MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Department of Social Services consultation on the Disability Employment Strategy

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Introduction

MS Australia is pleased to provide a submission to the Department of Social Services consultation regarding the Disability Employment Strategy.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS). The comments have been provided by representatives of our state organisations who assist people with MS to remain employed for as long as possible and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of all our state and territory-based member organisations to provide a voice for people living with MS across the country.

MSA's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with MS regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and **employment services**.

Employment Support requirements for people living with MS.

Employment Support Service programmes for people with MS must be driven by highly specialised, multidisciplinary teams of health professionals[1]. The role insists upon a solid understanding of the complexities of symptom management and the need for holistic and proactive management of barriers to maintaining employment including timely and effective provision of workplace accommodation and education of employers and the wider community[2]. New perspectives on activity and participation driven by the World Health Organisation necessitate that rehabilitation professionals constantly update their knowledge of MS, rehabilitation, and employment. Indeed, inadequately

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[1] 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.

[2] Sirvastava, S., & Chamberlain, M.A. (2005). Factors determining job retention and return to work for disabled employees: A questionnaire study of options of disabled people's organisations in the IK. Journal of Rehabilitation Medicine, 37, 17-22.

informed employment support personnel may contribute to excessive disability with respect to MS and employment[3].

Specialist Disability Employment Services (DES) Employment Support Services (ESS) are delivered by all members.

These member organisations provide employment support utilising experienced allied health professionals, occupational therapists, and physiotherapists to provide case-management for people living with MS. MS is an acquired condition, as described below, often when people are fully employed, planning a family, and making significant career choices.

The earliest point of intervention is at diagnosis and MS organisations networks within the broader health and allied health sector enables a referral pathway outside of conventional referral pathways. To be effective and achieve increased employment opportunities improve the financial security and personal wellbeing of people with MS, their families, and carers. MS specific employment support enables people with MS to plan for their future and exercise greater choice and control over their lives. It can also contribute to a sense of identity and bring social, health and wellbeing benefits to these individuals, families, and carers. Specialist knowledgeable is required about the impact of disease and disability on function in the workplace, and to be more responsive in providing expert, timely, intensive, and flexible vocational services tailored to meet individual needs. In relation to employers, there is a need to change negative attitudes to disability and to improve employer knowledge about the employee's condition and job capabilities.

Key factors about MS regarding employment

<u>Diagnosis and the impact of disease modifying drugs</u>

- Most people are diagnosed with MS between the ages of 20-40, but it can affect younger and older people too. Roughly three times as many women have MS as men[4]. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.
- Given that MS is a progressive, degenerative, neurological condition, where acquisition of disability often occurs gradually, a major focus for MS employment services is supporting people with MS to remain in employment for as long as possible.
- A study of the Health Economic Impact of Multiple Sclerosis in Australia in 2017 found that, "Of all the various categories that comprise the total cost of MS, lost wages now account for only 32% of the economic burden of MS compared to almost 50% in 2010"[5].

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[3] Johnson, K.L., Amtmann, D.,Yorkston, K. M., Klasner, E.R., & Kuehn, C. M. (2004). Medical, Psychological, social, and programmatic barriers to employment for people with multiple sclerosis. Journal of Rehabilitation, 70, 38-49.

[4] Understanding MS: An Introductory Guide, MS Australia, available from: www.msaustralia.org.au/about-ms/information-sheets

[5] https://msra.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf

- Further, the study reported that, “This is consistent with the findings of a recent study that demonstrated that the newer generation of higher efficacy disease modifying therapies (DMTs) are associated with better employment outcomes for people with MS.”[6]

Disclosing a diagnosis of MS in the workplace

- People living with MS are concerned by their ability to keep their job, their ability to progress in their career and completing assignments at work.[7]
- Disclosing a diagnosis of MS at work can be a daunting experience and there is no easy answer nor straightforward advice.[8] Anecdotal feedback indicates that people with MS have very mixed experiences when disclosing their MS at work, including concerns about the stigma associated with MS.
- Specialist MS employment services understand the difficulties associated with disclosing MS at work and can assist the employee with their decision-making and subsequently both the employee and employer through this process.

What the research tells us about disclosure of MS

Contrary to what many people may expect, research results show that disclosure of an MS diagnosis to an employer increased job retention. One factor leading to disclosure of diagnosis was severity of disability. However, employees who disclosed their diagnosis were more likely to be employed, and more likely to be employed for longer periods of time, even after taking level of disability into account. Results from one study suggest that after disclosure, employees may receive more assistance with workplace accommodations, social support and possibly more effective symptom management than non-disclosing employees. Future research will help determine these aspects. Previous research has shown that symptom management in the workplace is key to maintaining employment for people with MS.[9],[10]

These factors and research findings specific to the employment of people with MS, underpins the approach taken by MS employment services in supporting people in their whole of life circumstances. This support includes not only labour market interventions but more importantly vocational focused health interventions to enable the individual to manage their symptoms within their workplace.

