MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Department of Social Services consultation on Shaping the New Disability Employment Program

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Rohan Greenland
Chief Executive Officer

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988

www.msaustralia.org.au

Multiple Sclerosis Australia
ABN 51 008 515 508

Introduction

MS Australia is pleased to provide a submission to the Department of Social Services consultation on Shaping the New Disability Employment Program.

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 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

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 member organisations who assist people with MS to remain employed for as long as possible and, in some instances, directly from people living with MS.

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 acquired 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.

We, along with a local network of an additional 12 other for purpose community partners working across 367 sites, are members of CoAct.[1] CoAct is a national

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[1] To read more about CoAct, please visit: https://coact.org.au/wpcontent/uploads/2020/12/ImpactReport_2020.pdf

partnership of not-for-profit employment service providers for people from disadvantaged groups.

Key questions

This submission is set out to address the key questions in each of the nine sections of the consultation paper.

1. Eligibility and Access

<u>MS Australia recommends:</u>

1. Everyone living with multiple sclerosis (MS), seeking to secure employment or wanting to maintain employment should have access to specialist disability employment support and services, regardless of:
    1) their age
    2) if they are participating in education and training
    3) where they live
    4) what their level of income is
    5) their goals i.e. if they would like to maintain their current employment (have job currency) whilst seeking support to secure a more well-matched job
    6) their eligibility for the NDIS
    7) their geographical location.

2. Increased participant choice should also ensure improved choice in providers. Deed requirements such as having initial face-to-face contact between a participant and the provider, should not be a barrier to accessing choice in providers.

3. In keeping with modern labour force patterns, a participant's requirement of 30 hours of employment-focused activities, should be counted across multiple employment activities, including volunteering, part-time placements and other contractual obligations.

4. Allowing people with job currency, but in need of transition support, to access DES providers. This will allow them to continue to work whilst transition supports can be put in place that will allow participants to more into another more suitable career paths.

5. People should not be discriminated against either by disability or age. Older participants should have access to the same training, support pathways and programs as younger people.

6. Regardless of which program of support, people with disabilities should have the same access to training and support pathways as people accessing employment support who do not have disabilities.

7. A broader range of employment and education options for DES participants should

be supported, including volunteering positions, temporary contracts (short and longer term), work placements and experience.

8. Adding ‘multiple sclerosis’ to the pre-listed conditions for an Employment Services Assessment (ESAt) trigger, for entry into the Disability Employment Services program (DES).

Understanding MS and its impacts on employment:

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[2]. 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.

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. In fact, the MS International Federation[3] ranks employment as one of their seven principles to improve quality of life for people living with MS.

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”[4].

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.”[5] Even with these advances, people living with MS still experience barriers to employment participation.

Case study

Elaine (38 years old) was diagnosed with relapsing remitting MS (RRMS) 18 years ago. She has a tertiary qualification and currently works for a Federal Government department.

She experiences a number of MS symptoms that impact on her day-to-day life and ability to work. These include extreme fatigue and brain fog; neurological symptoms like hypersensitivity in the extremities to the point where it actually hurts to wear clothes, often feeling like her legs are on fire ‘like as if someone is poking hot needles at you’. She also

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

[3] See the full list at https://www.msif.org/living-with-ms/what-influences-quality-of-life/seven-principles-to-improve-quality-of-life/

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

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

experiences continual numbness in the left side of her body, particularly her left hand. Occasionally Elaine has trouble walking especially if she must walk too far or exert herself. She found at work, when she has very long days, her brain fog becomes particularly problematic at about 2-4pm – to the point where she can't concentrate. This is worsened when work becomes more stressful or if there's a requirement to work long hours. These periods of extreme fatigue and brain fog slows her productivity down to the point where she cannot do anything.

Case study

Pete was diagnosed with MS in 2008, now 13 years ago. He described himself at the time as a 'school jock' later playing in the VFL for Port Melbourne. For those who knew him then, he felt that they would probably be shocked to see him now.

Luckily, he worked at a desk job at the time of diagnosis. Initially he experienced diplopia or double vision but within 6 months, he started experiencing trouble moving his legs. Whilst only living with the double vision, he was able to keep his invisible disease quiet. But one day, as he walked through the office, he lost his balance and fell flat on his face. This prompted him to get in contact with his local specialist MS employment support service.

Pete now makes use of a walking stick to walk short distances but prefers using his wheelchair when commuting longer distances.

Several studies have however documented reduced work capacity and productivity as a result of someone's experience of living with MS.

The main factor associated with changed work productivity was the *change* in symptom severity (particularly pain and sensory symptoms, feelings of anxiety and depression, and fatigue and cognitive symptoms), rather than the *actual level* of symptom severity. This is important as it suggests that improving symptoms irrespective of their actual level, may significantly improve work productivity. To improve work productivity, employer support should focus on stabilising or improving symptoms and reducing the impact of these symptoms, and therefore the barriers these symptoms create, on work productivity.[6]

Lower work productivity in people living with MS was largely linked to higher levels of disability, more severe MS symptoms and higher education levels. Interventions that focus on minimising the impact of MS symptoms could benefit people who are at risk of reduced work productivity. These interventions will also encourage them to remain in the workforce, so that the benefits of employment may be achieved. In addition to the financial benefits, participation in the workforce enhances self-esteem and social inclusion, which can be important contributors to the overall wellbeing of people living with MS.[7]

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[6] Bessing B, Hussain MA, Claflin SB, Chen J, Blizzard L, van Dijk P, Kirk-Brown A, Taylor BV, van der Mei I. Changes in multiple sclerosis symptoms are associated with changes in work productivity of people living with multiple sclerosis. Mult Scler. 2021 Nov;27(13):2093-2102. doi: 10.1177/1352458521994557. Epub 2021 Feb 16. PMID: 33591218.

[7] See more of the study here https://www.msaustralia.org.au/news/tracking-work-productivity-of-people-with-ms/

Work change and transitions are therefore common amongst individuals with chronic illnesses such as MS. [8]

Case study

Justin approached the MS Employment Support Service (MS ESS) after a period of unemployment. He had been unable to sustain working as a real estate agent due to cognitive symptoms associated with his MS. Justin's MS did not impact his physical capacity other than issues with heat sensitivity. Justin was assisted by MS ESS with a subsidy for a Traffic Controller course and a specialised cooling vest. He is now successfully working in a new industry.

The severity of symptoms was associated with the level at which productivity at work was affected. Deterioration and the experience of fatigue, changes in cognition and physical functional impairments have a powerful impact on the probability of continuous employment. [9]

Males, people with progressive MS, those with a lower education level and those older at diagnosis were at a higher risk of leaving their employment due to MS, suggesting that they may need additional assistance to stay longer in the labour force. [10]

2. Simplifying Entry and Assessment

MS Australia recommends:

1. Entry and assessment should be based on participant choice and goals - addressing any barriers to achieve these employment goals. Long term support is often required to address these multiple barriers and flexibility is thus needed to facilitate long term outcomes.

2. For those in need of medical evidence to support Work Assist eligibility, the reality is that access to medical specialists and health care professionals is not always achievable in the 13-week period (as stipulated in the guidelines), either due to waiting times or geographical availability. Such restrictive time frames should be removed and not add to the barriers to their employment goals.

