MS
AUSTRALIA

Seeking the Cure.
Providing the Care.

Senate Community Affairs Committee

Inquiry into the Commonwealth State Disability Agreement

MS Australia

August 2006

1. Introduction

MS Australia is pleased that the Community Services Minister's Council agreed that there will be a 4th CSTDA. The original aim of the Agreement of facilitating national disability policy has still not been met. This must be a critical objective of this next agreement. MS Australia supports the negotiation of a 4th agreement, however it must be a more strategic and comprehensive agreement than the 3 previous ones.

We are at an important point for disability services coming into this next agreement. While previous agreements have turned on the split of services and dollars, this next 5 years will rely heavily on policy responding to the current range of challenges, including supporting informal care, aging and disability, workforce participation, transport and increasing demand.

In a generation, the community response to disability has become an industry. What used to be charity, family and government responsibility has changed markedly. The range of interests has expanded to include the needs of workers and organisations as well as individuals and families. In this time the industry and government have adopted the language of the disability movement, and major achievements have been made, however while the quantum investment in services has increased, many people still find it impossible to find adequate support.

Within the framework of the CSTDA individual jurisdictions have taken great steps forward in developing their response to disability services. Victoria with its Disability State Plan of 2002 and NSW with its Stronger Together framework are to be congratulated for making serious commitments to the area. These are examples of the way the next CSTDA should be structured – with a mix of strategic and operational plans.

This next agreement needs to look forward, not backwards, and must be more ambitious in its scope. The need for a national disability policy framework and the capacity to use technology and other tools to increase the sophistication of the system at large is also necessary. With the rhetoric of successive agreements being about individuals, the complete lack of ability to monitor and deliver a coordinated response to individuals is a failure of the current arrangement.

1.1 Basic facts about MS

Multiple sclerosis (MS) is a chronic disease of the central. nervous system (brain and spinal. cord) and is the most frequent neurological disease found in young and middle-aged adults in developed countries (Johnson, Amtmann, et al., 2004[1]; Verdier-Taillefer et al., 1995)[2]. Diagnosis usually occurs in the 20s and 30s, with a peak at 25-30 years. Thus, MS tends to strike people at the stage of life when careers,

---

[1] 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.

[2] Verdier-Taillefer, M. H., Sazdovitch, V., Borgel, F., Cesaro, P., Kurtz, A., Millet, M.-F., Roullet, E., & Marteau, R. (1995). Occupational environment as risk factor for unemployment in multiple sclerosis. *Acta Neurologica Scandinavica*, *92*, 59-62.

relationships, and adult life in the community are consolidating, with resulting impact on work, family, and social. life (Nodder et al., 2000)[3]

. Recent data from the Australian Multiple Sclerosis Longitudinal Study indicates that 80% of people with MS lose their employment within 10 years of diagnosis, often in their 30s or 40s, with inadequate retirement savings, risks of social. isolation and disadvantages in re-entering employment (Access Economics, 2005)[4]. Thus, the impact of unemployment on people with MS and their families is profound, due to its association with loss of income and impaired quality of life (Metz, 2003)[5]. Premature retirement also takes a significant economic toll on society (Johnson, Amtmann, et al., 2005; Metz, 2003).

Effective disability management is driven by a multidisciplinary philosophy (Surastava & Chamberlain, 2005)[6]. Due to the particular characteristics of MS, it is essential. that a disability management approach to MS and employment be driven by multidisciplinary teams capable of acting not only proactively but in an accessible, highly specialised, and responsive manner.

This is because MS is characterised by a variable and complex array of symptoms, including physical, sensory, and cognitive changes that interact in a complex manner. MS is also unpredictable in terms of occurrence of attacks and disability development, and symptoms may vary from day to day, so that the needs of the client change (Johnson, Amtmann, et al., 2005; Nodder et al., 2000). Indeed, unpredictability is seen as one of most difficult aspects of managing MS (Reynolds & Prior, 2003)[7].

1.2 People with MS and the health /disability system

People with MS and similar chronic progressive conditions use many parts of the health and community care system (including local Government and disability Services), but are especially affected by the well documented fragmentation of services, policies and funding programs.

MS is a disease that is largely treated in the community. People with MS have cause in the course of their disease to require services from all levels of government. This includes public and private hospitals.

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.

---

[3] Nodder, D., Chappell, B., Bates, D., Freeman, J., Hatch, J., Keen, J., Thomas, S., & Young, C. (2000). Multiple sclerosis: Care needs for 2000 and beyond. *Journal of the Royal Society of Medicine*, *93*, 219-224.

[4] Access Economics. (2005). *Acting positively: Strategic implications of the economic costs of multiple sclerosis in Australia*. Report for Multiple Sclerosis Australia, Winter 2005

[5] Metz, L. (2003) The psychosocial consequences of multiple sclerosis. In W. I. McDonald & J. H. Nosworthy (Eds.), *Multiple Sclerosis 2* (pp. 329-339). Philadelphia, PA: Butterworth-Heinemann.

[6] Sirvastava, S., & Chamberlain, M. A. (2005). Factors determining job retention and return to work for disabled employees: A questionnaire study of opinions of disabled people's organizations in the UK. *Journal of Rehabilitation Medicine*, *37*, 17-22.

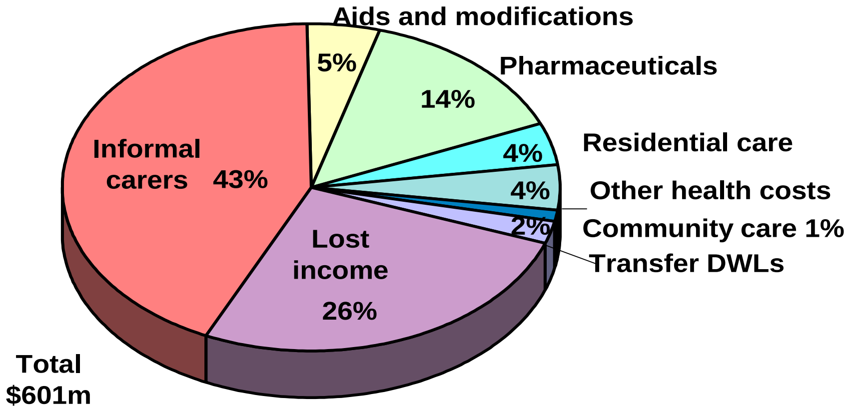
[7] Reynolds, F, & Prior, S. (2003). "Sticking jewels in your life": Exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research*, *13*, 1225-1251.

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 (Access Economics 2005).

The largest direct cost is that of the provision of informal care. The loss of productivity associated with MS of individuals and their carers is a significant issue in the design and function of the health system.

We must work to change attitudes that a diagnosis of MS condemns individuals to a wheelchair, bed or a nursing home. To the contrary, much can and should be done, as early as possible, to delay disability from MS and maximise functionality and quality of life. This is particularly pertinent for employers. Kidd (2001) is strongly supportive of early intervention concluding that it '*has the potential to make MS a truly manageable disease'.*

This points to the benefit of increasing the investment in overall disease management, including self management and education programs, so the management of the disease by individuals and families, and health workers is more effective.



MS direct financial cost (Access Economics 2005)

2. Summary of positions

Our positions on the 4th CSTDA can be summarised in the following 4 areas:

2.1 Expansion and Segmentation of the Agreement

The first Commonwealth State Disability Agreement was aimed primarily at shifting Federal responsibilities for disability services as it was in the 1980s. The structure and expectation of the agreement has changed little, and it has developed largely into a transactional agreement. Is time that it became a detailed partnership agreement that is capable of managing the strategic policy elements as well as funding arrangements.

We believe the landmark agreement about Young People in Nursing Homes at the Council of Australian Governments meeting in February has set a benchmark for how to address joint areas of gap and overlap in disability services. The COAG agreement recognised that to achieve a set of outcomes, a discrete approach was needed with a new funding formula (50/50) and a targeted strategy to develop and direct services to a particular target group. This issue based and outcome focused approach needs to be adopted in critical service areas in the CSTDA to ensure that the right strategic effort and funding goes into areas of disability services to achieve agreed outcomes.

While the primary service delivery responsibilities of the jurisdictions may remain, the old funding formulas need to be scrapped and re negotiated around national disability services outcomes. The CSTDA needs to detail the strategies and funding for each industry segment, with the measurable inputs and outcomes from each jurisdiction and the industry segment partners (providers etc).

We propose that the following outcome segments be negotiated into the agreement:

- Complex care services (including accommodation support)
- Chronic Illness Management
- Equipment Services (as part of developing a national scheme)
- Carer Support
- Employment/vocational services
- Transport

2.2 Carers

MS Australia believes that the suite of Carer programs and bureaucracies relevant to people with disabilities and their families should be brought within the ambit of the CSTDA.

