



Submission to the Legislative Council General Purpose Standing
Committee No. 2

Inquiry into The Program of Appliances for Disabled People
(PADP)

September 2008

MS Australia - ACT/NSW/VIC provides a range of health promotion and disability services including respite, case management, allied health, community nursing and information. We have 4,900 registered clients in NSW. We appreciate the opportunity to submit to this Aids and Equipment Inquiry, as aids and equipment are important parts of the support system for people with MS in NSW.

We would be happy to provide further evidence to the inquiry by request or at a public hearing.

1. What is MS?

MS is a chronic and incurable disease that randomly attacks the central nervous system (brain and spinal cord). Symptoms of MS are unpredictable and vary greatly from person to person and over time in the same person.

Symptoms may include: extreme fatigue, tingling, numbness, impaired vision, loss of balance and muscle co-ordination, slurred speech, tremors, stiffness, bladder and bowel problems, difficulty walking, problems with memory and concentration, mood swings and in severe cases, partial or complete paralysis. The summary of MS at the end of this submission provides a snapshot of the impact of MS in Australia.

2. People with MS and the health /disability system

Due to the complexity and relative unpredictability of the disease course in each person, a range of supports are required to manage the disease, many concurrently. MS is a disease that is largely treated in the community.

The chart below shows that less than 20% of the total cost to the health system relates to direct involvement with health professionals and hospitals, although this clinical input into the management of disease and disability is critical. Although MS is a long term chronic condition, there is clear benefit to early intervention and health self management programs to ease the disease burden, which stands at the value of \$1.3b per year.¹

Aids and equipment are a central part of this disease management strategy, and if disability and health policy supports evidence based practice, then the funding schemes need to provide for supports that lead to good outcomes.

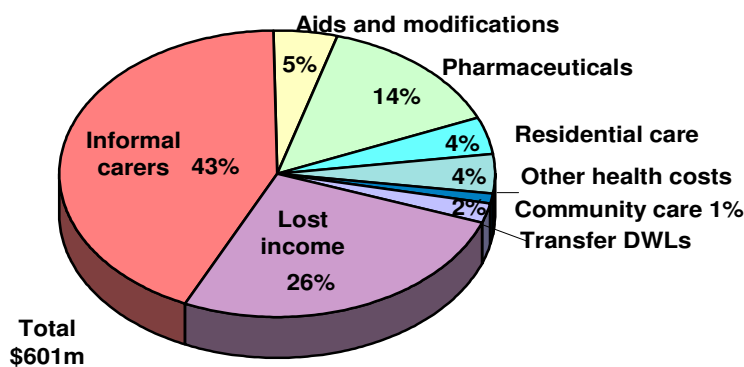


Figure 1: Direct financial costs of MS in Australia 2005 (Access Economics 2005)

¹ Access Economics 2005, *Acting Positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia*, Access Economics, Canberra. P iv

3. Economic impact of MS

There are significant costs associated with having MS. Access Economics (2005) found that the average annual costs to people with MS and their families in Australia is \$10,500 (\$3,893 out-of-pocket and \$6,593 for informal care). It is this overall cost burden that makes concessions so vital to people with MS on low incomes, many of whom are on partial and full government pensions.

These overall economic costs make it more likely that people on low incomes with MS will struggle to cover the additional costs of their disability, including aids and equipment.

These very significant economic costs are borne by people with MS and their families across the financial spectrum. However, like other people in the community with chronic illnesses, overall people with MS have lower income levels than the general community. Although 87% of people with MS are of working age, and most people with MS are employed when first diagnosed, 80% are not employed 10 years after diagnosis.

Consequently, although many people with MS are employed in the early stages of their disease process, ultimately most end up on fixed incomes provided through part and full pensions. The combination of low incomes and the high economic costs of MS means that the structure of Government programs (e.g. co-payments, subsidy levels for medications, equipment and home modifications) create significant financial stress in their daily lives.

4. People with MS and Aids and Equipment

In Australia, the Australian MS Longitudinal Study has estimated the cost of such modifications and aids for people with MS as \$1,646 per person per annum, based on expenditure over the five years to August 2003. Inflating this to 2005 prices (\$1,729 per person per annum) and multiplying by the prevalence of MS in NSW (approximately 6000 people) provides an estimate of **\$10.4m 2005**.

Of this, 85.7% (\$8.9m) is estimated to be borne by the individual and 14.3% by governments.² This is a disturbing figure and highlights the need to improve the coverage of equipment schemes. We have many instances where a person with MS self-fund equipment and home/vehicle modifications with their savings (in many cases with their superannuation or family assistance) because they cannot wait for state equipment schemes to respond, or because the modifications are either not funded or are short-funded.