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[8] Vijayasingham L, Jogulu U, Allotey P. Chronic illness and sustainable careers: How individuals with multiple sclerosis negotiate work transitions in a middle-income country. Soc Sci Med. 2020 Jan;245:112699. doi: 10.1016/j.socscimed.2019.112699. Epub 2019 Nov 23. PMID: 31785425.

[9] Kobelt, G., Langdon, D., & Jönsson, L. (2019). The effect of self-assessed fatigue and subjective cognitive impairment on work capacity: The case of multiple sclerosis. *Multiple sclerosis (Houndmills, Basingstoke, England)*, *25*(5), 740–749. https://doi.org/10.1177/1352458518769837

[10] Chen J, Taylor B, Blizzard L, Simpson-Yap S, Palmer AJ, Kirk-Brown A, Van Dijk P, van der Mei I. Risk factors for leaving employment due to multiple sclerosis and changes in risk over the past decades: Using competing risk survival analysis. Mult Scler. 2021 Jul;27(8):1250-1261. doi: 10.1177/1352458520954167. Epub 2020 Sep 3. PMID: 32880529.

3. Addressing the systemic registration difficulties of moving someone out of DHS or Services Australia (including those already registered online) to a DES type service.

4. Re-assessment or change of circumstances should not be limited to medical changes only, but should be all encompassing and holistic, taking into account social, family changes and psychosocial needs.

5. Allowing those with MS completing Job Capacity Assessment (JCA) to be referred to a specialist provider to complete a targeted ESAt by broadening the pre-listed conditions to include MS.

6. DES entry and assessment should focus on a person's career pathway and not just on securing a job. People will have different needs at different stages in their career. An individualised approach is needed to deal with, for example, a wish to disclose to an employer, or not taking into account the specific individual disability/condition (including episodic illness) and the resulting impacts on work capacity and sustained employment.

Value of specialist disability employment assessments:

Having access to a Disability Employment Service that provide a specialist approach to assisting people with MS to seek, transition or maintain employment is crucial in supporting the MS-specific cohort. The specialist experience and assessment skills of registered allied health professionals in our MS employment services, who truly understand and know how to support people with MS and other neurological conditions, are evidenced in the calibre of assessments but also the long-term outcomes achieved.

The value-add brought by a highly skilled, tertiary qualified allied health DES workforce with specialised experience in treating and working with people diagnosed with MS, is multi-fold.

People with MS seeking disability employment support are vastly different to the general DES population. As one of our front-line workers explained:

> '*We assess and ask about all symptoms that may impact a person with MS. Coming from an allied health background as well as being specialist in MS, we are often more aware than the person living with MS of symptoms and how they might impact. By exploring all possible symptoms & using a holistic approach, we often identify barriers that a participant hasn't even realised is impacting their life and work. For example, we may ask a participant if they have noticed a pattern around when they get fatigued and through this exploration we are able to identify that they are experiencing the symptom of heat intolerance. This is particularly relevant as many clients come to us newly diagnosed and often unaware of all the symptoms or functional impacts of MS as prior consultation with neurologist/s has been primarily medically focused.*'

The main reason for accessing employment support is not wanting to seek employment, but rather wanting support in continuing to do the jobs they want to do.

In contrast to the cohort accessing support through Centrelink or through online supports, specialist employment support provides assistance, utilising expertise in understanding MS. This is achieved through specialist assessments by a registered allied health professional that can assess work capacity and work practices, determine the need for modifications and work alongside employers (where there is disclosure) to assist people with MS to continue working in the jobs they prefer to work in.

Case study

John is a gardener/groundskeeper. Initially he was a jobseeker and he presented as a Post Placement Support client after he had acquired a role with the assistance of the Employment Development Consultant. The ESC completed an initial assessment with John and through discussing the impact of his MS symptoms on his employment during this assessment the ESC was able to create a plan for support.

John experiences significant functional impairments including muscle weakness, muscle spasticity (possibly contracture), muscle atrophy, foot drop and this results in difficulties with balance and mobility. Prior to speaking with the ESC, John had not had a Physiotherapist Assessment and had chosen to adapt how he did activities or cease participating in activities. One of the first actions taken was to setup an Initial Assessment with the MS Physiotherapist to assist with prescribing an individualised exercise program, prescribe mobility aids and to assist with applying to the NDIS. The MS ESS funded the Initial Assessment and subsequently funded an Exercise Physiologist Initial Assessment and now weekly EP gym sessions. These sessions help him to maintain his functional capacity for work by reducing the impact of his functional impairments.

Through formal assessments as well as ongoing discussions and through regular contacts, John and the ESC have also been able to identify workplace modifications that would assist him to reduce the impact his MS symptoms have on his ability to complete his duties. By accessing JobAccess funding the MS ESS has assisted in acquiring lightweight equipment such as a lightweight leaf blower and whipper snipper to reduce the impact of John's muscle weakness, fatigue (both neuromuscular and lassitude) as well as mobility and balance difficulties. They have also identified that John would benefit from a utility vehicle (similar to a golf buggy) at work to assist with reducing his need to carry his work equipment around his workplace for long distances as this would exacerbate his fatigue and mobility difficulties. This is just being purchased now after several work trials over 6 months and ESC making a submission to Job Access.

The MS specialist employment support team can assist with symptom management, consideration for domestic supports, aids and equipment assessments and procurement, and vehicle and office modifications, drawing on a range of referral pathways including health networks, MS Clinics, DES, NDIS and other funding sources. The value proposition for specialist disability supports can clearly demonstrate the economic and individual benefits over the short, medium and long term for both employees and employers.

Case study

Jennifer is an Executive for a large multinational organisation and lives with Secondary Progressive MS (SPMS) which creates the following barriers and symptoms to employment:

- *Foot drop requiring use of a functional electrical stimulation orthotic, walking stick and mobility scooter – reduced mobility limits her ability to attend networking and conferences and undertake travel*
- *Muscular weakness in lower limbs, stiffness and pain*
- *History of optic neuritis impacting visual fatigue when working on a screen*
- *Fatigue impacting endurance physically and cognitively – needs to pace herself throughout the workday and can impact productivity*
- *Sensory changes are distracting when trying to concentrate*
- *Dexterity / fine motor changes impacting typing accuracy*
- *Reduced confidence in ability and emotional / mood impacts*
- *Neurogenic bladder requiring daily management and for a period caused regular infections resulting in regular sick leave.*

She is a mum of two kids (ages 13 & 15) and lives with her husband. She was referred to the MS ESS through her MS Nurse at a major MS Clinic to assist with sustaining her ability to work as Jennifer was considering whether she could continue to work at such a high level given her recent change in her disease course from RRMS to SPMS. A specialist MS employment assessment was completed; a holistic allied health assessment looking at all possible symptoms which result in barriers to employment as well as whole of life factors.

Through weekly contacts an ESC Occupational Therapist has been able to provide a wide range of support and advice to put in place strategies to improve and maintain work capacity. Due to her working full time and cognitive fatigue, phone and face to face contacts were often followed up with a detailed email which allowed her to refer to earlier discussions.

