



AUSTRALIA

*Seeking the Cure.
Providing the Care.*

Multiple Sclerosis Australia

**Submission to the Inquiry into Employment and Workplace
Relations Legislation Amendment (Welfare to Work and other
Measures) Bill 2005 and Family and Community Services
Legislation Amendment (Welfare to Work) Bill 2005**

Senate Community Affairs Legislation Committee

16 November 2005

1. Introduction

MS Australia has mixed feelings about the Welfare to Work legislation. The policy imperative to improve participation of people in the workforce, particularly those with a disability is worthy, and the increase in disability employment support services, including workplace modification is welcome. Due to time constraints, this submission concentrates on analysis of the Bill's Explanatory Memorandum.

Our general view is that this Bill however lacks the sophistication required to cater to the range of needs of people with disabilities and chronic illness in the Welfare and Employment contexts. It is one dimensional in that it is about moving people from welfare to work, and will treat those going from work TO welfare, and those combining work AND welfare in exactly the same way, which will unfairly disadvantage these groups and not deliver the best outcomes for the Government's stated participation objectives in this area.

In almost every way, people with MS and similar progressive conditions are going against the tide of this package. This is a group of people who are diagnosed and begin to feel the effects of the disease WHILE they are working, and the role of the welfare system is to assist them to maintain their life and their employment. For people with no capacity left, this bill does not serve people well who want to hang on in the workplace – by making them comply with a regime that is totally designed for the tide going in the other direction.

The Grandfathering of the pre May 2005 Disability Support Pension cohort means that the first wave of people with MS who will be applying for the DSP after 1 July 2006 will be people in their 30's and 40's, and mostly working—probably more than 15 hours per week – but with ever diminishing capacity.

This is not the group that the Government originally wanted to assist off the DSP. They are balancing a debilitating chronic disease at home and at work, and must be protected.

The best social policy outcome is that they stay engaged at work even part time or casual– and placing additional stress on this group by lowering their income support and subjecting them to an unrealistic and punishing regime is simply bad policy. The likely outcome of the Bill defies all evidence based research conducted on the management of MS symptoms.

As far back as 2002, the government has wanted to target the growth in DSP, and has stated that its targets in this plan were older people with muscular skeletal injuries and those who retire early on the pension due to physical constraints.

The changes then were proposed to save \$1b per year. This outcome goes much further than cutting the growth, - it is cutting into the bone of the welfare system, and forcing people who have no further work capacity onto lower benefits and into risk situations with participation requirements and assessments. There could have been ways of targeting this growth without affecting many thousands of legitimate DSP applicants.

The most critical amendment we are seeking is the restoration of the Disability Support Pension (DSP) eligibility to those people who meet the DSP impairment requirements and who are working more than 15 hours per week. Newstart is simply the wrong benefit structure for this group, particularly because of participation requirements and lower benefits.

If this change can be achieved then other recommended amendments need to be focused on more effective processes and fairness, because the setting of the eligibility threshold at 15 hours will create more complex disputes at the margin than exist at the 30 hour mark.

The other amendment that is important to people with progressive illnesses is that the Comprehensive Work Capacity Assessment regime needs to be much more sensitive to the fluctuating symptoms of diagnosed chronic neurological conditions. It must not be able to predict capacity for such a long period as 2 years, and keep an otherwise eligible person for the DSP on Newstart for an extended period.

2. Background

2.1 What is Multiple Sclerosis?

Multiple sclerosis (MS) is a progressive, chronic disease of the central nervous system (brain and spinal cord). It is the most frequent neurological disease in young and middle-aged adults in developed countries (Johnson, Amtmann, et al., 2004; Verdier-Taillefer et al., 1995) and has a lifelong impact.

Because MS involves multiple areas of the central nervous system, it is characterised by a variable and complex range of symptoms, including visual disturbance, fatigue, pain, reduced mobility, incontinence and coordination, cognitive impairment, and mood changes (Polman et al., 2001).

