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Establishing a Disability Employment Centre of Excellence

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SUBMISSION



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Establishing a Disability Employment Centre of Excellence

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MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

Establishing a Disability Employment Centre of Excellence

MS Australia welcomes the opportunity to provide feedback on the establishment of a Disability Employment Centre of Excellence. MS Australia welcomes the establishment of this Centre and hopes this will improve employment outcomes for Australians living with MS.

MS and Employment

Most people are diagnosed with MS between the ages of 20-40, with 75% being women. Often a diagnosis of MS occurs when people are fully employed, consolidating income, planning a family and/or making significant career choices. MS is a progressive, degenerative, neurological condition, where acquisition of disability often occurs gradually and may vary from person to person. People living with MS may experience the following symptoms that can affect their ability to function in the workplace:

- Reduced mobility, balance and strength
- Cognitive issues including memory, concentration, planning and problem solving
- Sensory issues including heat sensitivity and numbness
- Extreme fatigue
- Double vision
- Bladder and bowel issues.

Symptoms can be triggered or made worse by stressful working conditions and requirements to work long hours. Additionally, many people living with MS have comorbidities that can substantially impact their employment outcomes including osteoarthritis, migraines, anxiety, depression and allergies¹.

Economic impact of MS

Analysis of the *Australian MS Longitudinal Study* (AMSL)² shows that the annual cost of a person living with MS is \$68,382, with \$21,858 of this attributed to indirect costs from lost wages. This represents a 17% increase in costs from 2010 (\$58,652 per person), however there was a significant reduction in the indirect costs of MS through lost wages and informal care. Lost wages now account for only 32% of the economic burden of MS compared to almost 50% in 2010. There are higher lost wage costs for men and those in rural and regional Australia.

This study shows that improving employment outcomes for people with MS in Australia and keeping more people in the labour market or returning to the workplace has a substantial positive economic impact. Increased work opportunities for people with MS and their carers significantly reduce the economic burden on both people with MS, their carers and the broader community. Employment can bring financial independence for people living with MS and help to meet MS related costs including home and car modifications, assistive technology, medications and health and community services.

Broader impacts of employment

Being employed has many benefits beyond the financial aspect. It can improve quality of life, contributing to a person's self-worth, independence and belonging, and provides a means of social interaction. The MS International Federation ranks employment as one of their seven principles to improve quality of life for people living with MS³. The principles state that equal participation in employment and education:

'Empowers and enables people with MS to contribute as valued members of the family and wider society. Participation also enhances visibility and public understanding of MS, which in turn contributes to removing stigma and discrimination.'

People with MS can contribute a range of skills, talents and qualifications to the workplace. Employing people with a disability can bring diverse and unique perspectives and skills to the workplace including creativity, problem solving, persistence and resilience. People with a disability generally take fewer days off work, stay in jobs longer, build strong connections with customers/clients and boost staff morale⁴.

Disability Employment Centre of Excellence

Why do we need a Centre?

1.1 Why do we need a Centre?

As outlined above, employment is central to improving economic, social and health outcomes for people living with MS. However, evidence indicates that accessing suitable employment is not straightforward.

In February 2022, MS Australia undertook a national survey⁵ involving 1,748 Australian adults (including 525 people living with MS) to examine workplace attitudes towards those with a physical or mental health condition – including flexible work practices, job prospects, stigma, and disclosure.

The findings show that the general community overwhelmingly agree (83%) that people with health conditions in the workplace are ‘just as capable’ as anyone when it comes to working and eight out of ten (85%) believe workplaces are now more receptive to adapting roles to better fit employees. Importantly, the findings reiterated a widely held belief that meaningful work is a critical part of enjoying a good quality of life – with seven out of ten (70%) Australians feeling more connected to people and community because of their employment. However, the findings also show the reality of the workplace for people living with MS:

- 52% reported missed work opportunities due to their MS.
- 28% were uncomfortable in the workplace because they felt people labelled them.
- 17% felt the culture of the company they worked at did not make them feel comfortable enough to disclose their condition.
- 41% chose not to disclose their condition at work saying it would ‘change people’s opinion’ of them and 25% that it would ‘jeopardise career prospects.’
- 48% think they won’t be seen as a ‘long-term team member to invest in and promote’.