Interventions and support and advice provided since registration in 2018 has enabled Jennifer to not only retain her employment but increase her hours from part time to full time and build her confidence to apply for a promotion which when she first registered with MS ESS, she didn't think she could possibly do due to the recent SPMS diagnosis.

Interventions and support provided by ESC who has a specialised understanding of MS and is an occupational therapist has included:

- *Meeting with the employer to provide education on MS and discuss reasonable accommodations including putting in place a working from home arrangement and making changes to the building to improve access. Employer was reassured that ESS can assist in funding equipment to enable Jennifer to work from home*
- *OT assessed equipment needs to improve fatigue management at work through more specialised ergonomics as well as assisted in trials of appropriate mobility aids*
- *Recommendation referral and assistance with seeing a psychologist trained in grief and chronic illness*
- *Recommendation referral and assistance to see a myotherapist to minimise the impact of pain and stiffness on productivity when working*
- *Referral to continence nurse and liaison to aid in holistic management of condition & help Jennifer implement strategies recommended by Continence Nurse*
- *Referral to neuro physiotherapy MS Pilates group for maintaining physical capacity*

- *Assistance to apply for the NDIS to ensure supports to maintain health and wellbeing were considered as well as assistive technology for mobility in the community, continence aids etc*
- *Coaching conversation to build confidence in work capacity / advice to address disability barriers considered when applying for a promotion at work and ways to manage fatigue in full time work when previously working part time.*
- *Advice to use dictation options to overcome fine motor issues when typing*
- *OT fatigue management strategies and sleep hygiene assessment*

Case study

[Example from an Ongoing Support Assessment (OSA) report by a National Panel of Assessors (NPA)]

John confirmed his permanent part-time employment for a large disability Not-For Profit Organisation, noting that he was presently working from home due to the COVID lockdown restrictions.

On explanation of the role and the purpose/possible outcomes of the OSA, John indicated a desire to remain a MS ESS client and was happy with a recommendation of the moderate level of funding as he did not believe he could commit to weekly contact given the busyness of his work and life.

He was very complimentary of his DES provider's services to date and especially praiseworthy of his DES consultant's expertise and determination. In reference to EAF & NDIS applications, he noted that without help, he would have just given up. He valued his DES consultant's advocacy as well as her advice re ongoing symptom management and workplace modifications and aids which, he said, has made the world of difference in his being able to operate effectively at work. He could not wait until his power assist lightweight wheelchair (it can be folded up and lifted into the work vehicle, used manually or electrically) arrived from overseas as it would really assist him to get around at work in the future. He was also looking forward to having regular remedial massage treatment once allied health practitioners were allowed to open up again; from past experience he said it made a real difference with his flexibility and stamina for work. John also expressed gratitude for help accessing the NDIS; he now had a plan that was being put into effect with linkages to an OT, exercise physiologist and dietitian which will all help with maintaining work effectiveness going forward.

3. Most helpful services and supports

MS Australia recommends:

1. The most helpful services and supports can only be achieved through person-centred and flexible delivery models. We recommend an individualised, tailored approach to the delivery of services and supports that promotes cross sector collaboration to achieve individual goals of sustained, long term employment outcomes.

2. Delivering rapid access to targeted services and supports with dedicated follow-up coaching, coordination and collaboration across a range of sectors and services, to ensure strong employment outcomes can be achieved.

3. Patient choice should be taken into account in the modes of support preferences (phone, online, face to face, email) and was as the pre-agreed regularity of these contacts. The type and frequency of contacts should not be restricted by claiming/compliance guidelines.

4. Less red tape will produce efficiencies in waiting times and will allow for continuity of service to DES participants.

5. Fund specialist DES providers appropriately and at the level of the registered employees they employ, aligned with the outcomes they achieve. Specialist providers with established resources and expertise facilitate and coordinate condition specific measures and supports that not only boost employability but provide a holistic approach to participants. Specialist providers draw on established networks of vocational, tertiary education partners and a network of services (including disease-specific allied health supports, housing and other community and social supports) that see participants as a whole, not only as an employee.

6. DES participants should have similar access to training, programs (i.e., CTA and Employment Skills) and service enhancements (i.e., apportioning calculator). These supports should be standardised across all programs.

7. Online information on various programs, rules and requirements should be made available in easy-to-understand language and through other accessible platforms. System navigation, understanding and usability of information is still reliant on front line staff explanations and time. The capacity building element of DES supports is not currently acknowledged in incentives or financial remuneration. This is particularly a need of those living with fluctuation or deterioration in cognition.

Example of MS ESS client feedback

I would like to take a moment to express my gratitude for your support and support of the Employment Support Service.

I have become dependent on our weekly connect sessions as they work so well at keeping me independent. Your knowledge and advice have been instrumental in assisting me to manage full time employment with a very heavy workload, managing fatigue, and managing my memory and cognitive challenges.

Accepting and acknowledging MS symptoms is a big step after diagnosis and how to manage the symptoms you experience is almost overwhelming. Your support and guidance have enabled me to continue work with confidence, pivot my activities when I need to and manage the impacts of my symptoms.

> *As you know I am a keen cyclist and keeping my fitness is important for my mental health also. It has been a new world on how to manage my efforts on the bike without exhausting myself for the week. Thanks to your advice on heat management and physical activity I continue to ride before work and then complete a full day's work. The early morning exercise has played an important role in maintaining happiness and positive attitude and the cool vests assisted me to maintain a comfortable temperature during work during the summer.*
>
> *You have also been encouraging of engaging other services such cognitive screening and digital solutions to assist me with my cognitive deterioration and managing employment*

Person-centred and flexible delivery models

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[11].

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.

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.

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

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.

Case study

Mr X was employed as a qualified Horticulturist who was diagnosed with Relapsing Remitting Multiple Sclerosis in July 2014. He connected with the MS ESS team in July 2017 to receive support and education about MS and how he could manage his work and home life with the degenerative neurological diagnosis.

He is a dad of two young children (ages 7 and 5) and lives with his wife who works full time in education at Wollongong University. Mr X was referred to the MS ESS team through MS Connect to assist with support in managing his symptoms and maintaining his full-time employment role. We completed a specialist MS employment assessment over a period of 4 contacts to gather information about Mr X, his background and the impact of his MS symptoms on his everyday life.

As an Occupational Therapist Employment Support Consultant (ESC), this assessment is very thorough covering areas including; clients background details, medical treatment and interventions being used, contacts of Mr X's treating team, specific details of each MS symptom Mr X experiences and their impact on daily life both at home and at work, supports already in place for Mr X, physical limitations due to the MS symptoms, psychosocial and emotional impacts of the MS diagnosis and symptoms, work duties and expectations, interactions with Mr X's employer about the diagnosis and any other relevant information that Mr X feels will impact him in the future.

This information is then detailed into a report which Mr X could share with his treating team or employer as required. The information is also used for all subsequent contacts with Mr X and developing a plan to assist and provide support for Mr X within the ESS program.
Mr X expressed a goal to remain in his current employment as a Horticulturist working for the local Council. However, he was also interested in learning about alternative roles that he could pursue in the future as the current role was very physical and he was unsure how long he would be able to remain safe working in this field.