Diagnosis usually occurs in a person's 20s or 30s, with a peak at 25-30 years. Thus, MS tends to strike people in their most productive years. It affects ability to fulfil expected life roles at a stage when careers, relationships, and adult life in the community are consolidating, with resulting impact on work, family, and social life (Metz, 2003; Nodder et al., 2000). Thus, MS may result in profound biographical disruption (Reynolds & Prior, 2003)

Employment and MS – a snapshot

- 87% of all people with MS in Australia are of working age
- People with MS often have lower income levels than the general Australian population
- People with MS are far more likely to forego full-time employment, and have higher rates of part-time employment to the general population
- 80% of people with MS in Australia lose their employment within 10 years of diagnosis
- A further third of people with MS feel their current employment was at risk
- People with MS in employment tended to be in higher skilled jobs than the general population
- 3,200 people with MS are not working in 2005, costing \$158 in lost productivity

* summarized from the Australian MS Longitudinal Study 2005 and the Access Economics Acting Positively Report 2005

2.2 The Value of Employment to people with MS

Employment is not only a basic human right but also a positive driving force within the everyday life of most individuals (Vansteenkiste et al., 2005).

In its contribution to physical, psychological, social, and independent wellbeing, employment can be viewed as a key aspect of positive quality of life. This precept remains as true for disabled workers as it does for their non-disabled counterparts.

Conversely, unemployment, with its potential reduction of many of these key aspects, may have a negative impact on an individual's quality of life (Metz, 2003; Robinson, 2000). For the millions of workers worldwide suffering from a chronic disability, the risk of unemployment is potentially a greater threat than for their non-disabled counterparts.

The literature highlights both the advantages of employment and the potentially damaging consequences of disability-related unemployment, for employee, employer, and society as a whole (Allaire et al., 2005; Habeck, 1999). People with chronic diseases who are employed report a higher quality of life than those who are unemployed (e.g., Feagan et al., 2005; Johnson, Amtmann, et al., 2004).

For the individual and their family, paid work also directly contributes to financial security through salary and superannuation benefits, and unemployment places these at risk. Further financial hardship will be incurred after July 2006 if Federal Parliament passes Budget changes to welfare, and people with disabilities who would have been entitled to current pension payments are instead placed on unemployment benefits (Victorian Council of Social Service, 2005).

The reward for continued active participation for people with chronic illness is the job itself, continued contributions to retirement incomes and income, as well as all the non monetary benefits.

Clearly, such changes reflect attempts to contain the impact of unemployment among disabled people on the public purse, which is impacted not only through the benefits system but also through lost productivity and taxation (British Society of Rehabilitation Medicine, 2003).

These points all highlight the importance of employment from the perspective of both the individual and society, a situation highlighted by the British Medical Journal editorial comment that, **“While this (vocational rehabilitation) is not a cheap option, a community with unemployed, disabled ex-workers is likely to be even more costly”** (Disler & Pallant, 2001, p. 122).

The imperative to save money on Welfare spending through the measures proposed in this Bill risks significant cost transfers to other areas such as health, pharmaceuticals, community support, housing and legal support, as people health management, work life and relationships are compromised by lower income levels and unrealistic labour market activity.

Genuine need cannot be suppressed by ignoring it or changing definitions to avoid its consequences.

2.3 The financial impact of MS

MS is one of the costliest diseases with which to live due to its onset in early adulthood, and progression over a lifetime. It often cuts short continuous employment. Any discussion of the interaction between welfare, employment and chronic illness must include the real cost of illness.

People living with MS also spend a high proportion of their income on health related goods and services. A recent Victorian study puts this as high as 20% of total income.

Although many people with MS work part time and have lower income levels, the cost of their disease remains high, and increases as a proportion of total expenditure as income levels decrease.

The need to have a reasonable level of income support is critical to maintenance of quality of life. The proposed lower benefit level offered by Newstart will lead to people being compromised severely in their capacity to manage their illness and their work.

65.9% of people with MS participating in the Australian MS Longitudinal Study maintain private health insurance. This is higher than the 43% for the general community. Health insurance comes at a very high price for people with MS given that they have generally lower incomes than other Australians – but the capacity to have choice and easy access to specialist neurologists and hospital care is essential, and for which people have made demonstrable financial sacrifices to maintain.