Why staying employed is important for people living with MS

According to Lauren Strober, PhD, a senior research scientist in the Center for Neuropsychology and Neuroscience Research at the Kessler Foundation in East Hanover,

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[6] https://msra.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf

[7] www.msaustralia.org.au/living-with-ms/expert-blog/workplace-strategies-%E2%80%93-defying-effects-career

[8] https://www.msaustralia.org.au/living-with-ms/expert-blog/tell-or-not-tell

[9] msra.org.au/news/disclosing-diagnosis-ms-workplace-may-improve-job-retention/

[10] Kirk-Brown A and Van Dijk P, 2014, An empowerment model of workplace support following disclosure for people with MS, Multiple Sclerosis Journal 2012, 1624-1632

New Jersey, there are several reasons staying employed is important for people with MS.[11]

“We know that MS affects women more than men, and when we just study women — not just women with MS — who are in the workforce, they value their work less because of prestige and the financial gain. For them, it’s more about their self-esteem and identity — even their main social support,” she says. These factors also hold true for women with MS, she says, which makes work an important aspect of a healthy life.

For individuals of both genders, within six months of becoming unemployed, there are drastic declines in mental and physical health, according to Strober. “There’s an increase in cardiovascular disease, more fatigue, more sleep problems, and more depression — and this is in healthy people,” says Strober. Because those same symptoms are already commonly found in people with MS, the thought is that they may even become sicker once leaving the workforce, and that may be a barrier to getting them back in, Strober says.

“It’s not necessarily about the financial gain or financial loss of leaving your job; we know that there are very significant mental and physical health outcomes that come with being unemployed, particularly at an age when your peers and the majority of people in your stage of life are still working,” says Strober. “That’s why it’s really imperative to try to keep people employed. Even when I have older patients planning to retire, I suggest they think about what they’re going to do after this to ward off getting unhealthy,” she says.

In addition to the benefits to the individual of maintaining employment, there are numerous studies demonstrating the broader economic benefits of keeping people with disabilities and chronic illnesses at work for as long as possible.[12,13]

In addition to the more obvious benefits of keeping employees at work paying taxes for longer, reducing calls on social security benefits and disability pensions, there are also well documented benefits in maintaining a diverse workforce that includes people living with chronic conditions (such as MS) who could be considered more determined and adaptable workers, as they are used to dealing with the, often invisible, symptoms of their condition.[14]

These benefits are reinforced by further evidence provided on page 7 of the National Disability Employment Strategy Consultation Paper itself where the findings of the Diversity Council of Australia are set out, which state that employees with disability have reduced rates of absenteeism, are less likely to be represented in workplace health and safety incidents, have often been reported to have a positive impact on other staff as well as organisational culture, represent the business well, and promote a positive public image.

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[11] https://www.everydayhealth.com/multiple-sclerosis/the-reasons-people-with-ms-leave-their-jobs-differs-by-stage-of-life-study-finds

[12] https://www2.deloitte.com/au/en/pages/economics/articles/economic-benefits-increasing-employment-for-people-with-disability.html

[13] The-Economic-Benefits-of-Disability-Employment

[14] https://www.forbes.com/sites/manondefelice/2019/09/04/the-surprising-truth-about-chronic-illness-and-the-future-of-work/

Meeting departmental and government priorities

The MS employment services are arranged and delivered in such a way so as to address each of the four proposed Employment Strategy priority areas:

1. Lifting employer engagement, capability and demand

MS employment services engage deeply and form long term relationships with employers, breaking down myths about the impact of MS on employees and often leading to further job opportunities.

2. Building employment skills, experience and confidence of young people with disability

As stated above, many people with MS need confidence and support to disclose their MS diagnosis in the workplace, others may need additional support to take their career in a different direction where the progress of their MS makes undertaking their work difficult or impossible, especially where their work has a significant physical element. The MS employment services have the tailored, individualised MS-focused expertise to provide this support.

3. Improving systems and services for jobseekers and employers

The MS employment services have years of experience and have developed a wide network of relationships to navigate and utilise government services to support both employees, jobseekers and employers. Suggestions for improvements to the administrative burden in the current system are set out below.

4. Changing community attitudes

All members of the family of MS organisations in Australia seek to change the broader community's perceptions about MS, including perceptions and expectations about the capability of people with MS in the workplace. This is achieved through various campaigns run from time to time by the state-based MS organisations and by the peak body, MS Australia. This work is underpinned by evidence obtained through the Australian Multiple Sclerosis Longitudinal Study (AMSLS) which, amongst other research topics, undertakes research specific to MS and employment. To read more, please visit: https://msra.org.au/amsls/key-findings/

Addressing the Disability Royal Commission's Employment Issues Paper

In mid-2020, The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission) sought feedback to understand the experiences of people with disability in employment. The Disability Royal Commission has since published the responses to the Employment Issues Paper[15].

