



MS Australia

**Submission to the Senate Employment Education
and Workplace Relations Committee Inquiry**

**The administration and purchasing of Disability
Employment Services in Australia**

4 October 2011

1. Introduction and background

As the peak organisation for MS organisations in Australia and for people living with Multiple Sclerosis, MS Australia is pleased to provide this submission to this inquiry. Our response is informed through the experience of people with MS in Australia as well as the working knowledge of the labour market programs area from the two MS Societies currently operating with Disability Employment Services (DES) contracts.

These are Multiple Solutions in South Australia operated by the MS Society of South Australia and the Northern Territory, who currently operate as a provider of generalist disability employment services but have a history as a specialist provider - and MS Australia Victoria, which currently is the only specialist neurological service in the DES sector providing tailored services to people with MS seeking to seek or retain employment.

Employment participation and financial security are major concerns for people living with MS. Employment makes a positive contribution to many aspects of wellbeing, and unemployment comes at great cost to the individual, their family, MS is the most frequent neurological disease in young and middle-aged adults in developed countries.

Timely access to capable and effective employment support is recognised as an important component of managing MS over the life course, and MS Australia supports structural measures to improve the employment support system in Australia to enable more people with MS to maintain their careers. MSA supports the proposed tendering arrangements for DES.

2. Multiple Sclerosis

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 impact¹.

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.²

The average age at onset is between 20 and 40, and 75% of people with MS are women. MS tends to strike people in their most productive years, and affects people's 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.³.

¹ Johnson, K.L., Yorkston, K. M., Klasner, E. R., Kuehn, C. M., Johnson, E., & Amtmann, D. (2004). The cost and benefits of employment: A qualitative study of experiences of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 85, 201-209.

² Polman, C. H., Thompson, A. J., Murray, T. J., & McDonald, W. I. (2001). *Multiple Sclerosis: The Guide to Treatment and Management* (5th ed.). New York: Demos

³ Metz, L. (2003) The psychosocial consequences of multiple sclerosis. In W. I. McDonald & J. H. Nosworthy (Eds.), *Multiple Sclerosis 2* (pp. 329-339). Philadelphia, PA: Butterworth-Heinemann

3. Employment and MS

Access Economics in their cost of MS study in 2005 found that 87% of people with MS were of working age. While most people with MS are employed when first diagnosed, 80% are not employed 10 years after diagnosis.⁴ North American data indicate that more than 90% of people with MS have a history of employment and 40% of those who are unemployed want to return to work. Thus, the high unemployment rate among people with MS appears to be occurring in a group of people who have a positive work history, a strong work ethic, and a desire to resume employment.⁵

Further, The Australian MS Longitudinal Study shows that there was a 5.9% increase in the number of people with MS not in the paid workforce (up to 64.2%) between 2003 and 2007.⁶ The AMSLS also reported that the main reasons for people with MS ceasing employment were related to disease symptoms (primarily fatigue), poor workplace adjustment and discrimination.⁷

As a consequence of poor labour market participation, many people with MS are in receipt of welfare benefits. Access Economics found that in 2005 84.1% of people with MS aged over 65 and over 50% of people with MS under the age of 65 were receiving Government income support. These compared with the general population where 16.6% of the general population under 64 and 70.6% of those aged 65 and over received some form of income support payment.⁸

Financial security and engagement in the workforce is a critical element of overall disease management. Generally in Australia people living with MS earn lower than average incomes but are faced 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.

Access Economics also found that the average annual disease costs to people with MS and their families in Australia is \$10,500 (\$3,893 out-of-pocket and \$6,593 for informal care). This is consistent with other cost data for chronic illness.⁹

While there is a significant loss of economic participation associated with MS, it is not an inevitable consequence of the disease.

Figure 1 below demonstrates that across all industry groups, employment participation falls following diagnosis.¹⁰ The nature of the disease makes it difficult to sustain employment in physically demanding jobs, but the high representation of professional and white collar occupations and the poor outcomes in those sectors is confounding given the potentially positive influence of active job retention support (including Job Services Australia services).

⁴ Access Economics, *Acting Positively: Strategic Implications of the economic cost of Multiple Sclerosis in Australia, Canberra 2005* p23

⁵ Roessler, R. T., Rumrill, P. D., & Fitzgerald, S. M. (2004). Factors affecting job satisfaction of employed adults with multiple sclerosis. *Journal of Rehabilitation, 70*, 42-50.