In order to manage the critical levels of unmet need for disability services, the involvement of families and carer programs is essential. The inclusion of carers in the CSTDA would reduce fragmentation of available support services and broaden the strategic policy process.

It would also enable the streamlining of data processes across the bureaucracies and enable the programs to better respond to the joint and separate needs of people with disabilities and their carers.

2.3 Outcome Standards

The notion of disability is a very loose concept, and assumes a level of homogeneity amongst the group of service users. This is obviously not the case, and there are some very practical and cultural differences between diagnostic groups.

People with acquired disability and chronic illness have totally different experiences and expectations when it comes to looking at using support services, and in many cases the services that are required do not exist, or are not in the ambit of the sector they find themselves in. (Try to locate job retention support services).

In order to ensure there is good cross jurisdictional linkages and that improvements in policy and funding programs are realised. MS Australia supports the adoption of outcome standards in each of the CSTDA segments that detail the type, quality and responsibilities of jurisdictions and providers. To illustrate this we have included the National Service Framework for Long Term Conditions from the UK as an example. For people with MS and similar neurological conditions, waiting lists designed for people with stable conditions can be dangerous, and time delays in service provision can actually cause greater levels of disability.

We need to have systems that can prioritise in discrete areas and allocate resources on the basis of need and urgency across acute, community or workplace settings. These also must be nationally consistent.

It is also no longer good enough to have a single portfolio at each level of Government representing that Government. The fact that FACSIA has a marginal programmatic responsibility for disability services means it cannot deliver on disability programs or policy in DEWR or Health. Equally, Disability Departments at the State level cannot deliver on educational or transportation policy that may be critical to disability policy ambition.

The relevant Commonwealth or State Portfolio would need to be signed up to outcome areas in the CSTDA.

2.4 National Long Term Care and Support strategy

In the life of this CSTDA we must confront the big question of where the money is going to come from to fund disability services and aged care into the next generation.

In previous agreements, the main focus has been on service models, and more recently on innovative approaches to service provision. The bigger question we are confronting now is about funding models.

The current framework of funding and service provision has been in place for nearly 15 years, and the work on service models has kept them largely in sync with contemporary thinking (the move to individualised funding shows that things have changed). Noticeable changes are that in response to demand, individual packages are now smaller and more in number. Any changes to service models now are largely variations on themes, and while the work has been largely worthwhile, attention on model design has taken us away from the larger question of how are we going to fund services to meet demand, or to develop better ways of encouraging informal care.

Clearly the first step is to streamline the current framework and eliminate waste and duplication in the funding transactions between Governments, providers and individuals in the of the disability sector. Reducing the programmatic silos in disability and aged care (including HACC) is part of this.

We must start looking at models of social insurance, compulsory taxation levies and co-contributions to ensure that the funding base for disability services is secure and adequate.

There are some good models of no-fault insurance in Victoria and Tasmania, and now NSW has extended its no-fault cover for catastrophic injury for transport accidents. We understand that some private health insurance funds are looking at lifetime care products that may be of benefit to people with chronic illness and disability. Insurance options need to be considered along with increased Government funding to expand the resource base for disability services.

Insurance has a triple possible impact on the CSDA program. People excluded from benefits (because of the fault aspects of insurance) create pressures for government schemes (the Disability Support Pension as well as the CSDA). Insurance costs are said to be impacting on the financial viability of Non-government organisations and the resources available for support services. And insurers can be reluctant to insure some high support needs and 'dangerous' clients.[8]

MS Australia believes that an insurance type model of funding and service planning is a far more appropriate model for people with chronic progressive conditions than the current disability services system. Services have to be planned knowing that resources and that the expertise that is required is available. Currently people with conditions like MS are marginalised in the disability system because the system is largely set up for people with stable conditions, and growth in new services for people with acquired disabilities has been very small in recent years.

As a step in this direction, we recommend that people with neurological conditions can access a pathway into the service system that involves HACC, health and rehabilitation services and disability services.

We require a model similar to an insurance scheme where needs-based support services can be delivered to ensure continuity for this priority group, and prevent those things we know are preventable: early exit from the workforce, early carer burnout and entry into aged care facilities.

---

[8] Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls, Disability Data Briefing No. 22,September 2002:

Recommendations

1. The 4th Agreement

1.1 The Australian and State Governments re-negotiate the 4th CSTDA

MS Australia supports there being a 4th Agreement. This next agreement must 'grow up' in order to be effective. To make the changes necessary, the existing agreement should be rolled over for 12 months while the policy, governance and outcome structure of a more comprehensive agreement is put in place.

1.2 The CSTDA be redrafted to be a comprehensive agreement with clear outcomes and areas of activity by and within the jurisdictions.

Establish segments within the agreement to detail government responses to key elements of disability services that cross the jurisdictional limits of current disability services departments

- Complex care services (including accommodation support)
- Chronic Illness Management
- Equipment Services (transitioning into a national scheme)
- Carer Support
- Employment/vocational services
- Transport

2. Equipment Services

We recommend that further work be undertaken to investigate the establishment of a national equipment brokerage scheme. There is a pressing need to reform the way equipment is managed in all segments of disability, aged care and health.

The current collection of small schemes with unmatched eligibility and service levels cannot be allowed to continue. Such a scheme could be designed along the same lines as the one used by the Department of Veteran's Affairs, and would include all current disability equipment schemes run by States and the Australian Government, compensation schemes, HACC, Aged Care and associated brokerage programs.

3 Employment

The Department of Employment and Workplace Relations should be a signatory to the 4th CSTDA.

Employment is a critical policy and service area, and the largest single Australian Government disability program it must be directly accountable to the CSTDA. This will assist in managing the tensions between welfare policy and disability policy that exist at the national level.

3.1 DEWR undertake work to establish a specialist job retention support program with in the labour market program group of services that can assist people with disabilities and chronic illness to maintain employment.

3.2 DEWR expands the eligibility criteria for the work based personal care program to make it consistent with other attendant support programs in the CSTDA. This will result in people with a genuine need for support at work getting access to a very useful program.

3.3 DEWR include efficacious non PBS medications in the Workplace Modifications Program to ensure that people who can benefit from such treatments can access them to assist them at work.

4. Continuous Neurological Support Packages

To recognise the need for timely and appropriate service responses for those people with progressive neurological conditions, a targeted package needs to be implemented for people with chronic progressive conditions. This package is designed to support and improve the quality of life of young people in need of support for daily living.

This type of package would be able to expand when required to meet the growing support needs of people in this category and would include articulating different options from HACC, Carers programs, Aged Care and the CSTDA sectors to form a comprehensive support program.

The implementation of such as package would mean creating deliberate linkages between jurisdictions that do not exist at present that would be a model for other target groups within the respective sectors.

5. Funding Base for Disability Services

5.1 The funding base for disability services be expanded and a growth plan be agreed for each of the service areas within the 4th agreement. This should be formally agreed by both levels of Government so that the short funding of growth services that has plagued the 2nd and 3rd CSTDA (and resulted in the YPINH crisis) is not repeated, and that the risk of disability services being politicised across the jurisdictions is avoided.

5.1 Individualised funding

The various jurisdictions undertake work to bring about the consistent application of case based/individualised funding throughout the CSTDA system. People who access a range of programs face different and sometimes perverse program guidelines in trying to access the support they need from different programs

6. Aged Care Services

The Department of Health and Ageing should be a signatory to the CSTDA. Given that the DoHA is the 3rd largest funder of disability accommodation in the country, and also that they run a suite of chronic illness programs and national carer programs, they should have direct input into Disability Services to assist with linkages and direct services.

6.1 Younger people with disabilities who are eligible for respite in aged care services for respite be allowed to cash out their entitlement to be used in more appropriate settings in the disability system.

6.2 Given that the COAG Young People in Residential Aged Care program is largely limited to those people under 50, access to the full range of disability services (including equipment) be made available to people with disabilities residing in aged care facilities who are over 50.

6.3 Maintain the Innovative Pool funding program to supplement the COAG YPIRAC initiative for projects to trial innovative practices within Aged Care and HACC, and to assist with diverting young people away from aged care

7. Long Term Care and Support Strategy

The Council of Australian Governments address the need for a national long term care strategy that includes the management of disabling chronic illness, ageing as well as disability. This strategy should aim to secure the resource base for disability services through taxation, insurance and private sources. It should also map a process to reduce the overlap, duplication and shortfalls that characterise the current systems in Australia.

