



MS AUSTRALIA

MS LTD

**Feedback to the Victorian
Department of Health and Human
Services Draft Disability Action
Plan 2018-2020 - Consultation**

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Introduction

MS Australia (the national peak body for people living with multiple sclerosis (MS) in Australia) and MS Ltd. (the entity which is the pre-eminent source of information, advice and services for people living with multiple sclerosis in the ACT, NSW, Victoria and Tasmania) are pleased to provide joint feedback to the Department of Health and Human Services' *Draft Disability Action Plan for 2018-2020 (the Plan, hereafter)*

The focus of the comments, suggestions and examples provided in this submission is on key areas that will impact on people affected by MS, particularly highlighting the support needs of people with MS in the workplace and how to improve their social inclusion within the greater Victorian community.

We would particularly like to congratulate the Department of Health and Human Services ('DHHS') on the inclusion of people with episodic, chronic and acquired disabilities and those with multiple support needs in the definition of 'disability' and how this cohort's symptoms and co-morbidities often impact on their ability to optimally participate in community life.

MS is a debilitating disease of the central nervous system (CNS). It is the most common chronic neurological condition affecting young adults in Australia. MS affects more than 25,000 people (those diagnosed) throughout Australia. Victoria has the second highest prevalence of MS in Australia.

Around a 1,000 more people are diagnosed every year. The average age of diagnosis is between 20 to 40 years old, a crucial time when most people are starting a family and/or building a career. 75% of people diagnosed are women.

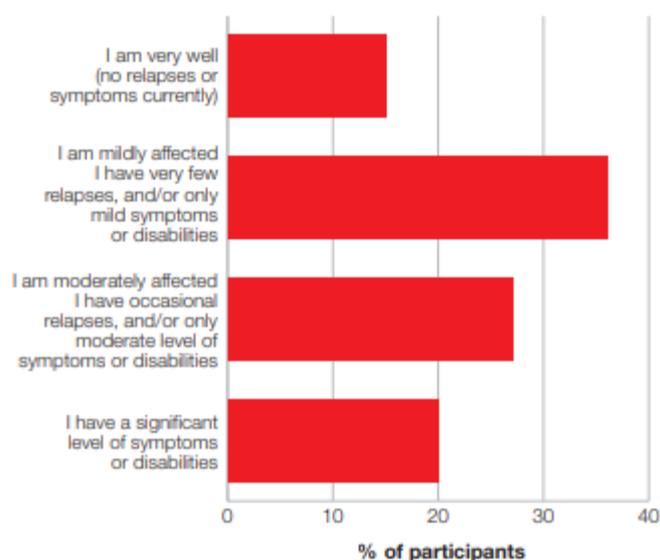
MS varies significantly from person to person, depending on the part of the CNS affected. For some people, it is a disease that fluctuates in severity with periods of unpredictable relapse and remission. For others, it is a progressive decline over time. For all, it is life changing.

MS is the leading cause of non-traumatic disability in young adults. The Australian census data suggests that approximately 48% of people with MS have profound and severe core-activity limitations (ABS 2012). Data from a 2016 MS Research Priorities Survey conducted (See Figure 1), indicates that approximately 50%, of the highly representative sample of people with MS, were either very well or mildly affected. Just over 27% had occasional relapses and or moderate level of functional impairments/disability. 20% had a significant level of disability and or symptoms.

The most common symptoms are often invisible. Symptoms may include debilitating fatigue, neuropathic pain, sensory issues such as numbness, tingling, pins and needles and muscle weakness; balance and mobility difficulties; sight impairments; bladder and bowel dysfunction and a variety of other symptoms unique to each individual. Each of these symptoms may interact with each other (and with other co-morbidities) causing functional impairments that impact on someone's ability to perform tasks of daily living, including workforce participation, without some type of support.

Figure 1. The degree of disability and symptoms experienced by people with MS who responded to the MS Research Australia survey

<https://msra.org.au/wp-content/uploads/2017/04/ms-research-priorities-survey-full-report.pdf>



An Economic Impact study of MS conducted by Prof. A. Palmer published in 2011 highlighted the considerable economic impact of MS on individuals, families and our society as a whole (all costs are based on 2010 Australian Dollars and using a prevalence figure of 21,283 people):

- Total cost of MS in Australia is estimated at \$1.04 billion per year
- \$500 million is due to lost productivity
- Replacement cost of informal care provided to Australians with MS is \$125m
- 50-80% of people with MS cease to work full time within 10 years of diagnosis
- Australians with MS pay \$78m per year out of their own pocket.¹

We therefore very much support this draft *Disability Action Plan* and believe that it will indeed become an important tool for building the capacity of organisations to be more accessible and responsive to people living with a disability.