⁶ Simmons, RD, Tribe, KL, McDonald, EA: Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *Journal of Neurology*, in press 2010, p1

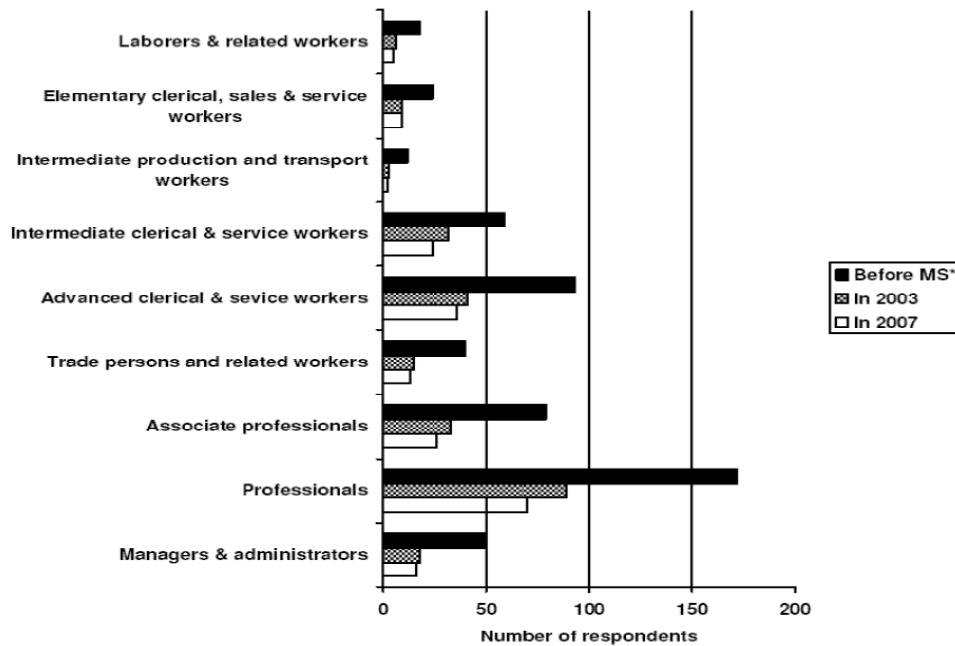
⁷ Ibid p.9

⁸ Access Economics 2005, p53

⁹ Ibid p44

¹⁰ Simmons et.al p8

Figure 1 Employment before and after MS:



MS Australia is aware that while positive job adjustment is certainly possible in these occupations, a lack of early and appropriate interventions and inflexible workplaces play a large part in premature loss of employment.

There is long-standing recognition that the chances of obtaining new employment after disability are far riskier than staying with an existing job. The literature strongly recommends a proactive approach to maintaining employment for people with chronic disease or acquired disability.¹¹ In this context, the current literature argues for aggressive, early accommodations to help preserve employment. The barriers confronting people with MS in employment arise from a complex set of interacting variables, including disease characteristics and environmental and social factors.

3.1 Providing an employment service to people with MS

Our experience is that job retention and job search services for people with MS need to be driven by highly specialised multidisciplinary teams of health professionals capable of simultaneously addressing both health and vocational issues. This is because the management of MS is complex, and interventions need to be clinically driven and informed by understandings about symptoms and treatments.

¹¹ See: Allaire, S. H., Niu, J., & LaValley, M. P. (2005). Employment and satisfaction outcomes from a job retention intervention delivered to persons with chronic diseases. *Rehabilitation Counseling Bulletin, 48*, 100-109; O'Connor, R. J., Cano, S. J., Ramio i Torrenta, L., Thompson, A. J., & Playford, E. D. (2005). Factors influencing work retention for people with multiple sclerosis: Cross-sectional studies using qualitative and quantitative methods. *Journal of Neurology*, DOI 10.1007/s00415-005-0765-4.

This approach necessitates that rehabilitation professionals constantly update their knowledge about MS, rehabilitation, and employment. Indeed, lack of health professional knowledge may contribute to excessive disability with respect to MS and employment.

This experience is supported by the literature that supports approaches to job retention that combine highly specialised clinical interventions focussing on individual symptom management, timely provision of workplace accommodations, and education of employers and the wider community.

Specialist providers with specific expertise in the conditions they are working with are well equipped to provide a broad spectrum of specialist, accessible, and timely interventions to assist in preserving employment for people with MS.

4. Taking a Broader View - Chronic Illness and Employment

MSA believes that the growing impact of chronic disease in Australia on employment participation is an issue that should be taken into account when looking at the make-up and capacity of DES sector going forward. Chronic disease in an ageing workforce is an emerging risk to productivity in the Australian economy and we believe the DES sector could be well placed to work with the labour market challenges this brings, but needs to be structurally better equipped.

While this is essentially a demand side scenario, the current tendering proposal provides an opportunity to update provider requirements and system processes to better enable the sector to meet the needs of workers with disabling chronic diseases. This will include cross sector collaboration and a more mature engagement with employers.