There are clear dangers with this situation of people going outside the system – mainly around cost and self-prescription. A common example is where people have purchased an electric scooter privately, only to find out that it does not offer the right trunk support or controls, and it becomes redundant very quickly and gets sold cheaply or sits at home in a shed – and the mobility needs of the person remain unmet. If they had sought a prescription, a customised electric wheelchair may have been selected that was more suitable for their needs.

² Calculated from data from Access Economics 2005, *Acting Positively: Strategic Implications of the Economic Costs of Multiple Sclerosis in Australia*, Access Economics, Canberra p56

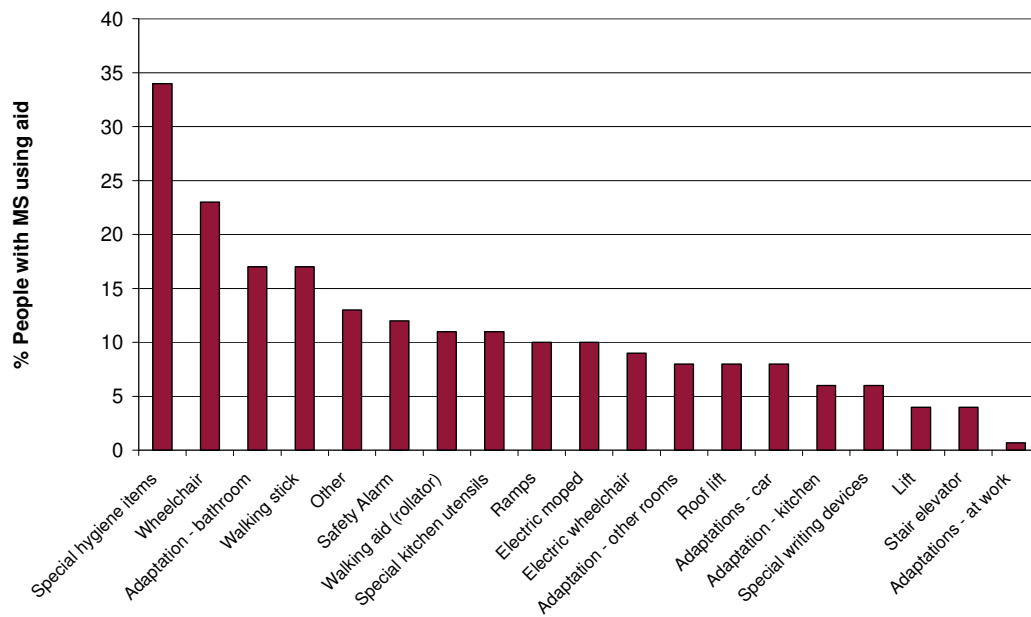


Figure 2: Types of Equipment required by people with MS³

5. Inquiry Terms of Reference

5.1 Adequacy of funding for present and projected program demand

A central point is that we need a model of recurrent funding for PADP at adequate and indexed levels - one-off injections of money out of each State budget do not solve the challenge of meeting the ongoing need for equipment in the community. The problems of the scheme are longstanding and as much about the administration of an underfunded scheme (that is more about rationing than providing equipment) as anything. Adequate recurrent funding would allow better operation of the program, and encourage operational policy aimed at delivering individual and program outcomes, not merely budget targets.

As a way of managing the demand for equipment, one-off injections of money in State Budgets is inert. It focuses on clearing waiting lists but does not contribute to PADP being able to deliver on its purpose more generally across the health or disability system. Waiting lists always leapfrog funding injections, so Government is always playing catch up. It also makes it almost impossible to establish what the program budget actually is – an essential number for any analysis.

The real and urgent equipment needs of people with disabilities should not be held captive to the political and budget cycle. These needs are permanent and ongoing, so the PADP funding model needs to keep in step with the need it is there to meet.

We need to address the long waiting periods for people with MS who cannot afford to wait due to their health status and complications that can arise through 'making do' with inadequate equipment. MS and other progressive diseases have no respect for waiting lists, and working with programs using waiting lists to manage budgets leads to poor health outcomes.

³ Ibid p 56

The lack of therapeutic equipment for daily living and even exercise for people with MS (e.g. passive exercisers, tilt table, exercise bikes) can hasten progression of disability and reduction in physical function, as well as psychological wellness and quality of life.

The modelling evidence from the PWC Review of the Program of Appliances for Disabled People (June 2006) and anecdotal evidence provided to the MS Society shows that funding for PADP is clearly inadequate. An added complication in resolving this is the poor data for measuring unmet and future demand. This is a problem that plagues all State/Territory Equipment schemes and indeed the national Disability Services system.