There's no cause or cure for MS but recent developments in medicine has provided some relief as these disease modifying therapies attempts to minimise the number and severity of symptoms – slowing down disease progression.

People living with MS can more than ever before continue to provide great value and an ongoing contribution to employers and their community. This is why we support developing the capacity of organisations and employers within the community, through the *Disability Action Plan*, achieving more accessible, equitable, inclusive and safe workplaces for people with disabilities in Victoria.

¹ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study*, September 2011, page 7.

Feedback on areas within the draft Disability Action Plan:

1. Focus area 1 (Internal Capabilities): Building internal department capability and creating an accessible, equitable, inclusive and safe workplace for people with disability

We would firstly like to congratulate DHHS on their stated goal to support a more positive workplace culture, reduce discriminatory attitudes and promote discussion about disability inclusion across the department. For many people with MS, having a supportive workplace culture is what is enabling them to remain in employment. Promoting an open, supportive and productive approach to employees living with MS, and providing reasonable adjustments could support someone to continue working and contributing long after diagnosis.

For many, deciding to disclose their MS diagnosis in the workplace does not come easy and some might have some well-founded fears of how such a disclosure might impact on their career in the short, medium and long term. Employees might fear that by disclosing, employers and colleagues might inaccurately stereotype them, thinking that they are unreliable or perceive them as less capable, and ultimately result in them being prevented from being considered for future promotion or training opportunities.

Improving the workplace culture, providing employer training and increasing the awareness of employees within DHHS and their partners would make a huge difference in people's decision to disclose at point of application, post diagnosis or when symptoms start to impact on their day to day functioning.

We support the need to raise awareness and understanding of disability to reduce ongoing disability related discrimination. We at MS Australia and MS Ltd offer to work closely with the Executive Disability Champions for Access and Inclusion, The VPS Enablers Network and their Community of Practice team to engage and build the capacity of staff e.g. training in supporting someone living with MS in the workplace. Similarly, we offer to work closely with both the DHHS and NDIS Sector Development Fund project team to deliver training and resources to various sectors in supporting families who live with MS in order to aid greater integration between community sectors. We have a wide range of resources already created that can assist with increasing the understanding of supporting someone with MS in the workplace.²

Designing for diversity, reducing barriers, promoting inclusion and improving access, leading in policy and innovation and providing an individualised approach should be commended.

Adjustments for people living with MS might be minor and may include re-negotiating an employee's hours, relocating or modifying an employee's workstation, allowing the employee to take time off work for medical appointments and treatment or, in some circumstances, changing an employee's job duties. We also commend your focus on consumer informed solutions, including your intent to consult on new technology solutions, accessible applications and upgrades. The DHHS Employment Team are

² See more here: <https://www.msaustralia.org.au/wellbeing-ms/workplace> and for Victorian specific employment support for both employees and employers here: <https://www.ms.org.au/support-services/employment-support.aspx>

welcome and encouraged to contact MS Ltd. or MSA who have access to a diverse range of volunteers who would love to assist in this project.

We would like to congratulate DHHS on suggesting improved accessibility to departmental facilities and informing the design of your Workplace of the Future initiative through employee engagement. For people with MS, heat sensitivity may impact on their levels of fatigue and concentration, and for some even trigger a relapse or exacerbation. Sometimes a simple solution such as office environment that has access to individualised climate control technology could make a huge difference. Providing a flexible, safe space in the workplace for staff to relax or rest/nap to assist in fatigue management, would also increase retention and improve productivity for our MS community within the workforce.

We support the adoption of digital standards in improving accessibility of departmental communications and media. MSA has been working on an international project, along with other members within the MS International Federation, to promote accessible digital communications and we would love to assist DHHS in considering how digital communication changes can enhance inclusion and accessibility.

We absolutely love the idea of a 'reasonable adjustment passbook' for all employees and linking all new starters with the VPS Enablers Network. MS Ltd have a dedicated Employment Support Service who could partner with DHHS in designing employer education and how workplace adjustments can benefit people with MS.

Lastly, your focus on building internal capability and workplace actions within People and Culture and Corporate Service on areas such as recruitment, including the review of recruitment policies and forms to increase accessibility and encouraging people with a disability to apply for positions in the department will cement the Disability Action Plan. Your leadership in achieving Disability Confident status through the Australian Network on Disability and investing in the 'RecruitAbility' platform would not only add value to the sector but also increased economic participation of people with MS in the workplace.