A loss of income due to a real reduction of DSP benefits or work hours will have a direct impact on the health care options for people with MS. The cost of MS drugs-ones that are essential for people to live as independently as possible are prohibitive without PBS subsidy.

If people working part time were to lose their DSP status, the extra dollars and have to pay the full rate for a number of scripts per month would create an unmanageable financial burden. As stated earlier, these people often are working to capacity and can do no more work, and their health needs still need to be properly met.

A system which in effect relegates skilled experienced workers to ‘part time dole recipients’ because of their diminishing capacity is at best insensitive- at worst cruel.

2.3.1 Cost of Medications

In a recent study on the costs of Chronic Illness in Victoria, the costs of medications and other health expenses were shown to be significant and persistent over a lifetime. It showed that households of people with chronic illness took care of their health needs first, regardless of their income. In many households, health costs contributed to increased poverty, and in the lower income groups studied, the cost of health was so great that at times led to dire poverty.

Chronic Illness Alliance report Table 1- cost of medications –

Annual income	<\$13,000	\$13-25,999	\$26-36,399	\$36,400-51,999	\$52-78,000
No of households	N=39	N=113	N=64	N=73	N=80
Av annual overall costs	\$3585	\$3539	\$4289	\$3585	\$5767
Av annual costs medications	\$747	\$934	\$1345	\$954	\$1162
Costs of medications as % of annual overall costs	21%	26%	31%	27%	20%

The importance of concessional medicines for households with chronic illnesses was amply demonstrated by the study. 92% of households in the lowest income group had concession cards, so they were eligible for medications at the concessional PBS rate. Medications accounted for 21% of their total health costs. In contrast, only 47% of households in the \$26–36,399 income group had concession cards. Medications accounted for 31% of their total health costs.

This highlights the poverty trap for people moving into income levels that are not high and losing their health card benefits. The CIA study showed a 10% increase across all chronic illness groups – people with MS who are heavily reliant on medications indicate a much greater burden.

3. Case examples

The following case examples of people with MS who are currently working part time and receiving part time DSP, indicate the need for protection of financial security, employment and health. These examples have been used elsewhere, and may be familiar to the committee, however they are closely representative of a large number of people – the next generation of whom will be severely disadvantaged by the abolition of the partial DSP in this Bill.

They also highlight the dangers of the reduction of general employment protections in the Work Choices legislation. At any point, for operational reasons, Andrew or Siobhan's (or their peers with MS) employer could terminate their employment so they can replace them with a healthy worker. This would place them in great jeopardy with little immediate practical redress to get their job back, and also place them in an invidious position in the welfare system, particularly if the loss of their job brought on a stress related deterioration of their condition.

Andrew

'My life is very finely balanced and cannot take any shocks. I desperately want to work and be independent but a lot of it is out of my control at present.'

Andrew has had Multiple Sclerosis for 12 years. As a result of cognitive impairment caused by his condition, Andrew cannot share accommodation with other people and so lives alone. He used to work full time, but can now only manage 20 hours per week. Andrew works in the retail sector and earns around \$600 per fortnight. He also receives a part pension (DSP) and rent assistance. Andrew is not eligible for the Mobility Allowance.

Andrew's fortnightly disposable income is \$970, which is already inadequate to meet his essential costs of living.

<u>Expense</u>	<u>Cost/fn</u>
Rent	\$480
Medication/modified diet	\$130
Food and household expenses	\$220
Car and fare expenses	\$155
Total Expenditure	\$985
Fortnightly shortfall	- \$15

Andrew relies on his family to meet the short fall in his income and to help him out with any unexpected costs. Andrew has no way of earning extra income to meet this shortfall. He is already working to his maximum capacity and may soon be forced to reduce his hours further.

If Andrew were on Newstart instead of the DSP, his fortnightly disposable income would drop to \$736, or only \$368 a week.

This would leave Andrew **short by \$249 per fortnight.**

Siobhan

Before this exacerbation I was working 38-40 hours a week. Then I didn't work for around 6-8 weeks. Slowly I got back to 20-25 hours a week. Now I have cut back again to 19 hours because I am not fully coping with the physical demands of my job."