As MS Australia also operates in Victoria, we can comment that although the per capita spend of \$3.73 in the Aids and Equipment scheme in Victoria is nearly 75% higher than NSW, it still falls short of adequacy, although the co-payment arrangements are also very different. The Victorian scheme is under similar demand and budgetary pressure as the NSW PADP, and caps on funding of home modifications, pressure equipment and wheelchairs make life difficult for people with disabilities and the service system. In 2006 the Coalition of Disability Rights, a group of advocacy and service provision agencies called for a \$20m increase in the Victorian Aids and Equipment Program (VA&EP).⁴ Work is ongoing in that State following the release of the KPMG review of the VA&EP.

5.1.1 Occupational Health and Safety

Additional demand for aids and equipment has been driven in recent years by the heightened OHS focus in the health and community care sectors. The need for a range of equipment (lifting equipment, hi-lo beds, electric wheelchairs) to meet OHS requirements as well as client needs means that the program effectively has an additional target group – workers.

The impact of OHS requirements is growing in the disability sector, and is creating conflict with the disability standards and the delivery of services. The service sector and Government need to address this impact across the board, as it is a limiting factor for the ability of people with disability and their families to make choices and to receive appropriate support services. Examples of workers not being allowed to push a manual wheelchair outside a building, or even use a lifting hoist on their own seriously compromises service delivery.

This needs to be factored into the funding levels required by PADP, and needs to be considered as part of a wider Government strategy for the management and development of the disability and aged care workforce. The OHS issue adds an additional dimension to the PADP equation that adds weight to the strategic importance of the reform of the program.

5.2 Impact of client waiting lists on other health sectors

Aids and equipment needs to be part of an integrated health and community support system. People with complex disabilities rarely need services from a single program, and in the case of MS the need to access multiple programs simultaneously is part of the disease management process.

⁴ Coalition for Disability Rights; Call to *Political Parties Victorian State Election 2006*, Melbourne

Denying or delaying access to PADP does not reduce or eliminate the need for equipment, it simply increases the burden on families and individuals and forces inappropriate, expensive and wasteful responses to manage the unmet need. While this inquiry is looking at program management issues, the context of the PADP cannot be overshadowed. The provision of aids and equipment serves a number of purposes – it can be preventative, it can provide independence at home and in the community for people, and it can complement a range of other disability support programs to achieve their goals.

PADP, despite its history and current operation is not an island program, and any reform to its management structure and funding must be directed at improving its linkages throughout the system.

In the same way that the Pharmaceutical Benefits scheme is integrated into the health system, equipment provision is something that needs to be systemically available across the life cycle to all citizens with illness or disability.

In her review of the first Commonwealth/State Disability Agreement, Professor Anna Yeatman highlighted the need to look at the aids and equipment issue in a systemic context:

What this would mean in any case cannot be resolved without giving attention to the policy issue of just what is and should be the strategic role and place of cost effective equipment services within an integrated disability service system. It is important to emphasise that 'it is a policy issue in the first place, not a program management one, as it has been taken to be'.⁵

MS Australia strongly supports this observation, and urges the Inquiry to make significant recommendations about how NSW can improve the integration of PADP. While funding levels will always struggle to cope with demand we are obliged to design the best system integration possible to create efficiencies and collaborative arrangements that offer practical and timely responses to need.

The eligibility rules and limits for PADP and other equipment schemes are designed to protect the program borders and budgets rather than promoting efficient and effective service delivery. The worst of this has been demonstrated through the inability of a young person with a disability in an aged care facility being able to access State equipment schemes due to the rationing imperative of their eligibility criteria.

5.2.1 YPRAC program

This particular problem has been given a short term but effective solution in NSW by the injection of \$2m from the Young People in Residential Aged Care Program to PADP to 'buy' eligibility for their target group in aged care who are in dire need of equipment. This focus on the person's needs rather than the program budget is particularly welcome, and demonstrates that these problems can be solved – however the solution needs to be made permanent in the re-design of PADP to

⁵ Yeatman, A. *The Final Report of the Review of the Commonwealth/State Disability Agreement*, Australian Government Publishing Service, Canberra, 1996, p22

ensure that people with disabilities in NSW are eligible for PADP regardless of where they live.

The targeted approach being used by the YPRAC program demonstrates the benefits that can be derived from comprehensive service planning and delivery for priority groups.

5.2.2 Pressure care – an example of cost shifting

Pressure ulcers have major impacts on the lives of people with MS and spinal cord injury, resulting in extended time out of circulation (work, social and family activities). They can become socially isolated as a result of having to spend long periods in hospital or bed. Surgery or expensive vacuum treatment sometimes is required and long term complications are an ever present risk.