Overall, the findings show that there is a disconnect between community attitudes and workplace realities for those with a health condition. Many Australian workplaces are not keeping pace with community expectation towards supporting employees.

The establishment of a Disability Employment Centre of Excellence provides a unique opportunity to improve employment outcomes for people living with disability using an evidence-based approach. The Centre provides leadership to the disability employment sector and sets a strong example for how best to improve the lives of people living with disability.

1.2 What should be the core functions of the Centre?

The Centre should have the primary focus of improving employment outcomes for people with disability. Other core functions should include:

- Develop evidence-based models of disability employment.
- Build the capacity of the Disability Employment Sector and the broader Australian workforce to meet the diverse needs of people with disability across Australia including:
 - ❖ Centering the needs of people with disability in any programs
 - ❖ Hiring, retaining and adapting to meet the needs of their employees
 - ❖ Training and professional development materials
 - ❖ Reviewing incentives and supports for employers.
- Providing education, information and resources for employers and the general public on the benefits of working with people with disability and to improve the general acceptance of people with disability into mainstream Australian society.

Who could the Centre Assist?

2.1 Who can the Centre assist? Are any groups missing from the following list that was included in the consultation paper?

MS Australia supports the options papers recommendations that the Centre assist people with disability and their families, employment service providers and employers. We also believe that the Australian public would benefit from improved understanding of working with people with disability and how to create inclusive communities. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability found that people with disability want to live and work in inclusive communities where they are accepted and not subject to exclusion or discrimination⁶. It is essential that any work in the disability employment space includes the engagement of the broader Australia society to achieve a fully inclusive employment sector.

2.2 How can the Centre work with stakeholders to increase the employment rate for people with disability?

The Centre can work with stakeholders to increase employment for people with disability by:

- Educating people on the benefits of employing people with disability
- Improving understanding of people with disability and how to create more inclusive communities
- Implementing best practice models of disability employment, training and professional development

2.3 What can the Centre do to increase the capability and capacity of employment service providers?

The Centre can increase the capability and capacity of employment service providers through:

- Focusing on improving outcomes for people with disability over compliance and profit
- Developing best practice models of disability employment
- Providing training and accompanying resources
- Creating communities of practice where providers can share experiences and ideas
- Promoting high performing employment providers

Research Centre Model

3.1 What are your views on the following models presented in the options paper?:

MS Australia supports a Research Centre Model as this provides a good opportunity to ensure the work of the Centre has a robust evidence base and is bringing together the best research and experts in disability employment. This is a model already in place across many research areas in Australia. It also provides a good opportunity to collaborate with the [National Disability Research Partnership](#) which has experience in research led by and with people with disability.

3.2 Are there any models Government should consider that are not included in the above list?

MS Australia has no further recommendations for models.

3.3 What can the Government take from existing models of Centre of Excellence? What should be ruled out?

The learnings that the Government can take from existing Centres of Excellence include:

- Having clear goals and objectives
- Ensuring a clear governance and leadership structure that is also flexible and adaptive
- Having policies that focus on diversity and inclusion in employment

- Funding from external sources that does not create a conflict of interest or undue pressure to achieve certain outcomes.

Next Steps Towards Implementation

4.1 Where could a Centre be best placed (for example, within a government agency, a university, or as a stand-alone institution)?

MS Australia has no preference for where the Centre is based as long as the Centre can:

- Collaborate effectively with a broad range of stakeholders and institutions including Australian and International research bodies
- Develop a high level of respect and influence across the disability, employment and education sectors
- Operate independently and without undue influence from the government.

4.2 Are there any other implementation issues that should be considered?

As part of the implementation process, the Centre should establish a lived experience expert panel/working group of people living with disability to help guide their decision making and policy development. The Centre should also have a strong focus on the employment of people with lived experience of disability.

4.3 What elements of the proposed role of the Centre or its functions should be prioritised?

The first priority should be on ensuring an immediate shift to a focus on the best outcomes for people with disability over the current focus on compliance and profit.

Reference

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