In its 2009 report into Chronic Disease and Participation in Work, the AIHW found that people with chronic disease are 60% more likely to not be in the labour force than people without chronic disease, and that the Australian economy loses over 500,000 full-time workers associated with the presence of chronic disease each year. Based on its data from 2004-05 the loss of half a million people represents nearly 10% of the full-time workforce.¹²

With the ageing of the workforce the issue of chronic disease becomes one that must be factored into labour market policy, and the tendering of disability employment services provides an opportunity for the Australian Government to seek new providers with greater expertise in this area to enter the market and target a group of workers/jobseekers (who have work experience and skills) that need support.

In recognition of the associated problems of chronic disease in an ageing workforce the Australian Government announced the Productive Ageing Package that created access to direct support for 2000 older workers with health issues or injury sequelae that compromised their ability to sustain employment.¹³

¹² Chronic Disease and Participation in Work, 2009, Australian Institute of Health and Welfare Canberra

¹³ See: http://www.deewr.gov.au/ministers/arbib/media/releases/pages/article_100201_124031.aspx

While this was a positive initiative, the DES sector should always have had the capacity and experience to routinely work with this group.

Although the current DES contract allows very broad eligibility for potential DES clients, the reality is that many workers in this group needing the suite of assistance that DES provides do not find their way to DES providers. The disability employment system has evolved from a traditional conception of disability that has meant that the sector's business models, networks and skills do not in many cases meet the needs of these people with a chronic disease, do not link with their organisations, or directly register them as clients.

The recently launched National Disability Strategy has included a more diverse and inclusive definition of disability that includes chronic disease, and this more expansive approach needs to characterise the next DES phase. The ability to test the capacity of providers within the NDS context is an essential step in bringing the NDS to life in the labour market sector and to enable the Australian Government to contract the most capable providers.

5. Brief responses to the terms of reference

a. the impact of tendering more than 80 per cent of the current DES on the clients with disability and employers they support under the current contracts;

We acknowledge that there is a diverse range of views within the sector on this issue across the disability sector. However it is a fact that disability employment services that provide long term support to individuals in the open labour market have not been subject to any competitive purchasing process. Case-based funding was introduced nearly 8 years ago, but only limited opportunities have existed for change in the industry make up through the uncapped program tender in 2006 and the Invitation to Tender (ITT) process. Disability employment has effectively been restricted to traditional providers since 2003.

Consequently it is difficult to predict what the impact of tendering may be as we cannot predict the makeup of the provider sector following a tender. We also have not seen the precise tender specifications that will dictate the operation of the sector. When previous competitive purchasing processes in Disability Management Service (DMS), Job Network (JN) and Job Services Australia (JSA) occurred, there were certainly some disruptions for individuals, but overall the systems transitioned relatively smoothly and individuals with disadvantages and disabilities continued to be assisted into and supported in employment.

If the transition arrangements are well-designed and implemented where the greatest emphasis is placed on continuity of service for individuals, any changeover can be accommodated. It will be important to DEEWR to work closely with the DES sector as well as other disability organisations to ensure that such a transition process is established.

b. the potential impact of losing experienced staff;

Under the proposal to tender DES it is probable that there will be a changeover of providers at some level. However if the size of the sector remains mostly the same, then experienced staff will always be required by new and old providers alike to deliver services.

Given that the sector currently has issues in this area the impact of tendering on the current workforce needs to be fully understood and incorporated into a detailed transition plan.

c. whether competitive tendering of more than 80 per cent of the market delivers the best value for money and is the most effective way in which to meet the stated objectives of:

(i) testing the market,

The tendering of DES services is a major decision by the Australian Government and the most should be made of the opportunity to best align the provider market and the contract requirements with social and economic policy imperatives. As well as testing current capacity to deliver to a wide target group, the tender process needs to be able to test for adaptability, innovation, creativity, and to meet the needs of current and future DES participants.

A key imperative in the lead up to the tender is to ensure that the tender specifications are designed in such a way as to not only include DEEWR's policy interests but also those of the National Disability Strategy, National Health Reform and the National Disability Agreement. There may be providers currently operating in the health or disability sector who could add significant value to the DES sector by bringing specific skill sets and linkages.

(ii) allowing new 'players' into the market and removing poor performers from the market

Any tender process should not just be a process for processes sake. The aim should be to have a system that best meet the needs of people with disabilities in respect to securing and maintaining sustainable employment in the labour market. It should also aim to deliver the key objective for the delivery of Disability Employment Services...which is to: *improve the nation's productive capacity by employment participation of people with disability, thereby fostering social inclusion.*

If new players are viewed able to best deliver services on a comprehensive set of evaluation criteria, they should be brought into the sector. In regard to using the tender process to remove poor performers from the market, it is important to be clear about. The contest for services needs to be open, fair and equitable to current and prospective providers.

MSA believes that setting the bar at tendering 80% is reasonable as it allows the market to be explored effectively, maintains a level of stability and allows for the potential expansion of current providers that are providing effective and innovative services.

