



POLICY ISSUES STATEMENT

2010 - 2011

AUSTRALIA

THIS Policy Issues Statement concentrates on crucial areas that can lead to improved social and economic outcomes for people with Multiple Sclerosis (MS), their families and the community. Overall, MS costs the Australian community \$2B per year.

MS is a lifelong degenerative condition affecting all aspects of life for individuals and families. There are over 18,000 people with MS in Australia, and 75% are women. The average age of diagnosis is 30. With the right supports, it is a manageable illness for many people.

Maintaining employment and financial security, managing the high costs of MS over the life cycle and navigating the fragmented health and community support systems are all features of life with a progressive illness. Discrimination and limited workplace flexibility continue to be major issues.

The most significant difficulty people with MS face is managing a high cost disease with reduced incomes. Including family caregiving, MS costs \$10,500 per year per household. As the Government's recent *Shut Out* consultation report notes:

The extraordinary gap between the level of income support and the cost of disability was seen as restricting the ability of people with disabilities both to live independently and to enjoy a decent standard of living.

Employment Participation

EMPLOYMENT is a key contributor to quality of life for people with a chronic illness. With the average age of diagnosis at 30, people with MS have built significant skills and experience, but nonetheless 80% lose their jobs within 10 years of diagnosis.

Strategies to keep people at work will reduce their reliance on the Disability Support Pension. Within the framework of the new *National Mental Health and Disability Employment Strategy* it is essential that government and business work together on job retention for people who

acquire disabilities and illnesses during their working life and who may need adjustments and support at work. Measures to increase workplace flexibility and responsiveness should include:

- development of an advisory service for employers;
- creation of business and industry-based sick leave pools that people who require paid leave over and above their accrued entitlement due to disability, chronic illness or caring duties can tap into;
- expansion of the Workplace Modifications Scheme to include non-capital items such as awareness training and non-PBS medications that can improve MS symptom management in the workplace;
- expansion of the Work-Based Personal Assistance Program to offer support to people with a range of attendant support needs in the workplace;
- the Pension Bonus needs to extend to those who qualify for the Disability Support Pension and can perform some work.



Simone Rutherford is living with MS and has maintained her job with some flexibility from her employer Gaz Man, and Paul Ansons, her General Manager has retained an experienced manager.



Assistive Technology

ASSISTIVE Technology or AT (often known as Aids & Equipment) is central to the day-to-day lives of many people with MS, and is also a major issue for their families. Without the right equipment at the right time, activities essential for social inclusion that we all take for granted can be impossible for people who rely on AT.

All the recent human services reviews including the *National Health and Hospitals Reform Commission Report*, the *Report on the Inquiry into Better Support for Carers*, the *Harmer Pension Review*, and the *Shut Out* report note the centrality of AT in enabling people to live full lives in an inclusive society, and the ongoing failures of existing programs to deliver this. One in ten Australians utilise AT according to the ABS.

Delays and inappropriate AT, such as the non-supply of a pressure mattress or ill-fitting mobility aids, routinely create avoidable and costly health problems, as well as impacting on the quality of their lives. These can also contribute to burn-out and injuries to family caregivers.

In spite of having over 30 funding schemes across Australia, far too often people with MS do not have their AT needs adequately met. 85% of AT costs including home modifications are met by people with MS and their families, some of which includes the often very high co-contributions required as part of many AT schemes.

At the broadest level major problems include:

- chronic under-funding of public AT programs;
- operational and supply chain inefficiencies;
- no coordination, linkages or integration between funding sources, jurisdictions, target groups and operational structures;
- preponderance of under-funded capped programs limited by means tests, large co-contributions, and restricted lists of 'eligible' equipment.

A major national Assistive Technology reform agenda is required, and should include:

- a national purchasing, distribution and recycling framework across all AT programs, including privately funded purchases, that aligns existing schemes and expands the funding base;
- an accurate determination of national costs and benefits of AT, to clarify the level of public funding needed;
- consideration of a PBS-style prescription system, particularly for low-cost/high-volume items that make up a very large proportion of AT expenditure;
- tax-deductibility for all privately purchased AT, including co-contributions to public-purchase programs;
- eligibility to equipment schemes for young people in nursing homes;
- initiation of an industry development plan for the Australian AT manufacturing industry.