Many of the suggestions, comments and criticisms included in the responses are addressed by the MS employment services delivery model. For example, flexibility in the workplace was a major theme across most responses and "flexibility" is a key mark of success for the MS employment services in negotiating and delivering workplace adjustments for employees with MS.

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[15] https://disability.royalcommission.gov.au/publications/employment

Many responses described employment supports that are person-centred, culturally safe and not subject to time restrictions as examples of good practice as were models that enable employees to secure and maintain work in competitive open environments. These supports and models are also hallmarks of the MS employment service, securing and maintaining employment for people with MS in the mainstream open employment market.

The benefits of an MS-specific specialised employment service

Providing an MS-specific specialised employment services, enables the service to operate in the mainstream, open employment market, ensuring clients of the service are able to maintain their capacity to do the work they are employed to do. This approach ensures a far better match between workforce supply and demand.

A major focus of the service is to ensure people with MS do not become unemployed in the first place. Once unemployed, it is much harder to regain employment. Also, it is far more cost effective and of far more benefit to both employee and employer to undertake any necessary interventions while the client remains employed.

A further essential focus of the service is intense, long-term ongoing support for participants and employer engagement to support individuals in their workplace. Developing these close ties with employers improves employer awareness of the needs of employees living with MS and improves opportunities for further recruitment in the future.

The National Disability Employment Strategy speaks about disability in the abstract. It does not make reference to expertise or speciality when considering program design. It is a generic system, though practical solutions and improvements to the system cannot also be generic – a “one size fits all” approach will not deliver improved outcomes.

Specialist MS-specific employment support is vital to meeting the needs of the MS community. Without this specialist support, people with MS may experience setbacks in their workplace, as interventions and adjustments need to be specifically tailored to the needs of the person with MS.

Recommendation
Ensure the National Disability Employment Strategy includes an enhanced role for specialist, expert disability employment providers to operate within the mainstream, open employment market, in a flexible fashion, with a renewed focus on measures of employment outcomes rather than measures focused on compliance requirements.

An unnecessary administrative burden

The current system imposes an illogical and unnecessary administrative compliance burden on providers and clients. The system should be flexible enough to cater for participants living with MS who, for example, are working full time, with young families, and coping with the additional burden of a range idiosyncratic MS symptoms. The current system takes a “one size fits all” approach, is inflexible in its compliance requirements and does not take into account the needs and circumstances of the individual.

Example:

Currently, to meet DES compliance requirements regarding “contacts”, face-to-face contact and contact by telephone does meet these requirements yet contact by a detailed professional email does not. For people living with MS, especially those living in regional or remote locations and those with family and fulltime work responsibilities, making the time for face-to-face contact and contact by telephone can be difficult. Surely an acknowledged email would suffice. An email is also helpful to those with MS who are experiencing cognitive, especially memory, difficulties. An email enables memory prompts and the opportunity to review information multiple times if necessary.

The overall success of a Disability Employment framework should be outcomes driven not compliance driven.

Recommendation
Review the arrangements of the disability employment system to reduce the administrative burden and ensure it is outcomes driven rather than compliance driven.

What do people in the MS community say about the MS employment services?

Two examples of feedback from members of the MS community about the specialist MS employment service and significance of knowledge suitably qualified staffing

Example 1:
[The MS employment service] is a great initiative with benefits for clients that are huge but hard to quantify and articulate. Like most things in life, the service would be nothing without great employment peeps like you two.

I'm so very grateful to all the cool stuff (literally - cooling gear - and figuratively)/provided services/health care card (the gift that keeps on giving)/ndis, but not least having non-judgemental ears to rant and rave to was oh so very helpful. I've transitioned from when I first started with MS employment to being firmly living in Denial St to somewhat being able articulate how MS not only affects me in my employment, but also in every aspect of my life.

Anyways, I'm not very good at thankyous but wanted to acknowledge your positive contribution to my little life and the fact I'm sure it takes an emotional toll dealing with us MSers and advocating on our behalf.

Example 2:
Mary’s professional manner, knowledge & commitment has simply been exceptional!

She is an absolute gem. Always staying in contact, she really cares & listens. She looks for solutions to my health issues and has practical advice and suggestions. Her emails are filled with useful links & information.

Working as a Finance Manager, long days of work in front of the pc are a norm. Mary has helped source so many helpful things to make working with MS manageable. I feel so blessed everyday and so appreciate my stand-to-sit desk (a true game changer with tingling legs!), a supremely comfortable chair, x2 HP monitors, ergonomic keyboard & mouse, Bose noise cancelling headphones .... need I say more? The list goes on and it’s really has made me feel better & work better. My family and friends are so amazed when I tell them & show them all I have received and the ongoing support!

Mary is always checking in with me and seeing how things are going and reminding me about the balance I need and keeping exercise as part of a routine. Thanks to the funding, I attend an online physio class via Zoom with ARC. Another game changer for me and something I would not have committed to if Mary had not suggested it!

It’s not till you get an MS diagnosis and go on this journey that you realise what a difference your organisation makes. However, an organisation is nothing without its people, so thank you ever so much!

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.