In 2001 it was estimated that \$350 million is spent on caring for patients with pressure ulcers. The inpatient recovery time for a serious pressure ulcer is measured in months or even years. In 2001 the cost of each pressure ulcer was \$61,000⁶. Using the CPI (which is less than the medical CPI), this has increased by 18% since 2001, and in 2007 would have cost over \$412m annually.

While not all pressure ulcers can be prevented, many are caused by inadequate equipment, notably seating and mattresses. Providing the correct pressure relieving equipment is not optional for the individual, however the waiting times and limits on types of products make it so.

It is common for people with MS with pressure ulcers unable to get the right equipment to spend up to 6 months in hospital recovering. Such a stay costs in the vicinity of \$80-100,000, and can result in increased community care costs and carer burden upon discharge. The purchase of an \$8,000 mattress and good seating in addition to self management support can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment.

This highlights the fact that it is false economy for Government to short-change aids and equipment schemes. This example is but one that demonstrates that it is more expensive and resource intensive to avoid providing the right equipment than to provide it. The fact that it is represented by cost shifting rather than cash deficits perhaps explains why it has been tolerated for so long.

The fact that we have allowed one of the lowest cost programs (PADP) to cost shift to the most expensive (hospitals) is poor economic and health policy.

5.2.3 HACC program

Client eligibility and commencement of HACC services are limited at times by the need to have timely provision of appropriate equipment due to OHS for direct care workers, family and clients. If equipment cannot be provided, clients may be impacted in the following ways:

⁶ Australian Wound Management Association. Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers. West Leederville WA, Cambridge Publishing, 2001

- The need for sponge bath in bed until shower chair/commode/bath seat provided and/or bathroom modified
- two person assist in transfers if hoist equipment is required, often carers/family members are asked to assist though they are in great need of respite from care or relationships have broken down
- approval of Home Care NSW referral may be on hold until equipment can be hired, provided or funded, therefore sit on wait list and lower in priority ranking, requiring constant follow-up by staff/client or family to progress referral
- increased load on family carers
- placement in aged care nursing home

5.2.4. Impact on MS Society allied health staff

The delay in funding approval and provision of equipment may mean sourcing alternative funding e.g. seeking assistance from the MS Australia Financial Assistance Fund (SAF), other charitable organisations such as Rotary, Lions or Sports Clubs.

Should funding from our SAF not be available to meet the request, it can exacerbate clients' disappointment, frustration, anger, stress, negative perception of allied health, MS Australia, government and/or community service providers. Staff with clinical expertise are spending time being diverted to fundraising activities rather than clinical or client related activity.

5.2.5 Cross program protocols

PADP needs to establish better links with key programs such as disability services HACC, Aged Care and the Continence Aids program to ensure needs can be identified globally and program staff and direct care workers can be trained appropriately.

A priority in this area is the development of a level protocol with NSW Health about the process of issuing equipment upon hospital discharge. We need faster issuing of equipment at this point. Ideally PADP should take responsibility for issuing equipment within its processes to stop the current buck passing and bickering at the local level that results in NO or substandard equipment provided by hospitals.

5.3 Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations

The MS Society supports the argument made in the PWC report for combining all equipment pools in NSW. The problem is a national one, but within the scope of this State, a lot can be done, and NSW reform may accelerate the national move to reform equipment schemes.

We also support the centralisation of PADP as part of that reform process. It is imperative that PADP becomes more streamlined, efficient and transparent. Centralised purchasing, administration and policy will assist to achieve this.

A central system with lodgement and distribution centres out in the regions is an efficient model. We see that a centralised model has the following advantages:

- It locates responsibility for the scheme in one administrative location
- It allows the development of clear policy and procedures
- It allows more sophisticated data management and reporting
- It creates the platform to better evaluate performance of the scheme
- It allows the negotiation of inter and cross program protocols regarding the provision and funding of equipment

The implementation and maintenance of this model will be time and resource intensive, however this investment is necessary.

5.3.1 Assessment

Assessment and prescription are extremely important components of the PADP and need to be reformed alongside the structure of the program. A failure to overhaul these parts of the system will result in a worse bottleneck at the front end of the scheme.

Assessment waiting periods are currently unacceptable, with people in some areas of NSW experiencing a waiting time for allied health assessment of 8-12 months. This is due to demand, staff shortages caused by burnout/turnover.

Information about the status of applications, once made, is very difficult to obtain, which increases frustration and exasperation with the program from clients and allied health staff.