The barriers and symptoms which impacted his ability to retain his employment full time included:

- *Fluctuating fatigue levels which created both muscular and cognitive changes impacting Mr X's productivity at work*
- *Physical limitations including sensation changes in his lower limbs, difficulty with heavy manual labour and problems with balance and coordination*
- *Long distance commute into work or to various sites within the council area causing increased levels of fatigue*
- *Difficulty managing in the heat – impacting and increasing all of his MS symptoms*
- *Difficulty and concerns about how he will maintain this physical role in the long term.*

To address these barriers, we implemented the following supports:

- *Education with Mr X about MS and how managing the symptoms of MS can support Mr X to continue to live the life he wants*
- *Discussion with Mr X about alternative work options that he might be interested in and follow up with options for future study programs that could add to his current profession*
- *Discussion with the employer and his colleagues about rotating roles including driving and heavy labour between the team to reduce the pressure on Mr X to manage these tasks every day*
- *Discussion with Mr X's team about changing work routines to reduce the impact of the hot weather on Mr X's fatigue levels – this included doing heavy tasks early in the morning, breaking indoors over lunch, finishing early after a heavier workday.*
- *Assessment and prescription of light weight work boots to reduce fatigue levels whilst working on site.*
- *Assessment and recommendation of cooling garments (hot, scarf and vest) to use in the hot weather.*
- *Assessment and prescription of sensory input innersoles to assist with providing feedback to Mr X's feet whilst working throughout the day.*
- *Review of Mr X's ability for learning when discussing alternative roles.*
- *Support and education to encourage Mr X to complete a Certificate in OHS coordination.*
- *Support and education for Mr X in applying for alternative roles. Mr X transferred into an Administrative Internship at the University of Wollongong in 2018.*
- *Assessment and application to Job Access (EAF) for funding for a home office set up to allow Mr X to work from home 1-2 days per week to reduce his overall fatigue levels. This included an ergonomic chair, monitor, keyboard and mouse.*
- *Support and review of application to transfer into the Work Health and Safety team at the completion of his internship.*
- *Further support and discussion around applying to study in 2022 to gain further qualification in OHS to be able to manage the team into the future.*

Mr X is contacted weekly by the Occupational Therapist ESC who discusses any new concerns for Mr X, how previous interventions are being used to manage Mr X's symptoms, and looking forward to any future changes that may arise due to Mr X's situation and MS. It is important that this contact is completed by the same ESC to develop rapport and connection with Mr X and maintain open communication to ensure support is provided at the right time.

As a result of engaging with our service Mr X has been able to be employed on a permanent full-time basis and has been able to move from a very physical role, into more administrative roles using his training and education that he has completed with support whilst being on the ESS program.

4. Supports for Young People

MS Australia recommends:

1. Current boundaries in Grant Agreements prevent specialist DES providers from reaching out or supporting young people in education (TAFE, University) or apprenticeship placements. System policy should acknowledge and remedy the current gap between DES provider's ability to advise and support young people who are outside the NDIS or who are in employment placements, including TAFE, apprenticeships or tertiary study who are in need of specialist DES supports to either plan for, obtain or maintain employment. This gap between young people engaged in education and DES provider's ability to advice and plan with young people on future career pathways should be recognised and policy adjustments should accordingly be made.
2. Young people who do not achieve eligibility to the NDIS but live with significant functional impairments as a result of their MS are missing out on specialist DES supports and services.
3. Generalist approaches to employment support do not work for people with complex neurological diseases such as MS. This also applies to young people living with this chronic disease.
4. Delaying young people's ability to access appropriately matched specialist supports from a DES provider until they have left their educational placements place young people living with MS at a disadvantage.
5. Building employment skills, experience and confidence of young people with disability should not be delayed. People (including young people) living with MS often need confidence and support to disclose their MS diagnosis to their workplace. Others may need additional support to take their career in a different direction where the progress of the MS symptoms makes undertaking work difficult or impossible.
6. Young people should be given a similarly tailored and individualised approach to their employment support and should be made aware of specialist support services such as MS ESS.

7. Changes should be made to broaden the apprenticeship framework allowing for remuneration (wage eligibility) for young people living with disabilities during their apprenticeship period and current time restrictions for completion should be more flexible for *those participants living with a disability.*

Case study:

Melita was diagnosed with relapsing-remitting multiple sclerosis in 2008, a year after her first son was born and right in the middle of her PhD. Through perseverance and meticulous organisation to work around cognitive fog, fatigue and nerve pain, Melita completed her PhD and embarked upon a career in academia – a career that's thriving despite ongoing health difficulties. But life is all about balance, and she could see it slowly getting away from her.

"I've used MS services since my diagnosis, including education sessions and webinars and even a Go for Gold scholarship during my studies, which allowed me to purchase a new laptop I desperately needed," she says. "But that was a few years ago now, and since then I've been ploughing my way through work and family life, fitting it all in but sometimes not really coming up for air.

"We recently built a new home, which was exhausting, and by the time we moved in I found myself wondering where 18 months had gone. "I work across several locations and travel frequently, and the visits to collaborators or conferences can be particularly fatiguing, which sometimes affects the time I should be enjoying with my family. That fatigue often rolls over into several days, which affects my capacity to work.

"I'd heard about the MS Employment Support Service, so I thought I've give them a call for a chat about my work situation and to get some advice on how I could manage it better."

That phone call led quickly to MS Employment Support Service consultant Leigh visiting Melita at home, assessing her situation and assisting her to access Employment Assistance Funding to purchase workstation equipment to enable her to work remotely. "I'd tried working from home before, but without dual screens for my laptop, it just wasn't possible to be as productive as I need to be,"

Melita says. "I work two days a week from home on average now, which means several hours' less commuting as well as saving time and energy used just to get ready to go into the office.

"I have more time and energy with the family, and because of the workstation, and also because people don't interrupt me, I'm often more productive at home than I am in the office!"

The MS Employment Support Service has also organised support to get Melita into exercise classes, purchased some cooling clothing and recommended phone applications that will help her organise her work and schedule.

One phone call helped Melita restore the balance in her hectic life "One of the things I struggle with is asking for help," Melita explains. "When you're doing OK outwardly, there's a guilt that can come with seeking assistance from an organisation like MS, where you tell yourself there are other people in harder situations that need more help than you, and you don't want to get in the way of that. "This perception is actually unjustified, though. Through my contact with MS, they've made it clear that they're there to help anyone living with multiple sclerosis at any time, no matter how well or otherwise they're travelling.

In fact, getting support at an early stage like this often helps keep us well. "Also, the help the MS Employment Support Service has given me now will allow me to work better, and for longer. If I'd just kept at it and been stubborn, what good would that stoicism have done anyone if I burned myself out, or my husband and kids weren't getting the best of me?"

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

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.

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/

We seek to ensure employers understand the benefits of employing people with disability such as those set out on page 7 of the National Disability Employment Strategy Consultation Paper where the findings of the Diversity Council of Australia are provided[12], 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.

5. Supports for Employers

MS Australia recommends:

1. Improve synchronicity between various programs for employers (i.e. wage subsidy) and create equity in recruitment by allowing DES providers to provide advice and information to employers that will allow applicants with a disability to be on an equal footing to other applicants.