3. Aims of the CSTDAs

The broad aims of the first CSDA in 1991 were:

To establish an initial framework for the rationalisation of the administration of disability services by the Commonwealth and the States: and

To develop on a national basis, integrated services to ensure that people with disabilities have access to appropriate services that meet their needs

Getting Real, the evaluation report of the first Commonwealth State Disability Agreement notes that in the life of the first agreement the focus of activity was almost exclusively on the first of these aims.[9]

The second aim has only been partially met in the course of subsequent agreements. The language of the jurisdictions has aligned to the aim, however there has been a total failure in the effect of the agreement to 'ensure' access to services. It also has failed to deliver national consistency or a national policy framework for disability services.

There are disability services and associated health services provided outside the CSTDA (HACC, Aged Care, Carers programs), however the agreement has done little to 'ensure' access to these sectors and the services they offer.

From an MS perspective, the system has grown and access to increased numbers of community attendant care services has been useful. Other services, such as specialist respite care and accommodation have remained largely static, meaning that people with MS have been one of the largest groups of people with disabilities who have been forced into aged care settings.

The complex and disabling symptoms of the disease mean that (sometimes concurrently) people will require discrete support from a range of programs, including HACC, acute health, employment services and equipment. In the main, MS is a condition that is managed in the community, and the disability system is one of the sectors that can provide support. However apart form the work of the MS Societies (and this is not all funded through the CSTDA) there is little leadership and coordination.

Despite there being a clause in the CSTDA (5(5) (b)) stating that the jurisdictions will:

'Agree to encourage and facilitate intersectoral action to promote access to services for people with a disability', [10]

---

[9] Yeatman, A. *The Final Report of the Review of the Commonwealth/State Disability Agreement*, Australian Government Publishing Service, Canberra, 1996, p xiii

[10] Commonwealth State/Territory Disability Agreement, http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/policy-cstda.htm

- there is little evidence of how this happens – and there is certainly no obligation and performance measures on the jurisdictions to demonstrate their activity and outcomes.

Services within and across sectors are not properly coordinated, leading to inefficiencies and the need to solve crisis situations rather than deliver properly planned care.

Providers in the sector can only do so much to make progress in the education and influence of other sectors. While the MS Societies work to provide education and secondary consultancy services, operators in the health sector or aged care sector are not obliged to implement any of our proposals.

It is like the proverbial brick wall to try to influence other providers from inside the system. With the large number of competing demands, it is virtually impossible to change practices in systems or individual providers across the board.

A clear example of this is the position of a number of HACC Linkages services in Victoria refusing to take people with progressive neurological conditions into their programs because they are expected to have escalating needs that will clog the program and put stress on their budgets and waiting lists.

Another example is the refusal of Aged Care Assessment Teams refusing to assess people under 65 for Aged Care services. While it may be an honourable position to take in order to keep young people out of aged care, it effectively closes off an entitlement for an individual – whether it is appropriate or not, if it is the only option, and there is an entitlement to it, it should be offered.

MS Societies, like other specialist providers, have had little or no success in influencing these practices. What we need is leadership from the top to set practices, expectations and culture across sectors. In theory the CSTDA could have provided this leadership – but has not.

A New Strategy for Community Care - The Way Forward[11] (department of Health and Ageing) was a serious attempt at conceiving a streamlined programmatic service funding, however it has not as yet reached the CSTDA sector.

Certainly more needs to be done to link Commonwealth and State disability services – Importantly this must include not only cross jurisdictional activity, but also within the same level of Government. Serious deficiencies exist in linkages at the State level between health and disability services, and between disability, aged care and health (HACC) at the Commonwealth level.

A highly visible failure of these connections is the admission of young people with MS into nursing homes.

---

[11] *A New Strategy for Community Care - The Way Forward*, Department of Health and Ageing; http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-research-commcare-wayf.htm

3.2 Leadership, Policy and the CSTDA – the need for consistent approaches

Policy has certainly developed within individual jurisdictions of the CSTDA, but it is unclear what, if any influence the agreement had over these developments, or just because the work had to happen. The NSW Stronger Together disability plan, and the Victorian Disability State Plan 2002 are very good policy framework documents

Since the first agreement, there has been significant progress in moving to a needs based structure for disability services, however this has been as a result of development through the disability sector and the States, not specifically because of the CSTDA.

3.1 Data collection and performance monitoring

One thing that has improved in the life of the 3 CSTDAs is reporting. A lot of effort has gone into reporting. The Commonwealth has made this a priority and there are now protocols such as Quarterly Data Collection (QDC). While the QDC satisfies the need of the Australian Government for accountability for the money it provides into the system, it is fundamentally output data, and does not measure the quality of the service interaction or report any outcomes.

The Agreement should have mechanisms to measure the jurisdictions performance on a number of outcome measures, including, but not limited to counting the number of people serviced.

Due to the long term nature of disability, there are a lot of people in the system who are there for life, and measures on the engagement of new people is as important as looking at a rolling total of long term clients. Currently the data collection system used by CSTDA departments cannot discriminate between new entrants and existing clients – so there is no measure on how quickly waiting lists can be cleared, or what happens to people while they wait.

There needs to be rolling evaluation and reporting of unmet need data – although the Community Services Ministers have commissioned another AIHWE study, it is too long sine 2004 to understand the full measure of unmet demand.

Decent planning cannot occur without good data, and the lack of data is a major barrier to progress in the sector. There clearly needs to be a better way of working out the future resourcing of disability services that what individual Ministers can squeeze out of treasury year by year by year.

The next CSTDA should have mechanisms to measure the jurisdictions performance on a number of outcome measures, including, but not limited to counting the number of people serviced, numbers needing particular services and an actuarial measure of the future demand and costs of the suite of services from early intervention through to aged care.

The following exchange at Senate Estimates shows that the CSTDA data set, and even its aims do not govern all aspects of government policy making.

Senator WONG—But I am asking you: have you modelled how many people with a disability might be worse off working?
Mr Sandison—No, we have not.
Senator WONG—You have not looked at that?
Mr Sandison—No, we have set the policy rules in place according to the government decisions.

Senator WONG—In terms of the $50 a fortnight decision, was that the subject of consultation with any interest groups or community groups?
Mr Carters—That was a decision that was taken by government. There was not separate consultation on a $50 a fortnight figure, no.
Senator WONG—So there was no discussion with any agencies, community groups, Job Network members, ACOSS or anyone else?
Dr Boxall—There was discussion with agencies, and it could well have been discussed at the welfare consultative forum.
Senator WONG—I am sorry?
Dr Boxall—You asked if there was discussion with other agencies. There was discussion with other agencies.
Senator WONG—Who was there discussion with?
Dr Boxall—Other agencies in government.
Senator WONG—No, sorry; I was not asking about internal. I was asking about external: community organisations, agencies in terms of Job Network, social welfare providers—
Mr Carters—No, there was not any specific consultation by the department with those agencies.

Senate estimates 29/0/06 Employment and Workplace Relations[12]

The CSTDA needs to be strong enough to be reflected in any disability policy making –whether as part of election policy or other legislation. This also shows that having a small department trying to control a larger portfolio for such a complex area as disability (such as FACSIA tries to do with DEWR and Health) is totally unrealistic and unfeasible unless there is a whole of Government commitment to the outcomes sought by such an agreement.

---

[12] Senate Hansard, Employment, Workplace Relations and Training Committee, Senate Estimates Hearing EWRE 19, Moday May 29 2006

4. Difference s in approach to disability services by the States and the Australian Government

In It is a fact that as some of the programs at the State level have become more flexible (vis a vis the Support and Choice program in Victoria, individualised funding in Queensland), the Commonwealth disability services programs have become more rigid and less needs focused. In general the States have moved to embrace the individual support approach in their policies, whereas the Australian Government has funded services where the provider is the main focus (employment and aged care). Even the implementation of case based funding in employment services has been targeted at providers, not clients.

The most obvious examples are:

4.1 Work Based Personal Assistance Program

Prior to the change in the machinery of Government in 2005, the Department of Family and Community Services ran a small pilot program to provide people with disabilities. This was a successful pilot that saw people in Queensland and Victoria receive up to 10 hours per week of attendant care to assist them to maintain employment.

A number of people with MS utilised the scheme through the MS Society of Victoria, receiving attendant care to assist with workplace environmental control, note taking, transport, personal care.

A number of clients in the project are receiving attendant support at home or to assist with home care transport/mobility to and from work. Most of the clients with MS in the Pilot have been in work for some years successfully with this assistance

The WBPA program is now run out of DEWR, and has adopted highly restrictive eligibility criteria. The areas of support that are now eligible are:

- Personal hygiene assistance
- Feeding or tube feeding
- Nursing attendance

People with MS who have demonstrated a need for attendant support in the workplace would have lost their job well and truly before they got to the point that they needed this kind of personal care.

The historical clients have not fitted into the DEWR WBPA category at all well and people with MS that have genuine need for attendant support that are at risk in the workplace have no way of getting the support they need.