The current restrictions on who can prescribe equipment in PADP are not efficient or effective, given the pressure on the allied health workforce in NSW (particularly in rural areas) and the need to prescribe quickly. This appears to be a clumsy administrative arrangement that is part of the response to rationing equipment rather than achieving good clinical and social outcomes.

In some areas of NSW the only staff with the relevant qualifications to conduct an assessment are in fact MS Society nurses and therapists, who undertake assessments – another example of cost shifting. These restrictions only serve to extend the waitlist and time delay - and compound the lack of capacity of MS Society staff to assist people with MS to adjust to diagnosis and live independently.

Part of the reform of PADP is for an increase in allied health staff in AHC and disability agencies that can make assessments and contribute to the care and support of people with disability. This will need to be funded from other programs, but will demonstrate a commitment to alignment of complementary programs.

5.3.3 Single equipment pool

The MS Society supports the notion of a single equipment pool in NSW. While equipment is recognised as a critical area of need for people with chronic illness and disability, our systems are grossly inefficient and poorly funded.

The inefficiency of having well over 40 separate equipment programs in Australia is overwhelming. State and Territory Governments, Workers Compensation and

CTP schemes, hospitals, aged care providers, HACC, disability brokerage programs, Veteran's Affairs, the DEEWR Workplace Modifications Scheme and School Education integration programs all are discrete purchasers of equipment.

The Lifetime Care Authority, MAA insurers and PADP have similar interests and would make a natural fit administratively to enter into an agreement about a joined up system.

The main issues here are:

- Enlarging the pool and breaking down some of the inequities that exist between schemes, particularly between insurance schemes and others
- There is currently limited capacity across programs (and in some cases within programs) to utilise any purchasing power for equipment
- Designing and implementing service level standards for suppliers for supply and repair of equipment
- Implementing benchmarks for Issuing or Lodgement Centres and any Central body covering information provision, application timelines and processing times.

This lack of attention to purchasing also means that there is little or no expectation to service level agreements with suppliers or customers. With the need for equipment supply being either time critical or functionally essential (particularly in MS) then why is it not seen as a priority by the equipment programs?

The impact on individuals of long delays in supply or repairs is becoming quite dramatic. Many care agencies have now declared pushing a manual wheelchair as an OHS risk, and so people who have their usual electric chairs in for repairs are very restricted – however there are no standards for service levels from suppliers within current equipment schemes.

Notwithstanding the reviews of some State/Territory equipment schemes currently underway (in Vic, SA and Qld), this sector is ripe for reform, and there is massive potential for better availability, resourcing, customer service and efficiency in getting a strong integrated national system.

The system used by the Department of Veterans Affairs (DVA) is a model that goes close to what is required in disability services, and whose model will be of interest to this Inquiry. The Victorian Transport Accident Commission also runs a statewide brokerage system for the sourcing, delivery, collection and recycling of equipment that delivers good price and service outcomes. The Inquiry may want to investigate these systems.

4. Appropriateness and equity of eligibility requirements

The eligibility requirements for PADP should be structured around need, not budgets. If the program can achieve adequate recurrent funding, then the eligibility criteria can be structured around clinical urgency and social needs to match the purpose of the program.

Eligibility for PADP is not one-dimensional. The redesign of PADP needs to be cognisant of the impact on other funding programs and the individual. If access to disability services or community care (including OHS requirements) depends on the provision of equipment, then this creates a shared priority that has to be a factor in determining eligibility. Links and cross program protocols need to cover eligibility.

Given the high cost of some essential equipment, and the urgency created by the progression of MS and similar degenerative conditions, we do not support income bands as an eligibility tool. The cost of MS is high and income levels on their own do not determine the urgency of need or the capacity to self-fund – or the impact of the consequences of non-provision of equipment.

A person with a moderate or above average family income can still end up having to be placed in aged care because of a lack of support, thereby creating allocative inefficiency in the health system and a devastating personal and family outcome.

As stated earlier the re-design of PADP should provide a disincentive to self-prescription and purchase of equipment by individuals.

Co-payments may need to be variable for each person, but as a minimum, there should be no means testing or co-payment for clinically urgent aids and equipment such as continence products, customised equipment or pressure care equipment.

5. Future departmental responsibility for the PADP

A number of factors will determine the location of PADP within the machinery of Government, but it is essential that the PADP has authority and reach across the Disability or Health areas. The imperative is for cross program linkages, so location is only part of this equation.

At their meeting on May 30 2008, National and State/Territory Disability Ministers agreed to work towards greater consistency in equipment schemes across Australia, so this indicates that they are taking responsibility for this development. In line with this agreement it appears that the responsibility for PADP needs to reside in the Minister for Ageing and Disability in NSW.

References

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