



**MS AUSTRALIA**

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# Submission to the Victorian State Disability Plan 2017-2020

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## **Introduction**

MS Australia (the national peak body for people living with multiple sclerosis in Australia) and MS (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 a joint submission in response to the discussion paper of the Victorian State Disability Plan 2017-2020.

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

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia. It is the most common chronic neurological condition affecting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS varies significantly from person to person. For some people, it is a disease that 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.

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

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, 'the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease.'<sup>1</sup>

Our organisations congratulate the Victorian State Government on the development of the State Disability Plan and on the consultation process undertaken thus far.

Given the state of flux and transition brought about by the implementation of the NDIS, we also understand that the 'plan' itself, at this stage, is in the form of a discussion paper and therefore lacks the specificity that will no doubt be included in the final State Disability Plan.

We appreciate the way the discussion paper is set out, and acknowledge the appropriateness of the four major themes as a way of addressing each aspect of the Plan.

## **Accountability**

The previous State Disability Plan lacked significant detail and evidence of how any of the broader aspirational statements would be achieved, how specific actions were to be undertaken by particular areas of government, and there were few accountability mechanisms or measures to inform how proposed actions were being achieved. Development of the 'Driving Outcomes' section of this current Discussion Paper will be critical to the final Plan's overall success. We believe that measures must include feedback from people with disability in a variety of ways, using both traditional forms of feedback and more modern innovative methods. This will achieve a broad range of feedback from people born with disability and those who acquire disability from a chronic illness such as MS, and clear reporting timelines.

## **Sector interface**

The health, aged and disability reform focus requires the creation of integrated pathways and protocols. For years there has been a gap in generating a genuine collaborative interface of specialist and mainstream services providers (i.e. aged care, health and primary care, and disability care). In the NDIS trial sites it has been demonstrated that this can be achieved simply, starting with the provision of practical checklists that include a clear communication protocol for sharing information.

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

The ability of the health and disability sectors to work together is central to meeting the needs of people with an acquired disability; it is non-negotiable for acquired and neurological conditions such as MS.

A collaborative interface will facilitate people moving seamlessly across service sectors as their needs demand and as their condition progresses, to achieve positive outcomes for both individuals, their carers and their families.

### **What is missing in the Plan**

We are concerned that there does not appear to be a sound understanding of the effectiveness of what specialist, disease-specific organisations such as ours are already doing, and have been doing for many years.

It appears to be expected, that ahead of the introduction of a fully competitive market environment brought about by the implementation of the NDIS, social purpose organisations will freely and readily share their well-established knowledge, expertise and intellectual property without due consideration and negotiation.

On what commercial basis will specialist NGOs such as ours be engaged? For example, under the NDIS, MS is not remunerated for providing advice to Local Area Coordinator (LAC) planners. It would be commercially naïve to act simply with goodwill, and share the knowledge and experience gained from over six decades of providing advice and services to the MS community in Victoria.

### **Planned proactive responses**

The existing disability system in Victoria is often difficult to negotiate and is crisis driven. The Plan does not appear to contain a strategy that addresses this 'crisis driven' approach, nor aspires to implement a planned proactive response to emerging needs. In terms of the implementation of the NDIS, the simple 'roll over' of existing systems and services until review in twelve months, for those in the current roll out areas, is inadequate. For those in areas where the NDIS is not due for immediate roll out, the message is simply 'there will be a different system, but you will have to wait'. This is an unacceptable situation and feels to some members of the MS community like a 'postcode lottery'.

Furthermore, the activation of the mainstream system will not suffice for those ineligible for the NDIS due to the episodic nature of their condition, as may be the case for some with multiple sclerosis and the lack of recognition of the impact of invisible symptoms experienced by people with MS.

### **Real choice**

The Discussion Paper does not appear to include any ideas for actions that will provide **real choice** regarding disability services. Real choice means being able to opt in or out of managing your own funds and services. Under the NDIS, support coordination will be a vital mechanism for people to navigate the systems and services. In particular, we advocate for the amplification of the provision of funds for Support Coordination. We would like to see Support Coordination available for those ineligible for the NDIS, in particular the over 65s.

### **Early intervention principles**

The previous plan had a strong emphasis on Early Intervention for children, but did not recognise or demonstrate an understanding, nor value Early Intervention for the acquired disability and neurological group; to keep people at home, retain their independence and community engagement, keep families financially viable, and as economic and social contributors to community.

Early Intervention principles are both understood in the context of Early Childhood services, and included in the NDIS pricing clusters. For those who acquire disability, early intervention after diagnosis also means access to funding to support reasonable and achievable goals, which keep people at home, in work and engaged in life roles. For example, timely access to incremental funding for aids and equipment for people with MS, such as cooling vests and air conditioners, and intervention activities including transport assistance and customised exercise programs to optimise function, are key effective early intervention supports. Outcomes from these interventions include employment retention and maintaining family and

social connectivity. The specialist knowledge and experience built over decades and leveraged by our organisations, cannot be replicated by LACs and planners within the NDIS.