The WBPA program has been of great value to those historical clients who obtained it prior to the transfer of disability employment responsibility to DEWR.

The program as it stands is very limited in its scope and needs to be widened to offer support that can keep people in their work for extended periods.

Some examples of the types of support that is required by clients with MS, but not available under this program include:

Occupation	**Support needed**	**reason**
Call centre worker	Mobility and transport	Fatigue management – has been falling on public transport on the way home from work due to fatigue stress
Science teacher	Workplace setup	Client lacks the physical strength to lift and set up lab equipment on benches for students and packing up after class
Manufacturing designer	Mobility Assistance	Requires assistance in transferring from car to the office, workplace set up and with moving around the workplace.

This type of support is something that is put in place following the specialist intervention of the job retention service, and it does not replace it. These kinds of supports would be provided by attendant carers, not employment specialists.
The clients are well established in their jobs and can manage the technical aspects of their jobs but need support.

The WBPA program has the potential to provide the same advantages to workers and employers as the Workplace Modifications Scheme, and could make huge differences to people with MS who already have jobs, and whose changed circumstances demand support.

4.2 Welfare to Work- Disability Employment Services

The move of the Disability Open Employment Program to DEWR in 2005 have been accompanied by very strict rules of eligibility, type of service and financial incentives for providers. While we would support the increased opportunities to work, much of the system is out of step with the other aims of the CSTDA of individualised service, linking to other sectors and choice.

This shift raises the interesting question about the merging of disability services policy with Welfare policy. While there is clearly a link at the Commonwealth level, it is important to keep the issues separate. There appears to have been an effort at the Commonwealth level over the years to achieve Budget neutrality in the pursuit of disability policy.

Indeed it was made clear in the negotiation of the 2002 CSTDA that the States should support the changes to the Disability Support Pension as that saving would go into funding CSTDA growth. Clearly this is not the job of the States, and this budget driven approach is certainly not conducive to the development of strategic national disability policy.

It is now widely accepted that people with MS may leave employment prematurely. As stated earlier, the literature suggests that 80% of people with MS leave employment within 10 years of their diagnosis.

The Australian Longitudinal MS study shows that although people with MS have a higher level of occupational skills in the workforce, they work part time more frequently.

49% of people with MS reported leaving paid employment specifically as a result of MS. This was higher for males than females with MS.
Reasons for loss of employment were a combination of disease, environmental and social factors.

40% of people with MS in current employment at time of EI Study believed their employment was at risk due to MS. Reasons were similar to those reasons reported by people who had left paid employment.

40% of working age people with MS are recipients of disability support pension. [Australian Population: 5%].[13]

Current opinion now is that the best solution from an economic and equity perspective involves policies that enable people with MS to retain employment where possible, while recognising the need to have a solid welfare response for those who are unable to remain employed (Access Economics, 2005).

This stance regarding a proactive approach to maintaining employment is consistent with arguments in the current MS literature. These arguments advocate the need for work retention programs that provide aggressive, early, and ongoing accommodations to help preserve employment (Johnson, Amtmann, et al., 2005; O'Connor et al., 2005[14]), that is, a disability management approach. These accommodations include not only symptom management but education within the workplace and wider society (Johnson, Amtmann, et al., 2005[15]).

The Welfare to Work Program is designed to achieve increased employment outcomes for those who are not working, and has not considered the impact on this system on those who are, but who need support.

It has mostly ignored the need for job retention services, and is almost totally geared for finding new jobs for people who are not working at all. In fact there are exclusions to Disability Employment Services being able to work with those clients who are working – so the opportunity for a person in this risk group to seek job retention support is close to zero.

---

[13] AMSLS Economic Impact of MS Working Party, Socio-economic Status of People with MS and Life Transitions Following its Onset, Working Paper no.3, MS Australia, April 2005,

[14] 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.

[15] Johnson, Amtmann, et al., 2005

4.3 Young People in Nursing Homes

The history of the young people in nursing homes issue is well known to the Community Affairs Committee. The growth of this problem over the years is a direct expression of the incapacity of the disability system to absorb additional demand – particularly those people with high and urgent support needs.

The Department of Health and Ageing (DoHA) took the initiative on the YPINH issue by including it in their innovative Pool funding program in 2003. Despite there being jurisdictional issues to resolve, DoHA realised the significance of the problem, and understood that it was at the wrong end of cost shifting from the disability sector, and it had to generate a defensive strategy.

The fact that the issue had to be taken up outside the CSTDA by DoHA and the Council of Australian Governments (COAG) to be resolved demonstrates the limitations of the CSTDA structure. There has been ample scope in the agreement to solve this problem historically, and YPINH was even a priority issue on the Disability Administrators workplan in the last CSTDA.

The Department of Health and Ageing is the third largest funder of disability accommodation in the country, after the State Governments of Victoria and NSW. Other than a small number of Innovative Pool projects they have left the responsibility up to FACSIA – something they have shown they are ill-equipped to handle, as they have little policy or practice experience in the area of complex care or accommodation services

What was needed was an agreement around a funding model, not a constant rework of service models, something the Disability Administrators could not get beyond. The elevation of a disability issue to COAG is a positive step in the recognition (particularly at the Commonwealth level) that there are national dimensions to the unmet need problem and that they are prepared to acknowledge them.

5. Unmet need

5.1 CSTDA context

The previous agreements have been blunt in their application of joint funding arrangements – the agreement has settled on an 80/20% funding split regardless of efficacy or strategic advantage to either or both level of Government.

The linkages across both levels of Government has been poor – at the Federal level the relationships between the key departments has not delivered- and there is little leverage (policy or financial) from the agreement in areas such as early intervention services, education and transport.

The role of FACSIA has changed and diminished over time as has their role in managing the Agreement as the lead government agency. The Department of health and Ageing is the third largest funder of accommodation serves in the country but is still not linked to the CSTDA – in fact the lack of proper planning and growth funding has resulted in the cost shift of YPINH to DoHA from the CSTDA.

The negotiation of the 2002 agreement is a case in point about the failure of the CSTDA to address unmet need. The Australian Government through the then Minister of Family and Community Services and the FACS Department itself, stood firm on the notion of an 80/20 funding split and drove a very hard bargain over growth funding – despite AIHW data indicating that demand was increasing – particularly the demand for accommodation.

While this may have been seen as a victory for the Australian Government in its argument over funding responsibility achieved through the Family and Community Services Portfolio, the overflow of people with complex needs who could not get a service in the disability sector flowed into aged care.

States have significantly increased their spending on disability services in recent years. This has happened out of both desire and necessity, however as fast as the budgets are growing, demand is outstripping supply. This is not a problem created by state budgets or recalcitrance – it is a national problem.

The CSTDA had failed its intent largely during the first agreement as a means of developing national disability policy. Yeatman's evaluation of the first CSDA was instructive as to the needs that it should have met – but did not.

She made a number of recommendations from the detailed study of the first CSDA that were not picked up but are still relevant:

- Carers be included in the agreement
- Research into the quantum and nature of unmet need
- Development of a recognised formula for the funding of growth in demand[16]

5.2 Unmet need of people with MS

Given the recognition of the young people in nursing homes issue and the absolute growth in demand, a plan must be agreed by all governments to manage this demand. The Inquiry will see a lot of submissions specifically dealing with the question of unmet need, so MS Australia will not seek to duplicate this information. Specific data about unmet need is largely unavailable from the AIHW or CSTDA, and MS Society data is not kept on the experience of people on waiting lists, although we have strong experience of the consequences of unmet need with the high rate of admission of young people with MS to aged care.

The submission from the MS Society of South Australia and the Northern Territory contains relevant material about unmet need in the MS area. We also refer the inquiry to the MS Australia submission to the Inquiry into Aged Care for unmet need analysis in this area. (MS Society of SA and NT CSTDA submission)

The case study of SW in NSW (attached) is illustrative of the fact that outcomes are achievable, but much of the work that goes on to achieve these is getting through the maze of the system.

---

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

Access Economics has estimated the incidence of MS to grow by 7% over the next 5 years, so this is something that demands solutions to the current logjam in disability services for this group. Access also found that the biggest single direct cost of MS was the replacement cost of informal care. The average care load for this group of carers was 12.5 hours per week, which is very high, and highlights the high needs and vulnerability of many people living with MS. (Access Economics 2005).

5.3 Community care packages getting smaller

We have noticed that the size of available care packages coming out of disability programs in some states (particularly Victoria) are getting progressively smaller as the demand on limited growth funds intensifies. Clearly, as in HACC, it appears that the position has been taken to spread available resources as thinly as possible over the largest group of people as a way of managing demand. While this meets the needs of some people, those who have high needs and progressive conditions have few, if any options.

