Submission to New Disability Employment Services from 2018

13 December 2016

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration
- Research

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – ‘A world without MS’

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.

- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.

- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.

- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.

- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.
Introduction

MS Australia (MSA) is pleased to provide a submission to the New Disability Employment Services from 2018 Discussion Paper.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia with a further 1,000 people diagnosed every year. It is the most common chronic neurological condition affecting young adults. The average age of diagnosis is between 20 and 40, and 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 is a progressive decline over time. For all, it is life changing.

Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems.

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, “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. Many of these people with MS develop other chronic conditions in the course of the disease.”

The episodic nature and invisible symptoms of MS

Diagnosis-specific, specialist advice services and support are essential to addressing and understanding the episodic nature of MS and the invisible symptoms associated with MS such as extreme fatigue, problems with balance, blurred vision, body temperature dramatically switching from burning hot to freezing cold, to name but a few examples, which may or may not progress as a person ages. The invisible and often relapsing/remitting nature of these symptoms has some synergy with the way mental health symptoms are also described. Common MS symptoms and their impacts are set out in the graphic below.

MS and employment – key facts

Employment is a key aspect of quality of life, due to its impact on physical, psychological, social and independent wellbeing. In contrast, lack of work comes at great cost to the individual, their family and wider society.

MS is the most common neurological disease in young and middle-aged adults, striking during the formative years of career development and planning for a family.2 Affecting predominantly women (75% of diagnoses), it produces a complex array of physical, cognitive and emotional changes3.

Loss of work is a common experience for people living with MS. Most people are working or in full-time education when they are diagnosed and 90% have a history of employment.4 Data from 18 European countries suggested that almost half the people leaving the workforce do so within three years of being diagnosed3. Ten years after diagnosis, employment rates are as low as 25%3. Not only do people living with MS lose their jobs, they often move from high-demand to low-demand jobs, find it difficult to be promoted, to move between jobs and once unemployed, to return to the workplace3.

Current employment support programs in Australia for people with disabilities emphasis finding “new” jobs for the unemployed, rather than the retention and protection of existing jobs, as is offered, for example, to the approximately 85% of the registered participants of the MS Employment Services3,7.

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**Recent research is encouraging**

Recent published research that looks at the longitudinal changes in employment for people with MS from 2010 to 2013, found that more people were able to remain working in 2013 compared to 2010. There now seems to be little difference between the percentage of working women with MS compared to the general population. The gap has also substantially reduced in men, but is still present (59.0% employed vs 67.3% in general population).

These findings are welcome news, as 2010 data from the Australian MS Longitudinal Study highlighted the significant difficulties for many people with MS in retaining employment in the years following a diagnosis. This data focussed the attention of Australian MS organisations and health professionals on advocacy and employment support for people with MS. This focus, together with improvements in treatments for MS, is now paying dividends.

These results emphasise the positive impact that MS societies, MS clinics and health professionals can have by continuing to focus on identifying potential employment difficulties in people with MS and referring them to the appropriate services for employment support and symptom management.

It was also reported that most people with MS who ask for adjustments to their work role or work environment were receiving them.\(^5\)

**The need for an integrated approach**

With the number of people diagnosed with a chronic illness growing and with an ageing population, the New Disability Employment Services model to commence in 2018 must articulate a vision that is shared and understood across all government portfolios.

The new model should integrate strongly and take into account the proposals and outcomes from other current reforms such as the introduction of the NDIS, the NDS Strategy 2010-2020 and the AHRC Willing to Work Report. For systemic improvements to occur, disability employment services must address individual issues holistically along with these other reforms to produce the maximum benefit for each individual and recognise that one size does not fit all.

One of the most critical issues for employment retention for people with disability is for government departments to work together, not in silos. The lack of “joined up support” and integrated pathways across government portfolios is a major factor in being able to maintain employment i.e. the ability to access transport, appropriate equipment, housing, personal assistance, education, information, healthcare are all fundamental priority issues to retain employment.

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Responses to the specific discussion points in the Discussion Paper

Discussion Point 1: More Choice for Participants

1. **What, if any, restrictions should there be (for example, region or distance) on participants choosing to attend a provider?**
2. **How often should participants be allowed to voluntarily transfer or switch providers?**
3. **What should be the basis of referral by Centrelink for participants who do not choose a provider?**

It is important that a participant be able to select the provider that best meets their needs, and in the case of people with MS, this may mean a specialist provider who understands the specific needs of people living with MS.