Siobhan works in retail but has recently had to give up her Sunday because of her disability, forgoing \$140 (gross) income and gaining \$25 additional pension to replace it. Siobhan is paying off a car loan that she took out when she was healthy.

Siobhan earns \$824 per fortnight and receives an additional \$386 per fortnight in DSP, rental assistance and various allowances. Her fortnightly disposable income is \$1,110.

After expenses, including \$70 per fortnight for medical and pharmaceutical costs, Siobhan has no income remaining, leaving her with no money in case of emergency.

*If Siobhan were on Newstart instead of the DSP, her fortnightly disposable income would drop by **\$238**, to \$872, leaving her unable to meet her day to day expenses.*

As her condition progresses, Siobhan will face additional costs for:

- taxis
- medicine to combat the side effects of the medication she takes for her condition
- products to counteract the effects of her condition such as:
 - o incontinence pads
 - o additional feminine hygiene products due to more regular menstruation
 - o iron tablets or injections to counter iron deficiency
- massage to promote circulation and to ease the pressure on her back caused by limping

Siobhan says:

"Since I got my disease my whole world has turned around. I can no longer work the hours I used to. I can no longer make the money I used to, to support myself. "Just the basic needs are a struggle."

4. Part time employment

People with MS work part time in greater numbers (29%) than the general Australian population (21%) (figure 1). Given the constraints of the disease, it is a logical outcome for people to choose part time employment so they can manage their disease and other life interests as well as work. While work is an essential part of a balanced life with a chronic illness, it is not the only one.

In addition to the higher representation in part time employment, 3 times as many people with MS of working age are receiving welfare payments than other working age Australians (figure 2).

This shows that many people who are still working also receiving income support – most commonly the Disability Support Pension. MSA knows that this group are those that want to continue working as much as possible, and many are working to their physical and intellectual capacity. No further incentives are required to keep them in the workforce than keeping a job.

These people are remaining productive and continue to make a contribution to the community and their families. Many people go to extraordinary lengths to maintain themselves in employment and maintain their independence.

The DSP is an important part of their financial and health support system, taking into account their higher health costs. People in this situation have very finely balanced lives.

For many people part time or casual work provides a useful balance with living with an unpredictable disease. Employment and welfare policy should protect and encourage those who work part time with DSP back up. These people are models of mutual obligation, and because of their restrictions, part time = full time work.

Part time work and DSP is the best outcome for this group in the face of potentially diminishing capacity and high costs of health.

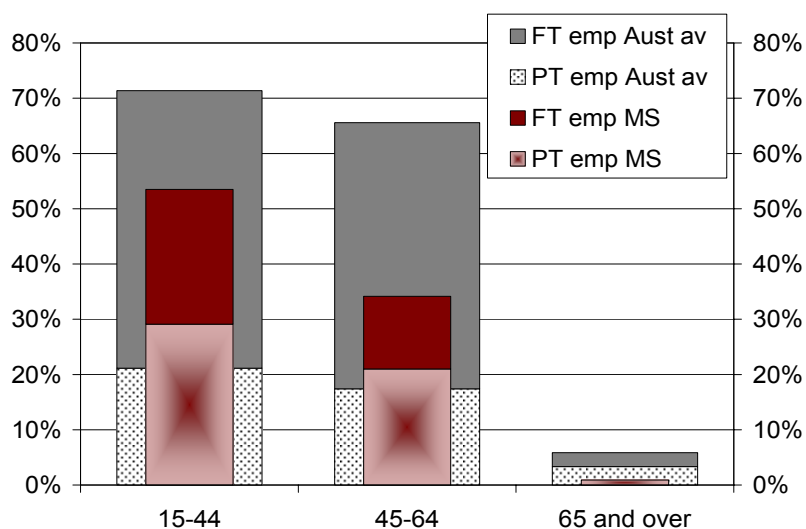
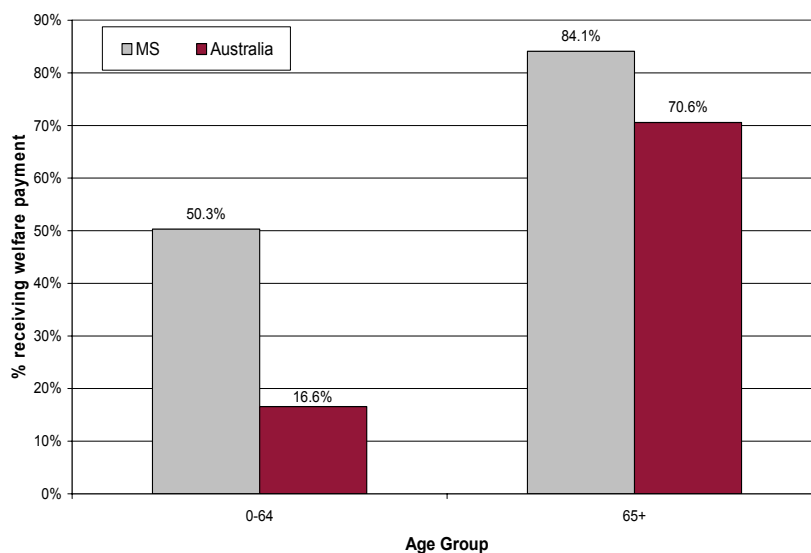