2. Extend financial incentives beyond the application process i.e., allow for work trials that will allow DES staff to work with employers to see the advantages and benefits of employing someone with a disability and become 'diversity champions'.

3. Build more awareness around the value of diversity in the workplace and employing someone with a disability. This could be facilitated by extending access to various current publications and resources such as Local Jobs Program, Labour Marker Information Portal and Parents Next to DES providers. This equity change will provide DES services an opportunity to promulgate the value of diversity employment on a regular basis and provide case examples to evidence this point across programs.

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[12] https://engage.dss.gov.au/wp-content/uploads/2021/04/national-disability-employment-strategy-consultation-paper.pdf

4. Appropriately fund specialist DES providers for their employer engagement activities delivered by experienced highly qualified (and registered) allied health professionals, including:

    a. Building awareness and explaining DES supports and advantages of employing someone with a disability to individuals and groups of employers and staff
    b. Effective coordination of workplace modifications often having to work within local authority guidelines, OHS considerations and specific building regulations
    c. Delivering of long term IWS for participants and employers.

5. Increased national public awareness campaigns on employing someone with a disability or highlighting the benefits of engaging with a DES provider. This should include the development of various resources (video, printable, online, podcast, webinar) options. MS Australia would very much like to assist in the creation of these resources, the provision of case examples that demonstrate good practice but also how specialist DES supports benefit both participant and employer.

Benefits of MS-specific networks and referral pathways for employers

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.

Employers benefit because they can keep employees that they have already invested in heavily and who have gathered valuable corporate knowledge, skills and experience. It also avoids expensive recruitments expenditure in trying to find someone with a similar skill set and who would match the workplace culture.

Unfortunately, there are still perceived barriers in hiring someone with a disability in our Australian community. Additional resources should be invested to change negative attitudes to disability and to improve employer knowledge about the employee’s condition and job capabilities.

Case study

Jack was working in corporate insurance sector, due to the impacts of MS fatigue and the stress associated with this type of work he approached MS ESS for advice and assistance around changing careers to the community / disability sector. MS ESS provided advice on suitable courses included NDIS short course, Cert IV Disability which Jack undertook. MS ESS provided Jack assistance with his CV and job applications and he has now successfully maintained 52 weeks in his new career as a Mental Health Care Worker.

An MS ESC OT has provided advice and assistance to Jack to address any barriers to employment he has had as a result of his MS symptoms, including cooling attire for when working in the community in summer, assessment of his foot drop impacting mobility and advice on suitable aids, assessment of cognitive fatigue issues associated with documentation aspects of his new role and an EAF Job Access application for an iPad to use as a memory aid during the work day rather than having to remember everything to the end of the day.

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.[13] Disclosing a diagnosis of MS at work can be a daunting experience and there is no easy answer nor straightforward advice.[14] 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

Organisational responses to disclosure demonstrating trust and inclusive decision making, and focussing on employee abilities, enhance perceptions of psychological safety at work. This increases the likelihood that employees with MS will retain their sense of work-efficacy and reduce their intentions to leave.

Contrary to what many people may expect, research findings 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

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

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

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.[15],[16]

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.

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.

Case study

Mrs X is employed as a School Administrative Office Manager who was diagnosed with Relapsing Remitting Multiple Sclerosis in January 2020. She connected with the Multiple Sclerosis Limited Employment Support Services (ESS) team shortly after her diagnosis and first relapse to receive support and education about MS and how she could manage her work and home life with the degenerative neurological diagnosis.

She is a mum of two kids (ages 18 and 15) and lives with her husband Mr X who works full time running his own construction business. She was referred to us through MS Connect to assist with support in managing her symptoms and maintaining her full-time employment role. We completed a specialist MS employment assessment over a period of 4 contacts to gather information about Mrs X, her background and the impact of her MS symptoms on her everyday life. As an Occupational Therapist Employment Support Consultant (ESC), this assessment is very thorough covering areas including; client's background details, medical treatment and interventions being used, contacts of Mrs X's treating team, specific details of each MS symptoms Mrs X experiences and their impact on daily life both at home and at work, supports already in place for Mrs X, physical limitations due to the MS symptoms, psychosocial and emotional impacts of the MS diagnosis and symptoms, work duties and expectations, interactions with Mrs X's employer about the diagnosis and any other relevant information that Mrs X feels will impact her in the future.

This information is then detailed into a report which Mrs X could share with her treating team or employer as required. The information is also used for all subsequent contacts with Mrs X and developing a plan to assist and provide support for Mrs X within the ESS program.

Ms X expressed a goal to remain in her current employment as the School Administrative Office Manager. She was however faced with barriers and symptoms which impact her ability to retain her employment full time. These included:

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

[16] 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

- *Fluctuating fatigue levels which created both muscular and cognitive changes impacting Mrs X's productivity in her role*
- *Difficulty with mobility in a school environment with multiple stairs*
- *Regular commute into the office causing increased levels of fatigue*
- *Difficulty managing in the heat – impacting and increasing all of her MS symptoms*
- *Difficulty managing the household tasks such as cooking, cleaning and transporting children to after school activities as her fatigue levels are high after working a full day at school*
- *Lack of understanding from her colleagues who expect her to maintain the same high-level output as she has been at the same school for over 5 years.*

To address these barriers, we implemented the following supports:

- *Education with Mrs X and her husband about MS and how managing the symptoms of MS can support Mrs X to continue to live the life she wants.*
- *Discussion with the employer to determine that Mrs X could reduce her full-time hours to working a 4-day week, having a day off to manage appointments and intervention session with a Physiotherapist and Exercise Physiologist.*
- *Discussion with the employer to allow Mrs X to work one day per week from home to reduce the commute to and from the office.*
- *Assessment of Mrs X's home space to apply to Job Access (EAF) for provision of a home office including ergonomic chair, desk, monitor, keyboard and mouse. Also application and installation for air conditioning within the home office space through Job Access (EAF) to allow Mrs X to manage her heat intolerance whilst working from home.*
- *Presentation at the school to Mrs X's colleagues about MS – its symptoms and impact on Mrs X. This allowed open discussion with the school staff and enabled Mrs X to feel understood about her condition.*
- *Support to apply for the Mobility allowance and Disability parking – allowing Mrs X greater capacity and independence in the community.*
- *Support to apply for access to the National Disability Insurance Scheme (NDIS) – including assessment and report as a treating Occupational Therapist to use as evidence in her application.*
- *Support to connect with providers using her NDIS funding once received – cleaning support, support workers and Allied Health professionals.*
- *Recommendations to an NDIS funded Occupational Therapist who was able to support Mrs X with the following – Apple watch (to increase independence and safety for Mrs X to go walking herself in the community), modifications to her kitchen and laundry space, and funding for an electric bike to participate in leisure activities with her family.*
- *Funding to attend a 6-week fatigue management course run through MSL to support education about how to manage Mrs X's fatigue levels.*

Mrs X is contacted weekly by the Occupational Therapist ESC who discusses any new concerns for Mrs X, how previous interventions are being used to manage Mrs X's symptoms, and looking forward to any future changes that may arise due to Mrs X's situation and MS. It is important that this contact is completed by the same ESC to develop rapport and connection with Mrs X and maintain open communication to ensure support is provided at the right time.