It may be necessary to restrict participants from transferring or switching too often, as some stability in the system is needed. The proposal set out on page 24 of the Discussion Paper, to allow participants to ‘voluntarily transfer to a new provider up to three times in their first 12 months…and up to twice in the following year’ seems reasonable.

MSA supports the proposal to establish a default allocation method, and we welcome the inclusion of provider specialisation, especially for people with MS.

Discussion Point 2: Provider/Participant Contacts

1. **Should face-to-face requirements remain as part of the DES service delivery?**
2. **How often should participants and providers be required to meet, either face-to-face or by other means?**

It is acknowledged that face-to-face meetings are important to establish and build rapport and gauge a job seeker’s commitment to their employment plans, but new technology also provides for high quality meetings using technology, especially for people who are already employed and seeking to remain employed.

A minimum of fortnightly contacts seems reasonable, augmented with regular contact and support via phone calls, text messages and emails.

Discussion Point 3: Job Plans

1. **Should Job Plans have minimum requirements beyond what is necessary for mutual obligation requirements? Or should this be determined between each participant and their provider?**
2. **How can we ensure that participants are actively involved in the development of their Job Plans, or will the ability of participants to change providers if unsatisfied be sufficient?**
3. **How should providers be held accountable to ensure activities in the Job Plan are undertaken and supports are delivered? Will the ability of participants to change providers if unsatisfied be sufficient?**

It could be expected that in a more competitive market for provision, the quality of Job Plans will improve as a mechanism for providers to attract clients. As the transitions to the new framework occurs, the provision, by the Department, of templates that set out both minimum requirements and additional supports that might be included in the Job Plan would no doubt assist participants.

It could also be expected, as suggested in the Discussion Paper and foreshadowed in questions 2 and 3 above, that the ability of the participant to change providers will allow the market to move away from providers that use inadequate or poor quality Job Plans that lead to participant dissatisfaction.

**Discussion Point 4: Better Information for Participants**

1. **What information should be available to participants, providers and employers?**
2. **Should there be mechanisms to ensure no false or misleading claims are made against DES providers?**
3. **Should the Department facilitate access to information on accessible and user friendly platforms, or should this be purely market led (with providers offering such information on platforms of their own choosing)?**

Providers should have the flexibility to offer information on their own platforms but a centralised, Department-led platform as suggested in question 3 above, would allow ease of access to participants, especially those whose disability makes accessing multiple sources difficult. A Department-led platform would also address question 2 above by providing a mechanism to mitigate against false and misleading claims.

More broadly, one of the areas for reform is to develop better incentives for providers to service all participants equally. Employment options outside of the traditional employment model i.e. in an office setting, should be considered. Questions such as identifying available support for those self-employed and mechanisms to encourage entrepreneurs and innovators including the adoption of new technologies and disruptive technology need addressing.

**Discussion Point 5: Participant Controlled Funding**

1. **There is considerable literature and experience in participant controlled funding in personal care. Is there any evidence of the effectiveness of participant control of third party funding in employment services?**
2. **In such a model, how much funding, if any, should be quarantined for job seekers to use through an account, how should this funding be made available to participants, and how could there be simple clarity as to what costs are to be met from participant controlled funds versus provider controlled funds?**
3. What principles should guide the appropriate expenditure of any individualised funding?

4. What restrictions should apply to the use of the funds by participants?

5. How can participants who are unwilling or unable to use individualised funding be supported during the decision making process?

6. What restrictions should apply to the expenditure of the funds on services from a participant’s provider or an associated organisation?

The proposal to introduce some individualised funding is welcomed and in some ways, mirrors the processes used by the NDIS to plan and implement individualise support packages, though we also recognise the administrative burden and opportunity for disputes that this proposal may bring about.

MSA agrees with the suggestion in the Discussion Paper on page 28 that “allowing participants to choose their provider and to change providers, with the funds following the participant, is more likely to achieve improved outcomes than simply placing the funding under the direct control of the participant”.