### **Access to key services for those with high support needs**

Access to respite, palliative care and a workforce skilled to effectively and efficiently deliver the necessary supports, is an emerging gap for people with high support needs ineligible for the NDIS. For example, many people with MS have co-morbidities on top of MS, including complications associated with MS and from necessary MS treatments, including conditions such as osteoporosis and diabetes (associated with steroid use), complications of immune suppression (including poor dental health, increased risk of some malignancies) and complications from the management of bladder and bowel dysfunction. They can have both fragile health and there can be an interplay where other illnesses can exacerbate previously well managed symptoms of MS. There is a clear need for access to health services (including dental and gynaecological services) managed by experts who understand the complex needs of those with MS and associated co-morbidities.

### **Human Rights**

All areas of the final Plan must embed the principles of Human Rights, and whilst this is referred to in the Introduction to the Discussion Paper, there seems to be a priority given to people aged less than 65.

The paper does not seem to express the same level of respect, dignity and equality for those who are aged over 65 with a disability. The final Plan needs to be inclusive of anyone with a disability regardless of age, and the needs of people over 65 must be specifically addressed.

We are concerned that those aged over 65, with the likelihood of their disability progressing, are at risk of becoming a forgotten group and their needs under the Aged Care reforms are not well understood. There has been little engagement on this issue to date. Many of those living with MS aged over 65 have done so for a long time with some level of disability, and they are economically disadvantaged. There needs to be equality of care to meet their disability needs, and support coordination to enable choice and control.

### **A preventative approach**

People affected by progressive neurological disorders such as MS, require a preventative approach to remain engaged within education and employment. What is required is access to interventions to support them to regain and remain in work and education for as long as possible. This helps avoid the financial hardship that generally occurs due to disease onset in early and middle adulthood, when there are considerable costs associated with raising children, paying a home mortgage, etc. Timely responses to needs allows the individual to remain at work as long as possible to maintain some financial viability, and the social connection that the workplace offers. Additionally, timely support of those with higher levels of disability allows the primary carer to remain engaged in work outside the home, with similar benefits.

### **Leadership and engagement**

To truly engage the other sectors to share in the development of a plan and process for implementation, leadership from the disability sector is required. There has been a great deal of discourse over many years around the need for engagement and growing community capacity, with limited success in terms of outcomes. At State Government and Department levels, the bureaucracy has not been able to deliver integrated and seamless service pathways. At the local service level, individual negotiations occur that are not sustainable, equitable or an efficient use of limited resources.

Fundamental to quality living, is access to and provision of, quality health services that understand and respond to the disability context. This is best supported in the progressive neurological arena, by the provision of key workers with the mandated ability to support the interface between health, aged care and disability.

### **People with disabilities moving into residential aged care services**

Our organisations are particularly concerned to prevent people, especially young people, being moved into residential aged care. To avoid moving into residential aged services all people with disability require:

- Age appropriate accommodation and respite services
- Ongoing and enduring rehabilitation to maintain or regain independence and functionality
- Personal care and support
- Disability aids and equipment
- Respite for the person with a disability, their carer and family
- Information, training and education for the individual, their family and carers (both primary and paid carers)
- Effective individual advocacy

A local focus, flexible and responsive funding, integrated services and a genuine interface between sectors, will avoid 'avoidable' incidences, loss of choice and control through carer burden, family breakdown and social isolation.

### **Disabled parking and public transport in Victoria**

A minor but frustrating aspect of the previous Plan was the lack of action on Outcome 7: More transport options, which stated, 'Finalise the detailed operational arrangements of the Australian Disability Parking Scheme in consultation with a range of stakeholders'.

Victoria still operates its own disability parking scheme through the many local councils in Victoria. Our organisations have received several complaints in recent years regarding confusion and frustration with the operation of this scheme, in the various jurisdictions across Victoria. The simplest and fairest way for these matters to be solved would be for Victoria to join the national scheme.

In addition, anecdotal evidence from the MS community indicates there is difficulty being experienced with access to the new low floor trams in the CBD on lines that head out to the hospital and university precinct by those people using wheelchairs and mobility scooters. There is no ability to alight from the trams in this precinct if you use a wheelchair or mobility scooter. Similarly, we hear that several tram lines with accessible stops are not serviced by low floor trams, and several lines without accessible stops are serviced by low floor trams. It seems there is more work to be done to iron out these difficulties and better communicate any improvements to the broader community.

Thank you once again for the opportunity to contribute to the development of the Victorian State Disability Plan 2017-2020.