National Disability Insurance Scheme

THE concept of the NDIS has received considerable attention and support recently, and offers a solution to the chronic unmet need for lifetime care services. Current funding arrangements are inadequate, and a NDIS would provide a more sustainable funding structure for government and the community as demand increases over time.

The nature of progressive neurological conditions means that waiting long periods for community care, assistive technology or respite can lead to disability exacerbation, so a funding methodology based on need has many benefits for people with MS and their families.

A major feasibility study to explore cost and design options should be initiated as soon as possible.



Universal Housing Design

THE lack of accessible housing and the cost of modifications is a significant barrier to people with MS and other conditions. As the population ages it is essential that Australia has more accessible housing stock. Such features include level entry, wider doorways and corridors and well designed bathrooms.

Designing accessible homes will reduce the cost of future modifications, increase the amenity of housing, and reduce requirements for, and costs associated with, assistive technology. Appropriate design need not add significantly to housing costs if incorporated at the beginning.

Universal design features compliant with Australian Standards for Adaptable Housing must be mandated in building regulations across Australia to ensure better housing options in the future.

Carers

THE demands on family caregivers of people with MS usually increase over time, and often have a lifelong impact. Consequently it is vital that families are well supported.

The support families provide to people with MS has an estimated economic value of over \$250M per year, and on average carers provide 12.5 hours per week of care. The Australia MS Longitudinal Study found that over 1300 MS carers either reduced or ceased their employment to accommodate their caring role.

MS Australia endorses the recommendations of the Parliamentary *Report on the Inquiry into Better Support for Carers*, and urges the government and industry bodies to incorporate them in policy, funding and practice across business, government and the community. In particular, the following actions are a priority:

- introduction of a dedicated labour market program for employed carers focused on job retention and re-engagement in the labour market;
- streamlining the contact points with the service system, including Centrelink;
- a feasibility study of possible financing schemes to contribute to the retirement savings of carers who have discontinuous employment;
- an increase in the 25 hours per week that a carer can work or study and still be eligible for the Carer Payment.



Health and Community Services

PEOPLE with MS utilise a wide range of health and community care services that must be accessible and well coordinated. MS and other progressive neurological conditions must be a greater priority in the National Chronic Disease program.

The health/disability interface needs significant upgrading to ensure coordinated care and streamlined access. Current gaps create adverse outcomes including hospital and residential aged care admissions and carer burn-out. Specific initiatives required include:

- funding of specialist neurological case coordinators to work with individuals and improve health outcomes;
- access to efficacious treatments not currently available for MS on the PBS;
- inclusion of disease-related private scripts in the Pharmaceutical Safety Net;
- inclusion of Baclofen pumps in the Medical Devices Schedule, to assist in the treatment of chronic spasticity and pain relief, and to reduce carer stress.



“MS is a lifelong degenerative condition affecting all aspects of life for individuals and families”

Energy Use and Climate Change

PEOPLE with MS typically use more energy in their homes than other households. 90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households.

This high use of energy comes at a significant economic and environmental cost. While several states (NSW, VIC and WA) provide vital assistance through means-tested energy rebates for people with a medical need to keep cool, much more needs to be done, including:

- implementation of appropriate and effective energy rebates nationally;
- development of new energy efficiency programs, and better targeting of existing programs for this group, including (a) energy audits; (b) replacement of older inefficient air conditioners; and (c) minor home retrofitting such as ceiling insulation and external window coverings.



A U S T R A L I A

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Research

THERE is no cure for MS. Without sufficient research, a cure and more effective treatments will not be found.

Government funds for medical research are delivered through the National Health and Medical Research Council (NHMRC). In 2009 NHMRC funding for research related to MS was \$7.7M, including approximately \$2.7M for projects specifically directed at the biological mechanisms of MS. This level of funding indicates both the importance of MS research, and the high quality of MS research undertaken in Australia.

In recognition of the need for increased research funding, MS Research Australia also distributed \$2.14M on MS research in 2008-09. This has generated important work including the possibility of preventing MS. However greater investment is needed in order to unlock the potential benefits from MS research for Australia and the world.

- It is vital that funding to the NHMRC be increased over time to support Australia's high quality research output.
- Additionally, the NHMRC should consider identifying progressive neurological diseases as a major research funding priority given the particularly high social and economic impact of illnesses such as MS.



MS Australia Advocates at Parliament House, Canberra.