Discussion Point 6: Entering the DES Market

1. How often should the Panel be open to entry by new providers?

2. How often should panellists be reviewed and what criteria should they be reviewed against?

3. What should the basic criteria be for joining the Panel?

4. How much time do providers need before entering into a market to set up their operations?

5. In order to supply DES in a specific ESA what should the requirements be for:
   a. a minimum caseload?
   b. ESA coverage?

The proposal to establish a DES Provider Panel is welcomed as is the recognition of provider specialisation and MSA supports the stated minimum criteria, and the proposed review arrangements set out on pages 30-31 of the Discussion Paper. It will be essential to ensure the proposed regular review arrangements include recognition of longer term outcomes and participant feedback (such as the level of complaints).

Discussion Point 7: A Single DES Contract

1. Would all providers have the capacity to deliver DES-DMS, DES-ESS and Ongoing Support under the proposed simplified contract arrangements?

Employment support service programs for people with MS must be driven by highly specialised, multidisciplinary teams of health professionals capable of working in collaboration with people with MS, the labour market and employers,

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medical and allied health professionals, extended supported networks such as family, as well as local, State and Federal Government support services. It requires an understanding of the complexities of symptom management and the need for holistic and proactive management of barriers to maintaining employment. This includes accommodating individual needs in the workplace in a timely and effective manner and the education of employers and the wider community.

Rehabilitation professionals need to constantly update their knowledge of MS, rehabilitation and employment. This is supported by the World Health Organisation. Indeed, inadequately informed rehabilitation professionals may contribute to excessive disability with respect to MS and employment. For example, health care workers may not inquire about cognitive and/or fatigue limitations, or be familiar with accommodation strategies that address these limitations. They also may inaccurately equate employment with stress and recommend termination of employment.

Financial modelling indicates the net benefit of maintaining employment to be greater than six times the cost of providing these services, equating to approximately $64k per person for each year they are employed.

Discussion Point 8: Removing Market Share Restrictions

1. What mechanisms should be adopted to ensure universal coverage in an ESA while maintaining a competitive marketplace?
2. How should provider diversity be maintained to ensure participants have adequate choice of provider?

The proposal to allow participants to go to a provider of their choice is welcomed. The MS organisations have previously suggested the removal of ESA boundaries and associated market shares to encourage consumer-based demand for provider services and to allow existing providers to expand into new regions. This allows the participant to select the service that best suits their individuals needs and circumstances and this is particularly important for people with MS for the reasons outlined in the introduction.

As noted by the Productivity Commission in the Independent Review of the Job Network:

“Competitive tendering is complex and expensive for providers and disruptive to services. Accordingly, licensing of providers should be adopted, ultimately with free entry to the Job Network by accredited agencies, subject to ongoing

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10 MS data 2010-2014
assessment of quality. Prices should be set administratively as quality of service cannot be assessed adequately ex ante.”

We support this recommendation by the Productivity Commission as it would:
• Enable entry to the market by providers that meets stipulated accreditation standards
• Facilitate automatic licensing renewal subject to a performance standard being met

Use of a licencing system for providers would enable a more flexible market attuned to the needs and demands of participants.

It is recognised there would be a need for a robust performance management framework and a fee structure that operates in conjunction with the performance framework.

Discussion Point 9: ESAs
1. Should there be ESAs, if so, how many ESAs should there be?
2. Should the number of ESAs be reduced if market share is removed?

As suggested in our response to Discussion Point 8, the MS organisations have previously suggested the removal of ESA boundaries, though we do recognise the structure and basis for administrative and management arrangements they provide.

To ensure participants with MS are able to attend specialist MS providers, MSA favours the option that keeps ESAs in place for administrative purposes, but allows participants to attend their provider of choice outside their ESA.

Discussion Point 10: Preventing Market Failure
1. What specific circumstances should be recognised as market failure warranting intervention?
2. If market share is continued in some areas, how should the level of market share be determined?
3. What interventions should be used to address market failure and ensure service availability?

MSA does not have any specific suggestions to make in response to these questions except to broadly agree with the approach set out in the Discussion Paper regarding interventions and triggers and the proposal to undertake regular reviews that should include a significant contribution from participants.

Discussion Point 11: Ratio between service fees and outcome fees
1. What should the ratio between service fees and outcome fees be and why?

