Multiple Sclerosis Limited (MSL)

Response to the
National Disability Employment Framework
- Issues Paper

July 2015
SUMMARY

The National Disability Employment Issues Framework – Issues Paper outlines what the Australian Government is currently doing to help people with disability find and keep jobs, and provides a platform for discussion about ways to improve current practice to lead to better employment outcomes for people with disability.

Having delivered a specialist employment service to people with multiple sclerosis for over 15 years, MS Employment Support Service (MS ESS) is in a somewhat unique position to provide comment and insight into the proposed Principles for Change to the Disability Employment Services - Service Delivery Framework. With departmental intervention and support the MS ESS is successfully delivering a specialist employment service within the current contractual framework that encompasses many of the proposed principles that are mooted to underpin the future service delivery framework for disability employment.

MS ESS agrees with the Principles for Changes to Disability Employment Services and the anticipated benefits.

To contribute to discussion and inform future policy direction, MS ESS present the following key recommendations:

1. Retain the following current programme components:
   a. Employment Assistance
   b. Job in Jeopardy
   c. Ongoing Support
   d. Employment Assistance Fund
2. Remove Employment Service Area (ESA) Boundaries
3. Encourage Specialist Providers
4. Develop a robust Assessment process
5. Reduce the administrative burden to enable greater flexibility of service
6. Use a licencing/accreditation process to enter the market
ORIGINS OF MS ESS

Multiple sclerosis:

Multiple sclerosis is a permanent and progressive neurological condition. Multiple sclerosis is the most common neurological disease in young and middle-aged adults, striking during formative years of career development\(^1\). Affecting predominantly females (75% of diagnoses), it produces a complex array of physical, cognitive, and emotional changes\(^2\).

Multiple sclerosis and employment:

For those living with multiple sclerosis, the risk of unemployment is potentially a greater threat than for their non-disabled counterparts. Eighty per cent of people with multiple sclerosis leave full time employment within ten years of diagnosis, despite 90% having a positive work history at time of diagnosis and typically in highly skilled jobs\(^2\).

Policy decisions that enable people with multiple sclerosis to retain employment where possible while recognising the need to have a solid welfare response for those unable to remain employed, are strongly recommended from an economic and equity perspective and supported by national and international literature on disability and employment\(^3\). Once a person is rendered unemployed due to disability, difficulties often surface in attempting to regain employment\(^8\)-\(^10\). People with progressive illness or whose level of disability varies face the greatest obstacles to re-employment due to the perceived risks to the employer\(^7\). This underscores the importance of obtaining accommodated work within a current employment situation rather than seeking new employment elsewhere.

Need for specialised knowledge:

Employment Support Service programmes for people with multiple sclerosis must be driven by highly specialised, multi-disciplinary teams of health professionals\(^4\). A study of the Australian cohort of people with multiple sclerosis reported disease-related factors and difficulty managing symptoms in the workplace contributed to loss of employment more than work-related factors such as discrimination and being asked to leave or sacked; findings consistent with several international studies\(^10\). The role of Employment Support Consultant therefore insists upon a solid understanding of the complexities of symptom management and the need for holistic and proactive management of other barriers to maintaining employment including timely and effective provision of workplace accommodation and education of employers and the wider community\(^5\). Indeed, inadequately informed employment support personnel may contribute to excessive disability with respect to multiple sclerosis and employment\(^1\).

New perspectives on activity and participation driven by the World Health Organisation necessitate that rehabilitation professionals constantly update their knowledge of multiple sclerosis, rehabilitation, and employment.

For these reasons, all MS ESS Employment Support Consultants are experienced, registered allied health care professionals, primarily Occupational Therapists and Physiotherapists.

Multiple Sclerosis Limited (MSL) as a Disability Employment Service Provider:

- MSL has been delivering a specialist employment service to people with MS since 1996
- 2012 special consideration enabled the MS ESS to continue as a sub-contractor delivering specialist employment support service under the current 2013 DES Deed
- Under special consideration, MS ESS can only directly register participants sourced through its networks and receives no market share via Centrelink.
- As a specialist provider MS ESS exercises the authorisation in the DES Deed and Guidelines to enable specialist providers to register and service participants from outside of their contracted ESA
- MS ESS can only directly register and service participants diagnosed with MS
KEY RECOMMENDATIONS:
The experience of MS ESS as both a Job Seeker Assistance and Job in Jeopardy Assistance Disability Employment Service Provider has informed these key recommendations:

1. Retain the following current programme components:
   a. Employment Assistance
   b. Job in Jeopardy
   c. Ongoing Support
   d. Employment Assistance Fund
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Recommendation 1:
Retain the following current programme components

a. Employment Assistance:
   The MS ESS model:
   All Job Seekers undergo a comprehensive multiple sclerosis-specific Initial Needs and Vocational Assessment administered by an MS ESS Employment Support Consultant (a registered allied healthcare professional).
   The Initial Needs and Vocational Assessment includes psychological, social, cognitive, physical and vocational domains to identify the Participant’s vocational interests, transferable skills and abilities, as well as multiple sclerosis-specific barriers to engaging in open employment.
   Detailed written reports include mutually agreed strategies and actions to mitigate identified barriers to gaining employment and assist in identifying suitable employment for the Participant.
   Support to seek employment is then provided by an Employment Development Consultant. (A tertiary qualified specialist)
   Identified constraints:
   The expertise of an Employment Development Consultant is essential to prepare Participants for employment.
   Anecdotal evidence suggests provision of Employment Assistance services across the sector is homogenous, with little attention to the individual or disability-related factors, or the societal or work-related factors presenting as barriers to the participant gaining meaningful employment.

b. Job in Jeopardy Assistance:
   The MS ESS model:
   Disease-related factors and difficulty managing symptoms in the workplace are the primary reasons for loss of employment for people with multiple sclerosis. This guides the MS ESS approach to the Job in Jeopardy Assistance service.
   MS ESS utilises a flexible, client-centred approach to symptom management to prevent loss of employment. This approach encompasses:
   - A comprehensive and holistic Initial Needs and Vocational Assessment as described for the Employment Assistance service to identify the Participant’s barriers to maintaining current employment. Detailed written reports include mutually agreed strategies and actions to mitigate identified barriers to maintaining current employment.

- Intensive case management strategies provided by an Employment Support Consultant focussed on the employment goals of the Participant
- Strong collaborative relationships with the Participant’s complementary support services
  - Medical, Allied Health, Domestic, Social
- Effective working relationships with employers

Identified constraints:
The limited impact of the *Job in Jeopardy Assistance* service stems from interpretation of the *Job in Jeopardy (JiJ)* eligibility criteria - Our experience is 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 evidence as demonstrating individuals 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.

Solution:
The *Job in Jeopardy Assistance* guidelines V2.8 section 4 clearly identifies evidence required for participants to be eligible to directly register. 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.

*Job in Jeopardy Assistance* service 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.

“Job in Jeopardy needs to be redesigned if it is to prevent people with disability moving from employment to unemployment, or worse, out of the labour force altogether” (*Evaluation of Disability Employment Services 2010–2013* report).

c. Ongoing Support:
The MS ESS model:

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

The Ongoing Support phase is vital in enabling the MS ESS Employment Support Consultant 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 difficulty managing symptoms in the workplace are the primary reasons for loss of employment for people with multiple sclerosis, Ongoing Support enables MS ESS 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 multiple sclerosis moving from
employment to unemployment, or worse, out of the labour force altogether. Being a progressive neurological disease this method of support would be transferable to other similar conditions.

**Identified constraints:**

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 by the MS ESS.

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 contacts with Participant.

**Solution:**

Ongoing Support Guidelines *Mode of Contact and Purchased services* was amended on a trial basis in April 2015. During an Ongoing Support Assessment, the Employment Support Consultant must demonstrate the services purchased are directly related to management of symptoms of multiple sclerosis presenting as barriers to maintaining employment. MS ESS supports this trial and future integration permanently into future guidelines.

Changes to the *Mode of contact* have enabled participants who are working to choose the most appropriate method of contact with the ESC.

MS ESS recommends better education for Assessors to recognise the amendments and trial changes to *Mode of Contact* and to use of EITHER support hours OR number of contacts as detailed in the current Ongoing Support Assessment guidelines.

d. Employment Assistance Fund:

**The MS ESS model:**

As registered allied health professionals (Occupational Therapists and Physiotherapists), the MS ESS Employment Support Consultants are well equipped to identify and source work-related modifications (including adaptive equipment) and services, and to present clinical reasoning and documentation to support any application for funding.

**Identified constraints:**

Participant’s who have elected not to disclose their diagnosis of multiple sclerosis to their employer are often unable to meet the documentation requirements specified by Job Access, for example *Statement of Ownership* forms.

Adaptive equipment essential to maintaining current employment may not be funded through the Employment Assistance Fund when it is deemed the equipment may also be used by the Participant within the community. While this may be true in some instances, the purpose of the funding application is because there is a real and immediate need for the equipment in the workplace to ensure the Participant maintains their current employment.