Should the range and type of service requirements change markedly from the current contract where the top 20% have excelled, a process should be put in place to enable DEEWR to satisfy themselves that these high performing providers can continue to perform well in a different service environment with different constraints and opportunities.

At the very least this group of providers should be required to satisfy DEEWR that they can contribute positively to the achievement of the policy goals of the National Disability Strategy.

- d. whether the DES Performance Framework provides the best means of assessing a provider's ability to deliver services which meet the stated objectives of the Disability Services Act 1986 such as enabling services that are flexible and responsive to the needs and aspirations of people with disabilities, and encourage innovation in the provision of such services;*

In a general sense the DES Performance Framework that includes the Star Rating and standards monitoring provides a guide to assessing a provider's ability to meet the objectives of the Disability Services Act 1986, although it is not a comprehensive set of measures. It certainly measures compliance and performance but cannot be relied upon to encourage innovation.

Star Rating

The star rating system does provide a general guide in respect to a provider's relative success in employment placement of individuals, but do create anomalies for providers that work with particular who work predominantly with clients who have particular demographic profiles.

Job in Jeopardy (JIJ) –Our experience with people with MS accessing both generalist and specialist DES is that the vast majority directly register as a Job in Jeopardy clients.

The often intense work required to assess and address these employment risks is not measured in the Star Rating system during the initial 26 weeks of service delivery, unless or until the participant moves to ongoing support post 26 weeks. In many cases presenting issues can be resolved during this time (they may include advising on disclosure, assessing and advising on symptom management, prescribing equipment and modifications and negotiating with the employer) and if successful the client can maintain their employment. This means a substantial amount of work done by a provider does not contribute to their star rating.

MSA acknowledges the ongoing difficulty in incorporating JIJ into the current Star Rating system (due to the JIJ guidelines and the small number of JIJ participants seeking assistance from generalist providers). It is an extremely valuable service for people with MS, and is one that is critical in addressing chronic disease issues in the workplace.

It can be an effective defensive strategy for keeping people engaged in work and prematurely retiring on to the Disability Support Pension, so the star rating system needs to incorporate more sensitivity to the way these programs are viewed within the performance framework.

KPI Efficiency 1.1 - *Responsive Proportion of referred job seekers who commence in the program.* Specialist providers are unable to commence and provide service to any participant that does not meet its contractual definition. All inappropriate referrals need to be transferred to other providers this is a negative in respect to the star rating.

e. the congruency of three year contracting periods with long-term relationship based nature of Disability Employment Services – Employment Support Services program, and the impact of moving to five year contract periods as recommended in the 2009 Education, Employment and Workplace Relations References Committee report, DEEWR tender process to award employment services contract;

MSA supports a move to a longer contract period of 5 years. A longer contract period would allow for providers to invest in longer term strategies to deliver sustainable outcomes that are required. This would include strategic engagement with employers to better identify and respond to their needs, improving their linkages with other services and community networks and workforce management.

As the DES sector is predominantly made up of not for profit organisations, the work done by the Productivity Commission in their inquiry into the Contribution of the Not-for Profit Sector provides some relevant commentary. While much of their analysis relates to grant-making, there is much said about the need to improve the machinery of contracting between the Government and the sector. In particular we agree with one of their key points that:

*The efficiency and effectiveness of delivery of services by NFPs on behalf of governments is adversely affected by inadequate contracting processes...with inappropriately short-term contracts. Substantial reform of the ways in which governments' engage with and contract NFPs is urgently needed.*¹⁴

Being the first major national tendering exercise in disability services since the report was released in 2010; we would expect the terms of the proposed contract will reflect some of the better thinking in the report. Whether or not the private sector enter into the DES sector, the contracting process needs to be efficient.

f. the timing of the tender process given the role of DES providers in implementing the Government's changes to the disability support pension

Providers in the DES sector are contracted by DEEWR to deliver a range of prescribed services, and the changes to the DSP will form part of the framework within which providers operate.

¹⁴ Productivity Commission: The Contribution of the Not for Profit Sector, Jan 2010 p xxiv

It is a reality that Governments change settings in welfare policy and that labour market program providers adapt to these changes. It is up to government to ensure that the fee and accountability structures create the best environment to allow providers to effectively deliver positive outcomes and provide long term employment support.

6. Summary

MS Australia believes that it is appropriate for the Australian Government to undertake the proposed tender process. It is important that the market is tested to ensure that the most capable and skilled providers are in place to deliver these important services to people with a disability.

The tendering process is also an opportunity to write in obligations and processes into the sector that directly address the needs of key demographic groups in the labour market.

It also forms part of the Government's implementation of the National Disability Strategy, and can contribute to the achievement of the Strategy's economic security policy objective, combined with other government and sector activity in the employment participation area.

7. Further Contact

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8. References

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