It must be acknowledged that there has been no indexation of fees and outcomes since the 2010–13 contract iteration. By the end of the current 2013–
18 contract fees and outcomes will have remained the same for 8 years, this is an effective funding cut and does not reflect the current cost of providing an effective service. Before a move to a more targeted and risk adjusted funding model the fees and outcomes should be indexed to reflect the resources to provide effective service provision.

This ratio should be weighted towards outcomes to ensure suitable job matches are made and post-placement support is provided to maximise the longevity of placements.

**Discussion Point 12: 4-week and 52-week Outcome Payments**

1. *What should constitute an employment outcome under DES in a modern Australian economy?*

2. *How should the DES funding model incorporate the growing number of short term jobs available in the economy?*

3. *Should the new model replace the job placement fee with a 4-week outcome payment, and how many 4-week outcome payments should be available for each job seeker?*

4. *How should job seekers be supported in the period between the 26-week outcome and the 52-week outcome?*

5. *What level of payment should be attached to the 52-week outcome while keeping total DES expenditure within the current funding envelope?*

The recent research described earlier in this submission regarding improved employment outcomes for people with MS is encouraging, though further research is needed to more clearly identify the reason for this trend.

The proposal to replace job placement fees with a 4-week outcome payment and the introduction of a 52-week payment to reward outcomes where the initial job match is better and where longer term outcomes are achieved seems reasonable.

**Discussion Point 13: Service Fees**

1. *How should service fees work in the context of a funding model with risk-adjusted outcome fees?*

As described earlier in this submission, employment support service programs for people with MS must be driven by highly specialised, multidisciplinary teams of health professionals.\(^1\) It requires an understanding of the complexities of symptom management and the need for holistic and proactive management of barriers to maintaining employment. This includes accommodating individual

needs in the workplace in a timely and effective manner and the education and support of employers and the wider community\textsuperscript{12}.

As stated earlier, we recommend that fees and outcomes are indexed to more accurately reflect the cost of service provision. If there is to be a move to a more targeted outcome structure that reflects the difficulty of placing and keeping a participant in employment it needs to be done in conjunction with a robust and accurate assessment process that reflects the barriers and interventions that will be required to be implemented to secure employment.

**Discussion Point 14: Pro-rata service and outcome fees**

1. *How should pro-rata service and outcome fees be calculated?*
2. *How should pro-rata fees apply in the event that a provider ceases to be a member of the Panel?*

Given that the Discussion Paper is proposing a model whereby services fees follow the participant and be paid pro-rata based on the number of days the participant spends at each provider, it seems reasonable to also apply this principle to outcome payments.

**Discussion Point 15: Determining Eligibility and Employment Outcomes for ESLs**

1. *Who should be able to qualify under revised assessment criteria for ESL? How could the level of disadvantage and work capacity be assessed for secondary school students?*

The suggestions set out in this section of the Discussion Paper seem reasonable.

**Discussion Point 16: Improving the Gateway (16 & 17 are considered together)**

1. *How can gateway arrangements be improved to enable a better connection to employment services for people with disability?*

**Discussion Point 17: Assessments Review**

1. *What other aspects of ESAts/ICAs should be examined in the review?*
2. *Should there be:
   a. greater separation of ESAts and provider’s own assessments, with ESAts focused on eligibility, work capacity and appropriate referral within DES and not extending to suggested interventions? OR
   b. should ESAts be developed and extended to provide more and better information on which providers could base their assistance, with less need to perform their own assessments?*

3. How should the revised assessment process fit with other options for DES reforms outlined in this Discussion Paper?

Currently entry into a DES programme as a Job Seeker can only occur once a Participant has undergone an Employment Services Assessment (ESAt), Job Capacity Assessment (JCA) and the participant has been deemed eligible for a programme of support.

ESAt/JCA are administered utilising generic principles in a time restricted manner and often conducted by assessors with limited knowledge of disability types. This can result in superficial and inaccurate assessment.

We recommend a more holistic assessment ideally conducted by an Employment Support Consultant with expertise in identifying barriers to employment and formulating strategies and activities to mitigate the effects of these barriers on the participant’s efforts to enter the workforce. This is most readily achieved through specialist Disability Employment Service providers.