6. Problems arising in part from the nature of service provision in State and Federal ‘silos’.

Government and community responses to disability and chronic illness do not begin and end with disability services. While service delivery is the main area of focus, many other mainstream areas of community life need to be cognisant of people with disabilities – and so most policy portfolios with the Australian and State Governments need to be led on disability issues.

FACSIA remains the lead Agency at the Australian Government level in regard to disability services despite being the smallest and least involved agency in the delivery of disability services. This is a situation that has definitely hindered development of the sector, due to its inability to lead and champion disability issues across Australian Government portfolios including employment, education and health.

This problem is mirrored in the States where key areas such as infrastructure, transport and health are not directly included in the CSTDA work of the lead disability departments who are CSTDA signatories, and where the general policy response is limited.

The Victorian State Disability Plan is one genuine attempt to influence whole of Government action on disability, and stands as an example of how the issue can be approached by a government.

The historical focus on service delivery by jurisdiction and portfolio by Governments has been one of the major barriers to greater progress on disability issues in Australia. In this next 5 year period covered by the CSTDA we need a disability policy framework as well as a disability services framework. They are linked, but are not the same thing.

Despite the existence of '*The Way Forward'* blueprint, there are some anomalies even within the Department of Health and Ageing suite of programs. Programs run in one Government Department are not known or are off limits to those receiving support in other jurisdictions.

The data set available to policy makers is not sophisticated enough to track needs or service engagement for the same target groups. Other submissions to this inquiry will also raise the issue of segmentation – MS Australia wants to raise some specific examples of how this is being perpetuated by the current CSTDA arrangements and not being addressed at the program level.

7. Equipment

Equipment is a vital ingredient to independence and best function for people with MS, whether at work, at home and in the community.

The availability, waiting times, and item related funding limits create major difficulties for people with MS. These problems are highlighted by the progression of the condition that does not wait for waiting lists

Access to aids and equipment is an important for people with MS. Home and workplace modifications, wheelchairs, pressure mattresses and like equipment are things required by many people in the course of their MS. With the progression of the condition, upgrades and refitting is often required. The timely provision of equipment can in some cases delay or replace the need for formal disability services.

The Aids and Equipment schemes are run by State Governments, and across the country the waiting times and funding limits are problematic. These schemes supply people with disabilities and older people, so demand is growing and specialised equipment can be expensive. It is the case that this equipment is essential, and that attempts to limit or deny access to some equipment is a false economy. If a person cannot get the equipment they need, other problems occur as a result.

We are aware that there are people with MS who have experienced long periods of hospitalisation for skin breakdown (pressure sores) because their equipment needs could not be met. In many situations the prescribed pressure mattress or wheelchair could not be fully funded through the Government schemes, and the additional resources could not be secured, so the person has tried to get by with inadequate or no equipment.

Funding limits for equipment like mattresses or wheelchairs can be as little as 50% of the purchase price, leaving the individual and the family to find the difference. In most cases the $4,000-6,000 required is simply not there. This is also a common reason for young people to end up being admitted to nursing homes, because either disability is worsened by the lack of correct equipment, or the effort required by families to care for a person with a severe disability without the right equipment is overwhelming.

It is an appalling and recurring experience that people are forced into long term, expensive institutional care as a consequence of one government program being under-funded and inflexible. MS Society staff and community case managers can spend a lot of their time chasing small pots of money from a range of programs to get the equipment people need – sometimes wasting more resources in the pursuit of this funding than the dollar amount actually required.

This cost shifting and splintered responsibilities of health and community care programs is wasteful and creates poor management practices based on bureaucratic structures rather than clinical imperatives.

7.1 Continence Equipment

The Continence Aids Assistance Scheme provides a subsidy for continence aids for people with MS and other disabilities. This subsidy is $470 per year. Depending on the nature of the person's needs, this is nowhere near enough, and the cost has to be met privately, or through supplementation from the State Aids and Equipment schemes where possible (this is mostly where spare capacity).

Also once a person turns 65 they are no longer eligible for this program and must find an alternative source of support. In many instances for people with MS the options for alternative support are unclear or unavailable.

It is imperative that this barrier be removed from the program and that a way found to continue funding people who require continence aids from the one program. There is an opportunity to fix this in the process of remaking the HACC agreement, and also in the upcoming renegotiation of the Commonwealth/State Disability Agreement. This is one area of split responsibilities that is difficult to defend from any standpoint.

7.2 Workplace Modifications

MS Australia is pleased with the expansion and streamlining of this scheme in the DEWR portfolio, and believes that this program should incorporate a wide view of the measures required to support a person at work.

Access to the non PBS medications detailed above to combat fatigue and neurogenic pain where indicated would be a boon to many people with MS for whom those symptoms affect their ability to work, and who have no other means of access.

Such a measure for Neurotin would cost in the order of $1,500 per year, but have many health and productivity benefits. Already DEWR fund workplace attendant care services to people with disabilities that cost up to $15,000 per year, so it is not expensive. This DEWR program has potential to be extremely effective if it takes a flexible and pragmatic approach to workplace support for people with MS

7.3 Strategic issues around equipment

In *Getting Real*, Yeatman highlighted the need to include equipment services in the suite of disability services. In particular, the report recommended that work be done around equipment services:

…that [equipment service] is strategically integrated with the rest of the specialist disability services system, is accessible to all people with disabilities who need equipment and is provided for in ways which are customised appropriately…"

The Equipment Study that was part of the evaluation also found that the provision of equipment then was fragmented, lacking in access, equity, effectiveness, efficiency and accountability. It was noted that it is an area that had not received its fair share of systemic policy attention.

In Getting Real, Yeatman says that just bringing equipment into the CSTDA is not enough:

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'. [17]

MS Australia agrees that the Yeatman's comments about equipment being a strategic policy imperative. 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.

The example below, quoted in the Access Economics report is very typical of a raft of cases on which MS Societies work. It shows the pressing issues and risks associated with the non provision of equipment to people with MS. Too often at present, services are provided that are neither timely nor consistent with the person's stage of progression of MS.

In practice, MS Society staff (mostly allied health professionals) spend a lot of time chasing top up money for equipment from service clubs and philanthropic trusts where the local equipment scheme's funding limits are well below the real cost of the prescribed item. This is particularly the case with electric wheelchairs, pressure care products and home modifications. This is fundamentally a misuse of professional time that should be available to actually provide services.

Peter has had MS for 14 years, and now permanently uses a wheelchair for mobility. In 2004 Peter was assessed as being at high risk of developing pressure ulcers that involve prolonged treatment and care.

He has already had one prolonged hospital stay (four months) in a rehabilitation bed in hospital because of difficulties managing his care and skin integrity, at a cost of around $45,000. His family currently provide all but seven hours per week of regular care, with Peter attending a community program one day per fortnight.

He has been prescribed a replacement pressure relieving mattress to manage his pressure ulcer risk, at a cost of $7,650. The State Disability Equipment program

---

[17] Ibid: p22

has a funding limit of $800 every two years for pressure care equipment, based on the cost of a wheelchair cushion. This program, that funds all disability equipment, has no provision for pressure mattresses and Peter is unable to meet the $6,850 shortfall.

His care regime, operated by his family, has adapted to a less optimal option to protect his skin, while on a waiting list for an attendant care package of 34 hours per week to share the care.

If Peter experiences further skin problems he faces further long stay admissions to hospital for treatment of pressure ulcer. In addition, if his family care arrangements falter without adequate attendant care support, he risks a high care permanent nursing home placement, for perhaps 30 or more years.

The provision of the pressure mattress and care program when required may well be the most cost-effective (and compassionate) response.
Peter, 51years, Melbourne

7.4 Equipment program management – the need for serious reform

While equipment is recognised as a critical area of need for people with chronic illness, we have a fragmented and nonsensical approach to the delivery of equipment.

Equipment can be an expensive service to provide, including the need for customised equipment, however 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 Workplace Modifications Scheme and School Education integration programs all are discrete purchasers of equipment.

The rules about the eligibility and limits to equipment programs are designed to protect the borders of each of these discrete programs, rather than to promote efficient and effective service delivery. The worst of this has been demonstrated through the inability of a young person in aged care being able to access required equipment, and in the fact that there are at least 3 different places to go to get continence equipment depending on whether you are under 16, over 16, or over 65, or whether you live in care or at home.

The CSTDA signatories are major purchasers of equipment however there is no mechanism across programs (and in some cases within programs) to improve purchasing power with suppliers and extract better pricing.

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 in long delays in supply or repairs is becoming quite dramatic. Many care agencies have now declared pushing a manual wheelchair as a 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. MS Australia is aware of a one DVA equipment broker – *E-Quip,* operated by the Yooralla Society of Victoria that delivers good price and service outcomes through purchasing agreements and referral processes. The E-Quip model is also worthy of evaluation.