As a result of engaging with our service Ms X has been able to be employed on a permanent part-time basis in her School Administrative Office Manager role providing her with support to maintaining her MS symptoms both at work and at home.

To learn more about what employers think about specialist DES providers such as MS ESS, please visit https://youtu.be/G5eRBnYvkwo.

One of the MS ESS front-line employment staff members observed:

> *"Employers are often reassured that we are involved in ongoing to support to the participant. It might be that we only meet with the employer once in the beginning for initial disclosure/ negotiating reasonable adjustments. They appreciate the help to put in place support for their employee and knowing that the participant has help in this area often behind the scenes into the future."*

6. Tailoring Mutual Obligation

MS Australia recommends:

1. Allow a sequence of employment activities and roles to contribute to participant knowledge, experience, networks and commitment to sustainable career pathways. Voluntary and community work are valuable opportunities for those struggling to access or maintain sustained employment to remain connected to the employment market. These activities bolster self-worth and meaning, but also often develop into career pathways that might identify suitable training opportunities or work placements that can lead to longer term employment outcomes.
2. MS Australia supports improved clarity and simplicity in reporting for both participants and employers.
3. Mutual obligations should not be completed indeterminately. At some point, a policy trigger should occur to refer participants who do not quite fit this 'one fits all approach', to more intensive or specialised supports. In the long term, this approach will provide obvious economic outcomes.
4. People with episodic conditions such as MS (similar to those living with psychosocial changes) often have difficulties attending appointments, job searches, interviews and being able to comply fully with Job Plans due to changes in their symptoms or their experience of exacerbations. These frequent change of circumstances do not quite fit DSS commitments, require medical certification and often result in demerits or penalties. Clearly this revolving door of failing obligations, reporting, initiating demerits or penalties will not deliver sustainable long-term outcomes for this cohort. A more specialist approach is needed. Previously, we advocated to add MS to the pre-listed conditions as an ESAt trigger. The benefits in relation to Mutual Obligations are clear. Having a specialist MS ESS supporting people in receipt of benefits would have definite improved, sustainable and longer-term outcomes than restricting someone within a more generalist employment pathway.

MS and Benefits Payments

One in six people with a disability lives in poverty according to an ACOSS/UNSW report in 2018[17]. These numbers are likely to be under-estimations as the report did not adjust for additional costs resulting from living with a disability day to day i.e., modifications at home, personal support and care, medical and pharmaceutical expenses and additional transport costs.

Although there are safety nets, such as the DSP or JobSeeker payments and some people living with disability do maintain some level of employment, "people with disability generally have a lower level of personal income than people without disability. Having a person with disability living in the household is also associated with lower levels of household income." They are also more likely to experience poor health, discrimination and violence than those without disability.

Roughly three times as many women have MS as men. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

Although MS Australia represents a very small part of people in need of DSP, for those effected by the current DSP process, the impacts are profound. DSP is seen the last resort, a sober point of facing up to the irreversible impacts of MS - and not something anyone wish upon for themselves or their families.

In 2017, the average cost of MS per person was $68,382 (comprising both individual and societal costs.) - similar to that of someone with Parkinson's disease or the first year after a stroke, triple that of a person with type 2 diabetes. The societal and individual burden of disease for MS, in comparison to other disease and disability types are high. For those lucky enough to qualify for DSP, the feedback was clear that the support does not meet the day to day living expenses for someone living with ill health, a chronic condition or a disability associated with multiple sclerosis. More worrying, those unable to meet the eligibility criteria of DSP have to survive on other benefit types which have already been criticised broadly for being inadequate for those living with full health.

Widely published reports of DSS demographic data, indicate that receipt of the DSP has been declining over time, largely because of changes to eligibility criteria that have reduced the number of people successfully claiming the payment. This results in more people on JobSeeker payments.

Feedback from applicants diagnosed with MS indicates that, even if successful, they will have their claim rejected several times; they are often exasperated by the application process which takes a considerable psychological toll.

Published reports and anecdotal feedback indicates that:

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[17] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/employment-rate-and-type

- **The application process for DSP is too complex**[18,19,20]. Despite the necessity of the DSP for those unable to work due to their increasing disability and functional impairments, successful applications are notoriously hard to achieve. Many applicants are simply overwhelmed by what is required of them.

- **The application process for DSP takes too long**[21]. An average claim can take anything from 6-18 months to complete.

- **During this process time, applicants receive a lower payment** which is totally inadequate even for those living without the burden of a disability[22], sentencing people with disabilities and their carers and children to a life of poverty – removing their choices, rights and inclusion.

Medical eligibility is currently based on evidencing how a condition or disability affects a person's ability and capacity to work. To meet the eligibility criteria, applicants must demonstrate that they have a 'fully diagnosed, treated and stabilised condition'. For a condition to be accepted as ***fully*** *diagnosed*, the diagnosis must be made by a qualified medical practitioner. Most people with MS are diagnosed by a specialist MS Neurologist.

DSP applications, however, require supporting evidence from other treating health professionals to evidence if the condition is *fully treated* or if 'reasonable treatment or rehabilitation has occurred'. The assessment considers the success rate, where "substantial improvements are expected, the effectiveness of past treatments and any plans of future treatments, including the duration of waiting lists". A condition should also satisfy the criteria of being '*fully stabilised*'. Other than a six-page, small print explanatory *Medical Evidence Checklist* for treating health professional (SA478) there are no proformas to guide health professionals to support and meet these requirements.

MS Australia believes that these criteria are often misunderstood by people assessing claims, leading to rejection of claims even though the person's condition will not change. The complexity and unpredictability of MS does not align with 'fully diagnosed, fully treated and fully stabilised'. Having a progressive, degenerative, episodic, chronic and often "invisible" disease should not make people ineligible to apply for the DSP. More so, this should not prevent someone from accessing specialist DES supports such as MS ESS.

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[18] https://www.nssrn.org.au/advantages-of-having-a-lawyer-handle-social-security-disability-cases/

[19] https://www.ejaustralia.org.au/wp/social-security-rights-review/disability-support-pension-fresh-pro-bono-lawyer-insights-from-hall-and-wilcox-volunteers/

[20] https://www.papergiant.net/projects/dsp-help

[21] Social Security Rights Victoria https://papergiant.net/work/dsp-help

[22] https://www.abc.net.au/news/2019-09-12/disability-support-pension-applicants-diverted-to-newstart/11486164

The **Program of Support** [23]is required for those ‘not manifestly medically eligible’ and ‘their condition attracts a total of at least 20 points under the Impairment Tables’. Applicants must show they are actively participating in this program *for at least 18 months in the 3 years before their claim.*

The DSP applicant has to attend a designated Program of Support Provider, who would provide them with vocational, rehabilitation or employment services with a particular focus on developing skills the person requires to improve the person's capacity to prepare for, find, gain or maintain work. “Any periods during which a person who started a POS does not participate in it for any reason (including when they are exempted on medical or any other grounds, are suspended from the program or are in the period of relief from the program) do not count as participation in a POS” (DSS Guide 1.1.A.30). This is particularly problematic for people with MS who live with unpredictable and episodic changes to their symptoms and functional capacity, often causing further delays in their application process.