Discussion Point 18: Ongoing Support
1. Should the fee-for-service funding model specify minimum contacts and hours of support?
2. What minimum servicing requirements should there be for each level of support?
3. How should payments be determined for each level of support?

MS is a chronic and progressive neurological condition. Symptoms can vary in severity through the day, week, month or year. A relapse, a significant and prolonged exacerbation of existing symptoms or the development of new MS symptoms, can greatly impact function temporarily, for example for a few months, or have a permanent effect.

The Ongoing Support phase is vital in enabling the specialist provider to respond to such events by, for example, facilitating appropriate symptom management, workplace modification or interaction with an employer.

Ongoing Support is also an integral part of assisting a participant to maintain their employment in times of relative symptom stability. As disease-related factors and difficult managing symptoms in the workplace are the primary reasons for loss of employment for people with MS, Ongoing Support enables the specialist provider to purchase services, treatments or intervention to assist participants in the management of symptoms that are presenting as ongoing barriers to maintaining employment. This is a prophylactic approach to prevent people with MS moving from employment to unemployment or out of the workforce altogether.
Interpretation of Ongoing Support guidelines varies amongst Ongoing Support Assessors. Some Assessors indicate purchased services are disallowed and therefore cannot be included in the hours of support provided.

Some Assessors indicate participant contacts must be face-to-face however when participants are working full time, have family commitments or medical appointments etc., email or phone contacts have been equally effective mode of contact with participants.

The current ongoing support structures and levels are workable and effective if utilised properly. The only current short coming has been the lack of indexing of service fees. Introducing a fee for service (individual packages) funding model not only will add an extra administrative burden on providers but reduce the flexibility of support available.

**Discussion Point 19: Job-in-Jeopardy**

1.  **How can we better define when someone’s employment is considered to be at risk due to their disability?**
2.  **How can we increase employer awareness of JiJ?**
3.  **Does the current fee structure reflect the services being provided and outcomes being achieved?**
4.  **What is a more appropriate name for Job-in-Jeopardy?**
5.  **If a JiJ participant chooses not to disclose their disability to an employer, how should providers assist them in the workforce?**
6.  **Should the JiJ service be integrated with Ongoing Support?**

The limited impact of the Job in Jeopardy Assistance service stems from interpretation of the Job in Jeopardy (JiJ) eligibility criteria – anecdotal evidence indicates that the DSS contract managers have little experience with JiJ. Despite providing detailed written reports from Allied Health staff and participants seeking direct registration support as they feel their employment is in jeopardy, DSS contract managers reject this evidence as demonstrating an individual’s employment is in imminent danger of being lost.

When barriers to maintaining employment have been identified, it is counter-productive to simply hope these barriers will not lead to loss of employment.

As noted in the Evaluation of Disability Employment Services 2010–2013 report: “The idea of intervening early, before employment ends, is sound but Job in Jeopardy has limited impact. Given the size of the employed segment of the DES target population it is reasonable to expect more than 827 Job in Jeopardy participants (as at 30 June 2012). The small number relates to the programme’s restrictive parameters. Demonstrating that a job is at risk because of sickness or disability seems problematic in practice because it may be seen as needing to demonstrate discrimination, when that is not the intent. Secondly, by the time a person realises that their job truly is in jeopardy they might not be able to evidence 13 consecutive weeks of employment.”
The JiJ guidelines clearly identify evidence required for participants to be eligible to register for JiJ. When this evidence is obtained by providers to demonstrate the need for assistance, contract managers must accept the expertise of the sector and not override and reject registrations. The specialist service provider and the participant are in the best position to identify if a job is in jeopardy.

JiJ is not only more effective for an employee to reach their employment goals, it is a far more cost effective intervention than allowing an individual to leave the labour market and attempt to re-enter.

A suggested name change for JiJ is *Employment Support*. Many people in the MS community do not identify with the word ‘disability’ and people with psychosocial issues may not see their condition as a disability. To further retain people with chronic illness and the ageing population in employment *Employment Support* is a possible alternative to Jobs in Jeopardy.

**Discussion Point 20: Transition Issues**

1. *How can we ensure that DES providers continue to provide quality services to participants towards the end of the current contracts?*

MSA has no specific suggestions, to make in response to this questions except to recognise that a robust system for increased monitoring will be required to ensure participants are not disadvantaged as contracts end.

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