8. Jurisdictional Interfaces

The Ageing/Disability interface issues have been highlighted in recent years through the Young People in Nursing Homes issue, something that the Community Affairs Committee is very well aware through its work in the Aged Care Inquiry.

There are a number of elements to the aged/disability interface problems that are related to generational issues and combination of age and disability factors, and others created by the system itself. These will be addressed by ACROD and others involved in Ageing and Disability Projects within the Sector.

Our references to this term of reference will concentrate on the experience of people with MS being forced into the residential aged care system, and the interaction of related aged care, carers and disability services.

The increasing numbers of people with disabilities entering residential aged care has been analysed by this Committee and the COAG Health group, and it is recognised through the COAG YPIRAC project that efforts need to go into stopping admissions of more young people as well as offering alternatives to the current group of young people in nursing homes.

Quite apart from the technical points about why people end up in nursing homes, it is clear that the disability system’s lack of capacity and poor rate of planned growth is a central issue.

The structure of the CSTDA has itself been a contributor to this problem. While States have the service delivery responsibility for accommodation and community support services, they only have a partial responsibility to finance the system.

8.1 Carers Programs

MS Australia is vitally interested in carer issues, as families play an important role in the course of the disease. Access Economics valued the replacement cost of informal care provided to Australians with MS at $257.7m in 2005[18].

---

[18] Access Economics, 2005

MS fell into the very high informal care group of diseases with an average of 12 hours per week in informal care being provided to people with MS and also 16% of longitudinal study respondents said that a carer/spouse had to change their employment arrangements because of the course of the disease.[19]

> *It's not just my wife who has to cope with MS – our whole family has it as well, it's just that no-one else notices. My fatigue levels are pretty bad as well trying to be a carer as well as a husband.*
>
> *Robert, 54, carer and part time accountant, Victoria*

The carer movement has been extremely successful in the last decade to ensure that carer issues are firmly on the policy agenda at all levels of Government. The Commonwealth has taken primary carriage of carer services through the Commonwealth Carer Resource Centres, although many State programs also include carers, particularly those aimed at children.

In many ways the Carer programs that have been funded in the last decade are part of the demand management strategy for care services. Since the first CSDA, Carer services have grown and have provided a major source of new funds to support people with a disability.

Carer Education programs, information and targeted respite and other services have made a significant difference in accessing services and preserving informal care relationships at home.

The fact that there is a separate bureaucracy now operating support for carers raises questions as to whether many of the direct disability services provided through the carer service networks (respite, personal care packages, day programs, equipment etc) are better provided through the same structures as the regular services provided for the individual with the disability.

The support of carers is something that must complement the disability system. In many ways this happens currently with the income support, information and brokerage – however there is duplication.

8.1.1 Brain Foundation DVD

The DVD clip we have submitted with this submission tells the stories of a number of families – in particular the story of Bushy and Mary who live with MS. It demonstrates the importance of approaching the care arrangements for families in an integrated way. [20]

More information about Brain Foundation Victoria is included in Appendix 2

---

[19] AMSLS Economic Impact of MS Working Party, Socio-economic Status of People with MS and Life Transitions Following its Onset, Working Paper no.3, MS Australia, April 2005, p.i

[20] The Brain Foundation provide a range of carer support services for people with neurological conditions. BFV is co-located with the MS Society of NSW/Vic in the Nerve Centre in Melbourne. The clip can also be viewed at http://www.msaustralia.org.au/bushy.wmv

The purpose of including this short clip is to show how important it is to make it simple to deliver care and support into families, who view their situation through very different eyes than policy makers or service providers.

Bushy and Mary only need a single point of reference for their disability services – which would include his support and respite. Bushy knows the difference between the various care programs, but essentially respite is respite, attendant care is attendant care and equipment is equipment – it all forms part of their care routine – and the less time he has to spend playing the bureaucratic game to get what he needs the better.

At certain points on the policy spectrum there is a risk that the carer movement is seen as being in competition for attention in the whole question of unmet need for people with disabilities. Having a whole separate system for carers that shares the same target group (in regard to the provision of direct services) as the disability programs and the distinction about who is the 'client' and whose needs predominate can be murky.

What is needed is a consolidation of the vision and objectives around community care and support, whether it is for people who live with family or alone or in shared supported settings. The recurrent funding for the suite of direct and indirect services must be secured taking account of the need to either share the care with families, or replace it when it is not available.

The recent budget initiative for respite care to assist employed carers is expanded to target the carers of people with MS to ensure that respite services are introduced in a dignified and relevant manner, and will offer greater employment continuity to carers – as long as it is extended to carers of working age people;

The Commonwealth National Respite for Carers program and State disability programs fund shared care and respite services for carers and people with MS (and other young people with disabilities) that:

- are lifestyle friendly, flexible and age-appropriate;
- are available over the long term course of the disease; and that
- offer improved case management input to ensure good planning and packaging of services.

Example of crazy boundaries – the National Respite for Carers Program

The National Respite for Carers Program ran a funding round in late 2005 for services and research to address the needs of working carers. The group of working carers is one that is being targeted because of the strategic importance in supporting them to maintain their workforce participation and caring role. The focus on this group is welcome, particularly since the AMSLS notes that 16% of people with MS report that family members have had to change their employment to accommodate their disease.

This funding round was expressly for those people caring for the frail elderly – despite the program having little data on the profile of the working carer group. The MS Society of Victoria was successful in this round for research into the needs of working carers in a number of large Victorian companies. To complete the picture and to be able to process data about carers of younger adults or children with disabilities, we will have to seek additional funding from other sources, despite these younger carers being targets of the National Carer Respite program and the Carers program generally.

In the CSTDA the Commonwealth ‘shall exercise a national leadership role in collaboration with the States and Territories in respect to research and development.’, however in this case, because the Carer’s program is operated in another Commonwealth Department than FACSIA, it has bypassed the notice of the Commonwealth

9. Home and Community Care

9.1 HACC Services

While HACC is not in the CCTDA, there is significant overlap and sharing of target groups with the disability sector at the State level. HACC can work as a good entry point for people with MS who are beginning to require support of a domestic nature, and can also provide social support programs that can be useful for those people who are no longer working. There are also some useful group HACC programs for carers and people with neurological conditions. The focus of this section is on individual care services within HACC.

The difficulty comes with matching the increasing needs of this group when they begin to need additional support. At present HACC providers have some flexibility in bulking up individual packages while alternatives are sought in disability services.

This is not easy or guaranteed in any way, as there is no protocol between HACC and Disability Services- even though the progression of the disease is guaranteed.

Any discussion of unmet need in the CSTDA sector cannot proceed without looking at how the HACC system and its suite of programs and local planning resources. The HACC service delivery framework must also be consistent with Disability Services objectives and policy. Major policy changes need to be canvassed with the disability jurisdictions before implementation, as some changes have profound effects.

One such change in recent years put great pressure on individuals and disability services – it was that people could not combine their HACC 6-7 hour per week package with an attendant care package. This was a useful option for those people that needed more than the 34 hours per week available through attendant care programs – and making people surrender their HACC hours did no good, and did not mean that any other hours were available anywhere else.

Currently the HACC model is taking some very disturbing turns. We have included a couple of examples from 2 States that demonstrate that people with chronic progressive illness, and those not on the rehabilitation pathway are going to be severely disadvantaged.

Example 1 – Victoria

The following email was circulated to providers in the Eastern Region of Melbourne outlining the move to ‘Person Centred Planning’ – a worthy model, but one that can be used by funding programs to mask cost-cutting and exclusion.

The move away from a ‘dependency’ model is not good news for those with genuine and growing needs for support.

> -----Original Message-----
> From: Lisa.Dean@dhs.vic.gov.au [mailto:Lisa.Dean@dhs.vic.gov.au]
> Sent: Wednesday, 9 August 2006 4:59 PM
> Subject: Please Note Change of Date due to a clash with a major Local Government Aged Care Conference - Introduction to Person Centred Approach -now on Thursday 5 October 2006
>
> ***Please note change of date due to a clash with major Local Govt
> Aged
> Care Conference in the EMR**
>
> Introduction to Person Centred Approaches
>
> As many of you may be aware, the HACC Program is currently undertaking the Active Service Model Project that aims to increase the Victorian HACC Program's effectiveness in maximising client independence through person centred and capacity building approaches to service delivery.
>
> *The challenge for the HACC Program is to move from a 'dependency' model of service delivery where tasks are largely done for clients, to a restorative care and capacity building approach where the aim is to retain or improve clients' independence. (our italics)*
>
> While there is much work to be done within the Active Service Model Project, this workshop aims to introduce participants to the general key aspects & principles of Person Centred Approaches and provides an opportunity for participants to start thinking about how this approach may be integrated (or further integrated) within the work place.
>
> Discussion around the topic will explore the importance of implementing a person centred approach within service structures and what this means for staff, HACC clients and their families/friends.

