service providers as they hold the expertise to develop these tools.

CHAPTER 6 WHO HAS THE DECISION MAKING POWER?

The Society fully supports the need for choice highlighted in the draft report and this would provide for a more customer service orientated delivery of services from the vast array of services on offer. This would also ensure that consumer choice drives the sector size and growth, which is in direct contrast to the current disability environment which has high levels of duplication.

To ensure that this works effectively, the consumer of services needs to be aware of the level, type and quality of services on offer, and therefore a centralised reporting system to maintain and be in “real time” to ensure the consumer has adequate choice is required.

The Society supports self directed funding as long as the client, their family etc understands the responsibilities that this entails. Particularly is this the case in relation to recruiting and employing their own support workers as this opens up clients to the current responsibilities for administering occupational health, safety and welfare laws and applying the conditions of employment under the Commonwealth Fair Work Act 2009. These obligations are onerous for most companies and would be extremely onerous for clients managing employees who do not have access to legal advice re these issues.

CHAPTER 7 – GOVERNANCE OF THE NDIS

Although increased funding and a single decision-making body/agency seem desirable in isolation, there is no point in bringing in these reforms if the execution and administration of the structure is not well conceived, efficient and empathetic to those whom they are serving.

The governance and design of the key administrative arms of the NDIS are therefore critical.

Further, the transition aspects of the reform, and the manner in which it is initially publicised and implemented, are similarly vital. The Society sees a strong need for the NDIS to involve closely in all this organisations like the Society, who are close to their members and have through expertise and service built up a relationship of trust and confidence with their members. Consideration could be given to small amounts of one-off funding to organisations like the Society to assist in the explanation to and take up of the scheme by its members.

Although the Society supports in principle the concept of one central agency controlling the disability scheme and the assessment of disability, the Society is also concerned, based on past experience, that:

- staff of the Agency need to be well trained and empathetic to the needs of people with disability;
- the most prominent part of the objectives of the Agency and its staff should be the service of people with a disability, rather than administration for its own sake – of course the objectives must include the sustainability of the scheme, and of course this is a proper priority for senior management and the Board, but it ought not to be allowed to dominate the way in which services are actually provided day-to-day.

To that end, the Society submits that the peak NDIS Board should:

- be required to have some representation from geographical areas who are often not adequately represented in central bodies of this nature, e.g. WA/SA, or the States less fortunately endowed with mineral resources, like SA and Tasmania. Particularly in the transition phase and the first few years of the scheme, there will be important local issues to deal with or to take account of. Certainly, the Board should not be dominated by people with Sydney/Melbourne/Canberra backgrounds;

- be required to include a significant number of people with a disability or people with a direct experience of living with people with a disability. However skilled and competent the other board directors will be in overseeing and directing a business like that of NDIS, it is healthy and necessary for them to be reminded of the reason for the existence of NDIS. It is of course accepted that the people with a disability on the NDIS Board should be able to contribute in their own right apart from their experience of disability.

The proceedings of the Board should be widely publicised and accessible. There is no reason why board papers and board agendas and board minutes, or at least most of them, should not be available to the wider disability community. There is no reason why key arrangements of the NDIS, including the contract with the CEO and his/her KPIs, should not also be available. The Board should be required to make to the wider disability community as well as to its Minister/s notification of matters which would be required to be disclosed under a continuous disclosure obligation by a listed Australian company.

Consideration should be given to making the Board and the scheme accountable, not only to the Treasurer (who is recognised to have an important role because of the financial impact of the scheme) but also to another minister like the minister representing the disabled. The board should be required to report both annually and each six months, and those reports should be made public as soon as they are completed.

In relation to complaints about the service of NDIA, and complaints about assessment, the Society strongly supports the need for a robust and independent review/appeal system, with a truly independent statutory officer to oversee the system, and makes the following related comments:

- the independent statutory officer must be appointed by a panel which includes consumer representation;
- there should be consumer input into the internal review mechanism where there are complaints against assessments;
- although an additional expense, a merits review to the Administrative Appeals Tribunal (in addition to judicial reviews), at least for the first few years of the scheme, would be advantageous in building up a useful body of nationally available jurisprudence in relation to assessment;
- reviews and appeals would be more efficiently despatched if a modest allowance could be made to consumer organisations like the Society to assist in preparation of reviews and appeals.

CHAPTER 13 – WORKFORCE ISSUES

The Society would recommend the following points in relation to Workforce issues:

- that a minimum qualification for disability support workers is essential to ensure quality services;
- that part of the training subsidies be put towards Occupational Health and safety requirements for both the support worker and the client as the risks are generally part of providing services to people with a disability;
- that a low level of literacy can also be a major barrier to work;
- that it is essential for all disability support workers to undertake a satisfactory police clearance to ensure the safety and quality of services provided as everyone can potentially be at risk from someone entering a home and having access to personal details etc.

The above suggestions of the Society are made for the purpose of ensuring the successful introduction and subsequent administration of NDIS. For the NDIS to be successful, it must be embraced sensibly and reasonably, and with realistic expectations by the disabled community and organisations like the Society which represent them. It is submitted that the above measures will promote that acceptance.

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