2) Focus area 2 (External Services and Programs): Ensuring department-delivered, funded and regulated services are inclusive of, and accessible to, people with disability.

We congratulate DHHS on adopting a **universal design approach** (see p17 of *the Plan*) to achieve a more inclusive community and challenging widespread social, cultural and physical barriers that impact on people with MS' quality of life.

MS Australia has a well-established position statement on the implementation of Australia's Liveable Housing Design Guidelines, to require all new and extensively modified housing, public spaces and buildings to meet accessibility and adaptability standards. The implementation of these standards would ensure viable accommodation and accessible public spaces/workplace options for everyone, regardless of age, family needs, disability and disease and resulting disability progression.

Existing building regulations do not require minimum access or universal design features, despite the low cost of including these features during construction as against the much larger cost of retrofitting.

Minimum access requirements and adaptability standards are defined by the Australian Network for Universal Housing Design (ANUHD), who now recommend equivalence to the “gold level” of the Liveable Housing Design Guidelines, which sets standards for parking spaces, doorway widths, adequate space in toilets, bathrooms and kitchens, and reinforced walls to allow for the installation of grab-rails.

The application of these standards would benefit all people with access needs, including older Australians, people with temporary impairments and people with disability.

Regulation is required to ensure an equitable system and to allow incentives to be applied for early adopters. Bonus incentives could apply as the higher standard (platinum level) is implemented.

MSA and MS Ltd recommend that:

- Regulatory intervention is necessary to meet the state disability plan indicator 2.1.3. Increase suitable housing.
- The regulatory intervention needed is an amendment of the National Construction Code (NCC) to include access features as specified in LHA’s Gold Level in all new and extensively modified housing
- Other incentives could be considered for making changes to existing dwellings, incentives such as GST exemptions for architects and draftsmen and exemptions from local government planning application costs should be considered.
- People with MS living in rental accommodation are particularly disadvantaged as there is limited opportunity or incentive to adapt or modify their homes to address their symptoms (through better heating, cooling and insulation) or to address their functional impairments. The creation of financial incentives for the rental market to provide a greater range of accessible options and encouraging landlords to make accessibility modifications is recommended.
- The Disability Action Plan include (a) the planning, design, management, and regulation of (ii) transport services and infrastructure.
- These changes to the NCC should be complemented by education and training of the housing sector and the broader community.

Increased physical health and healthy living: We are fully supportive of initiatives stated in the ‘health promotion’ and ‘sport and recreation infrastructure’ sections and highlight the benefits of modifiable lifestyle factors for improved outcomes for people with MS.

Emergency Management and readiness plans is of particular importance to the MS community as heat sensitivity in particular could render some incapable of moving or seeking support. Improved person-centred emergency preparedness, response and recovery would positively impact on the MS Community safety and health. We support any effective method of assessing vulnerability based on both geographical and social indicators and developing ‘safety nets’ including resources that enable people with chronic health and disabilities to put together an emergency plan, emergency kits and improving their resilience before, during and after these adverse events.

Enhancing health services in rural and remote locations: Referring to the case study provided on page 35 of *the Plan*, we would fully support increases in access to

telehealth services across Victoria. International consensus and endorsement of the 'Brain health – Time matters in multiple Sclerosis' report and recommendations³ supports early intervention, regular monitoring of disease activity and safety parameters as well as access to specialist treatment via MS specialist health professionals. The report noted that such a major public policy change directly translates to making a difference to the lives of people with MS – 'avoiding long-term economic and personal costs resulting from unnecessary irreversible disability.'

We congratulate DHHS on the decision to fund 24 organisations and two state-wide resource units to promote individual advocacy initiatives through the Victorian Disability Advocacy Program. It's commended and noted that the Victorian Government recognise the importance of ongoing funding for disability advocacy organisations in their 2018-2019 budget. MS Australia and MS Ltd offer to collaborate and work closely with the Self Advocacy Resource Unit to deliver the Voice at the Table initiative – through our National Advocates program or partnering with our volunteers within MS Ltd's member services advisory committee (MSAC). Similarly we have highly capable volunteers (MSA advocates and MSAC) who would be suited to represent people with disabilities on the Victorian public sector boards and committees.

Lastly, we support the need to inform future policy through the development of an evidenced based outcomes framework and approach. We would like to recommend the inclusion of people living with MS when administrating the Standard Disability Identifier survey to identify and track user outcomes for this specific cohort.

MS Australia and MS Ltd offer to be part of any future consultation process, consumer informed initiatives or innovations and will continue to partner with DHHS to ensure the delivery of better outcomes for Victorians living with chronic conditions and disability.

³ The publication is available online at www.msbrainhealth.org