Example 2 – Western Australia

This example is drawn from guidelines circulated to HACC providers by the Department of Health in Western Australia. It is an attempt to manage demand, and effectively cuts off avenues for people with progressive conditions and their providers to be flexible in meeting their needs.

Perhaps the most disturbing part of these guidelines for people with MS is the section that and makes a low priority (read exclude) people on the basis of simply being eligible for other services. There are numbers of people with MS who are eligible for Disability Services Commission Services but do not get them. In the meantime, if they are not at obvious risk of entry into a nursing home, then they are also a lower priority.

The fact that there is a limit now of $12,000 per client for a client from **all** providers also limits flexible and creative use of packages to meet need to bridge the gap until DSC funding can be delivered.

These guidelines have been written clearly to protect the program and encourage throughput, however unless there is a complementary expansion of DSC and other funding to service those who will no longer receive the level of service required by HACC, they will simply serve to exclude people with progressive conditions. This will inevitably lead to the adoption of policies we have seen in Victoria where HACC providers do not take on people with MS because they have increasing needs and will create problems for the program trying to accommodate them.

Priority of access to services should be given to HACC eligible clients who:

- are receiving no formal services;
- are living alone with no informal support;
- are carers with demonstrated high levels of carer stress;
- do not have access to, or are ineligible for, assistance through other government programs (for example, Australian Government Community Aged Care Packages (CACP)/Extended Aged Care at Home (EACH); DSC (Intensive Family Support, Accommodation Support Funding and Alternatives to Employment));

and/or

- have completed an independence program episode (for example, Personal Enablement packages (PEP), Home Improvement Program (HIP), Wellness Approach to Community Homecare (WATCH).

Therefore, priority of access will be lower for HACC eligible clients who:

- have access to, *or are eligible for, other government programs*; and/or
- are considered less *at risk of premature or inappropriate long term residential care* (for example, younger people with disabilities under the age of 16 years who may have other funding and family support options).

5. Service Levels

- Service levels relate to the aggregated amount of services provided to a HACC eligible client from **all** agencies, not just one agency. It is anticipated that agencies will have better access to the sharing of client information in line with the ongoing development of technology….
- If a person requires services in excess of $12,000 per year, agencies need to consider whether to refer the client to an Aged Care Assessment Team (ACAT) or DSC for a comprehensive assessment. A comprehensive assessment will provide the agency with information to support the ongoing delivery of appropriate HACC services or a referral to a more appropriate service.

- *Agencies need to be aware that increasing service levels may not meet targeting strategies and may not bring about the best outcome for the individual.*[21]

The last dot point in this guideline is also of concern, particularly when the 'individual' has MS and has no bridge between HACC and the Disability Services Commission. It may be trying to cover other situations including risk situations for

---

[21] Health Department of WA, Guidelines for Service Provision Levels in the Home and Community Care (HACC) Program in Western Australia, Aged Care Policy Directorate August 2006, *pp 4,5*

older people at home – but that is exactly the problem – different groups with competing needs need different treatment, but do not get it.

There is talk between Governments about transferring PWD into CSTDA from HACC. – this is a discussion that needs to be had – and must be in the context of meeting demand and unmet need. Given that HACC tries to manage two very different target groups – one long term (younger people with Disabilities) and one relatively short term (frail aged people) they need to have programs that are designed for each of these groups, not simply apply one model.

10. Disease management of MS - The need for a model and pathways through the health and disability system

Most of the MS Societies in Australia are funded traditionally through disability services, and the focus of our work has been in this sector, with linkages into other acute, sub acute, community health and aged care services. When symptoms begin to show, and supports are needed, it is often services in the suite of disability services that are required.

What is required is a disease management approach that can provide responses to the individual and their family at every stage of the disease process. Although this is an initiative goes beyond the scope of the CSTDA, the agreement and policy framework must support, assist and reward service coordination.

A lot of store has been placed in various case management approaches, although in the disability context their reach has been limited. The current national chronic disease management strategy for long term conditions recognises the need for a continuum of prevention and care interventions that correspond to different stages of the disease. Care coordination within a disease management context is being used effectively for chronic illnesses such as diabetes, dementia, and congestive heart failure. The efficacy of this approach for people with MS is just beginning to emerge.

The US National Multiple Sclerosis Society has issued an Expert Opinion Paper on the use of rehabilitation in MS and concluded that:

"While the disease course cannot be altered by rehabilitation, a growing body of evidence indicates that improvement in mobility, activities of daily living (ADL), quality of life, prevention of complications, reduction in health care utilisation, and gains in safety and independence may be realised by a carefully planned program of exercise, functional training and activities that address the specific needs of the individual." National MS Society US (2005).[22]

The Access Economics report, too, recommends the benefits of early and timely intervention for people with MS.

---

[22] National Multiple Sclerosis Society (US) (2005) Expert Opinion Paper: Medical Advisory Board of the National Multiple Sclerosis Society. Disease Management Consensus Statement.

"Timely and cost effective health interventions have the potential to retard growth in future direct and indirect costs of MS and enhance the quality of life of people with MS in Australia over the longer term. These include pharmacotherapies, psychosocial interventions, achieving better linkages between health and disability programs, developing care pathways across jurisdictional boundaries, health promotion programs, enhancing collaboration, meeting the special needs of disadvantaged groups" (MS is over represented in rural areas) and adopting innovative financing solutions. [23]

10.1 National Service Framework for Long Term Conditions

The UK example of the development of the National Service Framework for Long Term Conditions is well worth following here in Australia.

It is a mandated program that aims to get a focus on the individual and best practice care/service across jurisdictional responsibilities. The imperative is to follow the course of the disease in service provision not the bureaucratic landscape, and the Quality Requirements (standards) include all areas of life and intersections with the service system – health, acute care, employment, community support, palliative care and carers.

These standards are being promoted by the UK Department of Health with an expected complete inclusion date of 2015. In Australia we would expect to have them in place sooner than 10 years with a commitment to good disease management strategies.

The full National Service Framework for Long Term Conditions document has been attached to this submission and is also located at http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/LongtermNeurologicalConditionsNSF/fs/en

The Foreword by John Reid, the Minister for Health to the British National Service Framework for Long Term Care also highlights the need for coordination and joined up systems

'many people living with conditions such as Multiple Sclerosis or Parkinson's Disease the main issue, until science can find a cure, is improving the quality of their lives, supporting them to manage their symptoms and live as independently as possible. We now need to build on what the NHS and social services have achieved and develop services which can respond better to the needs of this group of people.

The NHS Improvement Plan: Putting People at the Heart of Public Services sets a new strategic model for management of long term conditions through self care, disease management and case management. This NSF is a further demonstration of the priority health ministers attach to improving the lives of people with long term conditions by:

- *giving people choice, through services planned and delivered around their individual needs;*

---

[23] Access Economics 2005, p. v

- *supporting people to live independently and play their full part in society;*
- *coordinating partnership working between health and social services and other local agencies.*[24]

Access Economics identified the challenges in delivering appropriate care in managing MS in the Australian context:

- *Specific care pathways are required. The goal and benefit of tailored service provision is thus avoidance or delay of costly and inappropriate institutionalisation. An alternative and more appropriate model of care would be HACC-type annex services that are age appropriate and flexible, to grow as the needs of people with MS grow, without having to change systems as the disease progresses*
- *skilled workforce shortages in allied health, community health and general practice, particularly in certain areas;*

- *insufficient appropriate education and training in the formal health care sector or to adapt/adopt more effective models of care for young people with disabilities;*

- . *the need for a special type of carer (as with palliative care), who has the training and capacity to cope with the chronic progressive illness compared to acute illness with a 'cure';*

- *disability service awards are lower than hospital awards for the same class of workers, leading to higher turnover and more junior staff than desirable in disability services*

- *episodic case mix funding does not take into account the progressive nature of MS. Moreover, because of the younger age profile of people with MS, aged care services are seldom appropriate.*[25]

In many cases people with MS do not apply for disability services because they are settled in a routine with their support arrangements, and practically, a 'just in case' application for future and unknown needs is purely speculative.

10.2 A dedicated Continuous Care Package for people with progressive conditions

A solution to the problem of having to shift jurisdictions and programs as a persons needs increase lies in the development of a package of care that can grow and adapt to meet the various needs.

We are attracted to the model of continuous care that was proposed in the aged care context by McCallum et al in 2001. It could be easily adapted for people with progressive conditions within the disability context.