**Solution:**

Maintain flexibility within the Employment Assistance Fund guidelines to enable Job Access Advisors to use their own clinical judgement when assessing applications for funding.
Recommendation 2:
Remove Employment Service Area (ESA) Boundaries

The MS ESS model:
As a defined specialist provider MS ESS exercises the allowance within the current DES Deed and guidelines to directly register from outside of the contracted ESA. Stipulation being that only the specified cohort supported by the service is engaged.

Identified constraints:
The arbitrary geographical boundaries that ESA define restrict consumer choice to a set number of Providers. This is contrary to the principles of market-based service provision and increased open employment options, two of the principles identified in the Disability Employment Issues Paper to underpin the new framework for disability employment.

Solution:
Remove the ESA boundaries and associated market shares to encourage consumer-based demand for Provider services. This allows the consumer to select a Disability Employment Service to best suit their individual needs and circumstances.

Recommendation 3:
Encourage Specialist Providers

The MS ESS model:
Both research and the experience of the current specialist MS ESS indicates employment services for people with multiple sclerosis, whether in a Job Seeker Assistance or a Job in Jeopardy Assistance service, must be driven by highly specialised multidisciplinary teams of health professionals capable of working in collaboration with people with multiple sclerosis, the labour market and employers, medical and allied health professionals, extended support networks such as family, as well as local, State and Federal Government support services.

As noted in the Evaluation of Disability Employment Services 2010–2013 report:
“Depending on a person’s level of disability the most appropriate programme may be a specialist disability or mainstream programme. Failure to direct people who need specialist assistance to a specialist programme significantly reduces their chance of labour market success and the resources expended, however low, are a waste”.

Identified constraints:
As noted in the Evaluation of Disability Employment Services 2010–2013 report:
“Directing people with lower support needs to a specialist programme results in high deadweight costs because they are likely to achieve outcomes without the added expense of specialist intervention”

Solution:
MS ESS is an example of a disability-specific employment support programme, however there is also potential for industry- or employer-specific specialist Disability Employment Services.

Specialist Disability Employment Services would be better equipped to:
- Offer greater choice in the type of services available
- Foster innovation
- Provide a better match between Job Seekers and employment opportunity
- Offer more appropriate service provision based on needs
Recommendation 4:
Develop more appropriate assessment process

The MS ESS model:
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.

In addition to the ESAt/JCA, MS ESS utilises its own Initial Needs and Vocational Assessment to better understand an individual’s eligibility for a programme of support. This assessment is conducted by an Employment Support Consultant (a specialist registered allied healthcare professional) to determine a Participant’s barriers to entering and maintaining workforce participation and is completed within the context of the Participants own employment goals and the wider labour market. This report is provided to Centrelink Assessors prior to ESAt/JCA.

Identified constraints:
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.

Solution:
MS ESS recommends a more holistic assessment ideally conducted by Employment Support Consultants 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.

Recommendation 5:
Reduce the administrative burden to enable greater flexibility of service

Anecdotal evidence suggests a considerable amount of time is spent on administrative duties by staff.

It is acknowledged that a balance is required in achieving the best possible employment outcomes against the expenditure of public monies. What needs to be emphasised is the difference between quality of service and compliance of service delivery. Quality in the form of suitable and sustainable employment outcomes should be the measure of success of the Employment Support Service, rather than a focus on the administrative and compliance oversight to drive service delivery.

Recommendation 6:
Use a licencing system to enter the market

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 assessment of quality. Prices should be set administratively as quality of service cannot be assessed adequately ex ante.”

MS ESS supports 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.
CONCLUSION

MS ESS supports the proposed Principles for Change outlined in the National Disability Employment Framework – Issues Paper and believes the anticipated benefits are achievable.

If implemented, these changes could lead to greater opportunities for people with disabilities resulting in increased employment participation.

MS ESS appreciates this opportunity to contribute to the discussion about ways the Australian Government can improve current services to lead to better employment outcomes for people with disability. MS ESS welcomes feedback on these positions and looks forward to contributing further to the development of the future National Disability Employment Framework.

MS ESS will continue to advocate strongly to Government to ensure Australia has a successful and vibrant disability employment sector.

REFERENCES

6. MS Data, 2010-2012
10. Simmons, R., Hendrie, D., McDonald, E., Tribe, K., & Vowels, L. (2004). The economic impact of multiple sclerosis in Australia: Summary statement of preliminary results from the Australian MS Longitudinal Study. 26 November, Canberra Hospital