The Program of Support in its essence deters successful DSP applications – creating hurdle after hurdle - unnecessarily prolonging the time to complete an application for DSP. The Program of Support, especially and specifically, is causing many people, including those living with MS, to miss out.

Case study:

Mandy Hunwick used to love going to work, but then it all became too stressful.

Her vision became blurry, she couldn't remember simple tasks and became increasingly fatigued.

The 42-year-old was eventually diagnosed with MS, along with auto-immune arthritis and vasculitis, a disease that restricts blood flow.

Ms Hunwick was forced to leave her job at a Queensland government department and applied for the Disability Support Pension (DSP).

"I thought that it was going to be a short, easy process," she said.

"It took 17 months. And I had to fight for it. I literally went through hell just trying to get it. And it caused me to almost want to kill myself," she said.

She applied for the DSP in January 2018, providing Centrelink with statements from doctors and occupational therapists.

Eight months later, she was rejected. She applied for a Centrelink review and her application was turned down again.

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[23] https://guides.dss.gov.au/guide-social-security-law/1/1/a/30

"To be told you're not disabled enough when you can barely get out of bed some days, you can't understand how somebody can judge you that way," she said.

While applying for the DSP, Ms Hunwick received a Newstart allowance but a medical exemption meant she didn't have to search for a job.

Ms Hunwick is one of a record number of people with disabilities being put on Newstart payments, with Centrelink having denied their applications for the more generous disability support pension.

Ms Hunwick's application was overturned by the Administrative Appeals Tribunal in June 2019, which effectively ordered Centrelink to approve her for the DSP.

"Why would you want to make it so hard for somebody who's already living such a hard life?" she said.

Case study:

Rachel Park knows all about those additional costs, after being diagnosed with an aggressive form of MS in 2017.

Her symptoms include severe fatigue, muscle pain, blurry vision, memory loss and partial paralysis on the left side of her body.

Like Ms Hunwick, the 24-year-old also thought it would be straightforward when she submitted her DSP application to Centrelink.

"I kind of assumed that they were going to be medical professionals. But they are not," she said.

Her application was rejected and she was put on Newstart.

"I have to go see Disability Employment Services every fortnight and I have to do a job plan and apply for a certain amount of jobs per month," she said.

To meet her Newstart requirements, she sends online inquiries to employers and said she rarely gets a response.

Finally, after 1) a person meets the medical evidence criteria, 2) the impairment tables rating and 3) has successfully completed the program of support criteria, the next hurdle is to prove that they have a continuing inability to work. According to Centrelink advice, an applicant meets this requirement after medical evidence demonstrates that the person is ‘unable to work, or be retrained for work, within the next 2 years because of impairment’. For the purpose of assessment, ‘work ‘includes at least 15 hours per week at or above the minimum wage and if the work exists in Australia, “even if not within the person’s locally accessible labour market” - 15 hours work per week is a sentence to poverty and not sustainable.

From our feedback sought from our members and the MS community, it was also evident that improvements are needed in the way the DSP program communicates its process of application and decisions to applicants and those seeking to support applicants in the process. Our MS community often does not fully understand what information they have missed, what further evidence do they need to provide or how they can ensure their evidence meets the requirements of the application process – because this is not adequately communicated to them.

DSP information should include what the DSP is; how to apply; proformas and templates for all conditions and clear guidance on why an application was not successful and what can be done to improve future applications. Communications that enable individual and systemic capacity building.

7. Funding Arrangements to incentivise good work outcomes

MS Australia recommends:

1. Existing markets have been established for specialist providers such as MS ESS. The effectiveness of our specialisation is reflected in our current ratings. Grant agreement periods of less than 3-5 years would not make these services sustainable as committed funds for set up costs, staff training and capacity building, retention and creation of market share will require longer-term financial commitments.
2. Grant Agreements should acknowledge and adequately reward programs and services that employ highly skilled and registered allied health staff within their business models. Specialised and intensive supports and services cannot be delivered without appropriate investment in our workforce. Some employment support providers experience a high turnover of staff (which is costly) and those workforce cohorts often lack expertise. For specialist DES supports, current DES financial modelling is built on front line staff earning $55-60K per annum. This does not allow for experienced hiring and therefore would not attract and retain experienced staff. MS ESS's core workforce employs registered allied health professionals. The current funding allocation and financial modelling does not adequately reward specialist workforce recruitment or retention of staff and should be raised to reflect the reality of our workforce expenditure.
3. Funding should be provided "upfront", similar to an insurance model, so as to set people up with services and supports when they first become an employment service participant.
4. Current funding methodology is based on the delivery of units of activities i.e. weekly phone calls to participants, which does not allow for mutual agreement, choice or need. More flexibility is needed in claiming guidelines in the types and frequency of contacts to participants and employers.
5. Recognition of the value of mentorship and time investment needed to achieve sustained mainstream employment.
6. The consultation paper appears to have a focus on securing jobs but less on supporting career progression. There is economic benefit in supporting participants in establishing the next stage of their career, and incentives should support these types of activities and support.

7. Incentivise both primary (achievement in securing, maintaining employment) and secondary outcomes (experience and outcomes measures).
8. Appropriately fund specialist DES provider contracts according to the outcomes and success they achieve. Incentivise how these providers reduce a reliance of welfare; reward expertise and services quality (i.e., successfully remove barriers to employment).

With the introduction of the New Employment Services Model (NESM), DES providers will increasingly be required to support participants with complex needs. Our experienced and highly qualified staff are best placed to assist participants in finding career pathways that are sustainable and deliver long term outcomes. Specialist DES provides such as MS ESS delivered services aim to eliminate or overcome both vocational and non-vocational barriers. A future funding methodology should recognise and reflect the value of specialist DES providers.

Financial supports to DES providers should allow for flexibility and ongoing supports as people with living with a disability's circumstances and career pathways change, or workplace needs change.

In line with current labour force analysis, funding arrangements should allow DES participants to pause or restart their engagement with the program. This is particularly important for people living with episodic conditions such as MS.

The focus of financial incentives should not just promote successful job placements as an end point, resulting in a placement fee. Participants living with chronic conditions such as MS will benefit from continuity measures such as allowing for more longer-term incentives and supports that will provide them with support across change of circumstances, changes in casual placements, activities and experiences.

For MS specific employment services, the provision of supports to maintain participants connection to ongoing employment should be appropriately financially rewarded. A major focus of this service is to ensure that participants do not become unemployed. Once unemployed, it is so much harder to reconnect them to the workforce. 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.

Service quality should be measured and remunerated over a longer period of accumulation, incentivising providers to build lasting participant and employer relationships and outcomes.

8. Driving High Quality Services

MS Australia recommends:

1. Create (through co-design) a transparent, easy-to-understand performance assessment framework for DES providers.

2. A framework of consumer (participant and employer) experience and outcomes measures should be developed that measures both primary (economic participation) and secondary outcomes measures (Quality of Life outcomes measures).
3. Data gathering should be utilised to inform research projects within the NESM that can evidence and highlight innovation, and what models are highly effective and achieve results.
4. Planned reviews should ideally take place every 24 months with provision of automated minimum data set reports and the provision of qualitative self-reporting every six months.
5. Innovation and growth should not be stifled by parameters that are too narrow on geographic boundaries, capped income measures of participants or regulation (red tape) that does not actually add value to the overall program.