---

[24] Department of Health (UK) National Service Framework for Long Term Conditions, March 2005, Best Practice Guidelines, Gateway Reference 4377., p1

[25] Access Economics 2005, p 78

McCallum et al called it the *Continuous Care Restructuring Program (CCRP)".*

The Continuous Care service structure would require us to revisit the way public funding is provided to subsidize long term care for older people who have high levels of dependency and require specialized assistance with activities of daily living. The concept realises the potential to remove the boundaries between residential care and community care, and to focus on assessed care needs, care planning, and choice of care setting as an outcome of those.[26]

This is described diagrammatically in the 'continuous care attachment. It is an adaptation of the original concept. This describes how a package of continuous care could work through the various systems.

11 Solutions to overlap, inefficiency and targeting of resources - Segmenting the CSTDA

The CSTDA is a very blunt and ineffective vehicle to manage an important and growing need in the community

The framework for disability services also needs to recognise that the disability group is not homogeneous and a range of approaches and linkages need to be made

The carers' movement has grown up to a point that it is potentially competing with people with disabilities for resources, and could be seen as adding to the complexity of the system. – The suite of carer services relevant to disability services need to be included in the agreement

Segments need to be included into the CSTDA to reflect the sophisticated response that is required to meet the growing demand and complexity that will come in the next agreement timeframe.

Across all these segments, appropriate levels of growth funding needs to be agreed and built in to the Agreement. Much of what is wrong with the system can be attributed to lack of resources, meaning that programs have tortured well meaning policy in order to deal with the lack of money for demand.

These segments are:

11.1 High care needs - accommodation and community care-

The recent COAG fix for the young people in nursing homes was a milestone in disability policy making in Australia. After years of buck-passing, the governments came to the decision that the issue was important enough to go 50-50 on funding.

The $244m that was announced will certainly assist some people but will not completely solve the problem – particularly for the group over 50.

---

[26] Mccallum, et.al Australian Aged Care & the New International Paradigm. AUSTRALASIAN JOURNAL ON AGEING, VOL 20.3 SUPPLEMENT 2, SEPTEMBER 2001 PP 5 - 14

.

The 50-50 partnership needs to become permanent to reflect the joint interests of both levels of government. The Commonwealth needs to invest in a defensive strategy for aged care and the States require the innovation at the local level to meet this critical need. The governments have already noted that this is a shared task

In this segment, specific provisions need to be made in regard to

- Health promotion and research
- Ageing and disability
- Interface between Health and Disability Sectors
- Service and funding models
- Workforce development
- Clinical services

11.2 Equipment and continence aids

Equipment is a central area of need that really needs a separate national program. At present in the disability context the Commonwealth funds continence aids and workplace modifications and the states fund rehabilitation and disability equipment. A national approach is required that would allow for consistent supply of equipment across jurisdictions.

- Workplace modifications
- Continence aids (for children and adults)
- Rehab and independence aids
- Technology
- Equipment for people in aged care facilities
- Regulating performance of private sector providers

11.3 Chronic illness

People with a chronic illness and disabilities have a very different experience of disability and do interact with many sectors. Issues such as access to pharmaceuticals, case management and need for quick access to equipment, treatment and services is required. The jurisdictions also have a special responsibility to open doors across portfolios into health, housing, income support etc

This segment would include the jurisdictions responsibilities

- Linkages into other sectors – health, aged care, PBS (specified and targets set)
- Policy setting around prioritisation and access to services
- Workplace support
- Palliative Care

11.4 Employment and non employment services

Coordination between these two areas was recommended in the Getting Real report and is no less important now. At present the states have no role in employment services – but they should – including in work based personal care, equipment, pre and post vocational services and their own employment programs – and managing the needs of people who do not succeed in achieving sustainable employment through the DEN or Job Network.

This should be 80-20 funding arrangement (with the 80% coming from the Australian Government)

11.5 Community care Services

This would include therapy services, respite, attendant support and community access services, and would operate as it does at present with the States being the main delivery manager, however revisions to ensure adequate growth funding and the linking of these services to other segments.

11.6 Carers

As recommended by Anna Yeatman in 1996, carers should be included in the CSTDA to reduce overlap and duplication in the provision of direct service and carer supports.

11.7 Intersectoral Linkages

Each of the segments above must also contain binding objectives to create and expand links across portfolios at each level of Government.

In the same vain as the NSW and Victorian disability plans, the CSTDA need to have indicators to bind governments to make progress on key issues such as health, infrastructure, (including transport), employment and education and cross divisional programs.

The chronic inability of State Governments and the taxi industry to get a working accessible transport system going, despite reviews, inquiries and consumer campaigns is exasperating, and is an issue that needs Government championing to force change.

These areas of Government are critical to the participation of people with a disability being part of the community, and must be in place if many of the other aims of existing disability policy are to be achieved. FACSIA and the State Disability Departments are not active across Government on a range of issues, and it is important that they are.

12. The Aged Care system

The MS Australia Submission to the Community Affairs Inquiry into Aged Care contains detailed material about the experience of young people with MS in aged care.[27]

One point we wish to repeat in this context is the anomaly that a younger person with a complex disability has an ’entitlement’ to aged care services but not for disability services.

Current Department of Health and Ageing guidelines have strengthened this language to give young people with disabilities an ‘entitlement’ to enter aged care facilities.

Younger people with disabilities are entitled to enter aged care facilities. This entitlement should however only be exercised if, and only if, they need the intensity,

---

[27] MS Society of Victoria and Australian Home Care Services, Submission to the Inquiry into Aged Care 2004.

type and model of care provided in such facilities and no other more appropriate service is available[28]

As well as the well known issue of having to go and live in an aged care facility with MS gets an ACAS assessment for respite – they are entitled to 63 days per year- however they cannot cash this out to have at home or in a more appropriate facility – but they have to wait indeterminate periods for decent disability respite. Some people with MS and their families take up this option because of sheer necessity (particularly in rural areas) however there are a great number who do not seek or access this respite because of its sheer inappropriateness.

---

[28] **Commonwealth Department of Health and Family Services (now Department of Health and Aging)** Residential Care Manual **Published July 1997**, **Aged and Community Care Division**

References

Access Economics. (2005). *Acting positively: Strategic implications of the economic costs of multiple sclerosis in Australia*. Report for Multiple Sclerosis Australia, Winter 2005

AMSLS Economic Impact of MS Working Party, Socio-economic Status of People with MS and Life Transitions Following its Onset, Working Paper no.3, MS Australia, April 2005,

Commonwealth Department of Health and Family Services (now Department of Health and Aging, Residential Care Manual, Aged and Community Care Division, Published July 1997

Department of Health (UK) National Service Framework for Long Term Conditions, March 2005, Best Practice Guidelines, Gateway Reference 4377. http://www.dh.gov.uk/assetRoot/04/10/53/70/04105370.pdf

Health Department of WA, Guidelines for Service Provision Levels in the Home and Community Care (HACC) Program in Western Australia, Aged Care Policy Directorate August 2006

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*,

Kidd, P. (2001). Multiple sclerosis, and autoimmune inflammatory disease: prospects for its integrative management. *Alternative Medicine Review*, 6, 540(27).

McCallum, et.al Australian Aged Care & the New International Paradigm. AUSTRALASIAN JOURNAL ON AGEING, VOL 20.3 SUPPLEMENT 2, SEPTEMBER 2001

Metz, L. (2003) The psychosocial consequences of multiple sclerosis. In W. I. McDonald & J. H. Nosworthy (Eds.), *Multiple Sclerosis 2* Philadelphia, PA: Butterworth-Heinemann.

MS Society of Victoria and Australian Home Care Services, Submission to the Inquiry into Aged Care 2004.

National Multiple Sclerosis Society (US) (2005) Expert Opinion Paper: Medical Advisory Board of the National Multiple Sclerosis Society. Disease Management Consensus Statement.

Nodder, D., Chappell, B., Bates, D., Freeman, J., Hatch, J., Keen, J., Thomas, S., & Young, C. (2000). Multiple sclerosis: Care needs for 2000 and beyond. *Journal of the Royal Society of Medicine*, *93*

Reynolds, F, & Prior, S. (2003). “Sticking jewels in your life”: Exploring women’s strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research*, *13*

Sirvastava, S., & Chamberlain, M. A. (2005). Factors determining job retention and return to work for disabled employees: A questionnaire study of opinions of disabled people’s organizations in the UK. *Journal of Rehabilitation Medicine*, *37*

Verdier-Taillefer, M. H., Sazdovitch, V., Borgel, F., Cesaro, P., Kurtz, A., Millet, M.-F., Roullet, E., & Marteau, R. (1995). Occupational environment as risk factor for unemployment in multiple sclerosis. *Acta Neurologica Scandinavica*, *92*,

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