Reduce the 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.

Service Quality and Expertise balanced against Quantity of Outcomes

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

The definition of secure employment has to adapt to modern labour market reality. Labour is market driven, based on demand and supply. A balance between resources employed to achieve long term outcomes either through employment gained or maintained should be reflected in the fee structure.

Employment Support Service programs for people with MS must be driven by highly specialised, multidisciplinary teams of health professionals[24]. The role insists upon timely and effective provision of workplace accommodation and education of employers and the wider community[25]. 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 informed employment support personnel may contribute to excessive disability with respect to MS and employment[26].

9. Measuring Success

MS Australia recommends:

1. The new future disability employment model has to be in step with modern labour force participation and distribution [27] data, the use of a forward factors approach to seasonal adjustment (to i.e. account for Covid) to better align with outcomes to be achieved through the new service model and the Community Development Program and the associated fee and activity schedules within the various programs. Outcomes should better align with modern employment trends and participation and therefore allow for flexibility and adjustments.
2. More closely align the trajectory of participant progress and outcomes with provider performance. This might allow for separate quality frameworks for those DES partners that deliver more intensive, specialised supports appose to measuring all providers (including generic providers) with the same Quality Framework.
3. Develop a quality framework that recognises small cumulative goals to sustainable employment.
4. Measure success over a longer period of time and not only point in time outcomes. Potentially utilise a customer journey approach to identify the effectiveness of supports and services against the delivery of desired outcomes (primary and secondary).
5. Measure the value of ongoing supports and services for all stakeholders and commission research grants to create an evidence base to support programs and policy settings that delivering success.
6. Create awards and recognition of providers that provide outstanding services and

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[24] 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.

[25] 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.

[26] 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.

[27] https://www.abs.gov.au/statistics/labour/employment-and-unemployment/labour-force-australia/jun-2021

supports.

Case study

Jacquie works in customer service at the checkout for Woolworths. She has issues with her mobility as well as continence and fatigue. Jacquie was assisted by MS ESC OT to review her workplace environment and look at solutions to enable her to get to the toilet without having accidents in the workplace as the toilets were located up a set of stairs which she was able to manage but needed to take significant time, increasing the risk of embarrassing incontinence at work.

Trials and liaison with a number of suppliers to obtain quotes for a motorised stair chair, along with Job Access Employment Assistance Fund, Woolworths's management/facilities, and local council for planning approvals to enable the item to be installed was successfully completed by MS ESS over a number months.

10.Other acquired neurological conditions

Multiple sclerosis is one of a number of acquired, progressive, degenerative, neurological or neuromuscular conditions that many Australians live with such as Motor Neurone Disease, Huntington's Disease, Parkinson's Disease, Dementia and many others. Whilst the causes and treatments (if any) of these neurological and neuromuscular conditions differ, there is considerable overlap in the symptoms that are experienced by those diagnosed and there are no cures. In most cases, each of these conditions and the disease trajectory is experienced differently by every individual, though there are many common factors experienced by all such as a generally lower quality of life than the general population and an increased need for support and services (such as the NDIS).

Many of the peak bodies representing these conditions are members of the Neurological Alliance Australia (NAA) - a collective of national not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular conditions in Australia. The Alliance works collaboratively to identify and advocate for opportunities that will promote improved quality of life for people living with these conditions and funding to support research.

For more information about the membership and work of the NAA, please visit: https://www.msaustralia.org.au/neurological-alliance-australia-naa/

We believe that this submission, clearly sets out the case for the continuity and expansion of the MS-specialist employment support service. The solid understanding of the complexities of symptom management and the need for holistic and proactive management of barriers to maintaining employment are keys to its success.

Given the expansion of services and support to other neurological conditions already undertaken by our state organisations in areas such as NDIS Support Coordination and specialist accommodation, we believe that the existing MS-specialist employment service could also be expanded to include employment support for people with other neurological and neuromuscular conditions. In some cases, people with these conditions are not represented by a disease-specific peak body, or an organisation that offers employment support and services targeted to the condition. The specialist knowledge, skills, training, understanding and years of experience already held by the MS Employment Support Services team lends itself to offering this premium support and service to those individuals living with neurological and neuromuscular conditions that wish to maintain their employment.

Conclusion:

Various MS symptoms, external factors such as temperature sensitivities that impact on symptom severity, disease progression and the accumulation of disability (hidden and invisible or those of a more physical nature) affects how people feel and perform in their daily activities. This includes their day-to-day management of their family life, their various abilities to fulfill roles and responsibilities, how they add value to their community and how they participate in employment.

‘Whilst independence and empowerment can mean different things to different people, they are often the first thing a person affected by MS talks about when considering quality of life. Rights to education, work and leisure are recognised human rights. Participating in these activities as equals, 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.’[28]

What makes specialist DES providers such as our MS Employment Support Services unique is that our consultants understand MS and that everyone’s experience of MS is unique.

As a member of CoAct, a national network of locally embedded community service providers, we work together to create social and economic opportunities for those disadvantaged Australians who require our support and services to overcome their barriers to employment and continue to provide an economic benefit to their communities and their families.

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[28] See https://www.msif.org/living-with-ms/what-influences-quality-of-life/seven-principles-to-improve-quality-of-life/

Appendix 1

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

Three 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!

Example 3:

Bill is a 53 year old man who was diagnosed with Primary Progressive Multiple Sclerosis (PPMS) in 2018. He works as a Nurse Unit Manager at a busy hospital. He came to the MS Employment Service in April 2020 seeking advice to continue to work full time.
Bill's Employment Support Consultant, an Occupational Therapist, was able to give him specialist advice on managing his MS. She attended his workplace and recommended specific equipment that would minimise any barriers that he had, as well as speaking with members of his team. Bill's ESC assisted him to access the NDIS and has continued to give him ongoing support and advice regarding managing his MS. Being a health professional himself, Bill has been able to see the value that this specialist knowledge and advice has provided him. Specifically, he sent this email (dated 9 April, 2021):

"I was just writing to say as a health care professional, the importance of the role your Allied Health Occupational Therapist Team provides to me in my workplace.
As a health care professional when you visited my work area, you were able to provide the required information on Multiple Sclerosis. This was provided to both my managers and other team members that I work with.

This could not be done by nonprofessional staff as they would be working outside of their scope of practice.

My team felt it was a fantastic service, as it was provided to me with staff who have a professional health background.

I feel it is extremely important to me that this service continue in its current form.
As your staff are registered with AHPRA [Australian Health Practitioner Regulation Agency], and as a Registered Nurse, I am aware that your team would need to meet specific educational requirements to be registered.
This gave me the knowledge that I am being managed by registered health care professionals, not just by another carer or office worker.

If this service was ever to change to a non-Occupational Health care team, you would not be any different to other non-professional disability employment agencies.
This service is the only reason I can continue in full time employment. This service is needed for professional working members of the Multiple Sclerosis community.
I would not be happy to stay with the service if it was not provided by an Occupational Therapists.

I am happy to discuss this further with any of your Multiple Sclerosis management team.

Kind regards

Bill"

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.