Figure 1: MS FULL-TIME AND PART-TIME EMPLOYMENT RATES RELATIVE TO AUSTRALIAN AVERAGES, 2003 (Access Economics 2005)



While 84.1% of people with MS aged 65 and over receive a Government benefit in 2005 over 50% of people with MS under the age of 65 are also receiving income support.

These are significantly higher rates of reliance than for the Australian population as a whole - only 16.6% of the general population under 64 and 70.6% of those aged 65 and over received some form of income support payment.

Figure 2: PROPORTION OF PEOPLE RECEIVING A WELFARE PAYMENT, AUSTRALIA 2003 (Access Economics 2005)

4.1 Definition of partial capacity to work in the Bill

At Page 9 of the Explanatory Memorandum, there is a definition of Partial Capacity to work:

This definition will be used to determine when Newstart allowance and youth allowance recipients and/or claimants who have a physical, intellectual or psychiatric impairment and an assessed work capacity of less than 30 hours per week will have reduced participation requirements and access to certain concession and allowances.

It is absolutely essential that partial capacity to work is defined so clearly as not to be confused with part time work.

Many people with MS work part time but are at full capacity. – and should not have to fit into a regime of further job seeking when it is unrealistic.

The interaction of part time (but at full capacity) workers with Newstart's participation requirements must be avoided at all costs.

The treatment of partial capacity to work has the potential to trap many people with MS working over 15 hours per week into an entirely inappropriate and damaging benefit and participation regime.

Although the section gives the Secretary some discretion to determine partial capacity to work (and indeed work capacity independent of a program of support), it is far preferable to avoid the need to individually exempt people from these requirement when they do not work and design the system properly in the first place.

The difficulty in defining partial capacity to work in people with a progressive illness is another pointer to the need to allow this group to continue to access the part time DSP.

4.2 The Purpose of the Bill – a Poor Fit for People With Ms

The Explanatory Memorandum states at page 14, the purpose of the Welfare to Work changes:

The changes to income support arrangements and the increased funding for employment services are designed to encourage and assist people with disabilities to test their capacity to work. In many cases people with disabilities, who have skills to offer but cannot work fulltime, could do part-time jobs, in many cases receiving a part-rate of income support.

The measures in this Bill will help people claiming disability support pension, and people already receiving disability support pension to become more independent and active in the community. More people with disabilities will be able to share in the rewards and benefits of work—increased income, improved standards of living, better links to the community and enhanced self esteem and wellbeing.

These purposes are directly aimed at people who are not working. Notions of becoming 'more independent and active in the community', and enjoying the 'rewards and benefits of work' are applicable to people with congenital disability, however an adult onset chronic illness like MS means something quite different.

People with MS are already ‘in the community and generally already working, and their issues revolve around maintaining and protecting independence and social engagement, not increasing them. Therefore the vast majority of disability services are inappropriately targeted, and do not have the skills and methodology to be useful.

Working fulltime is too tiring for me (even desk-bound admin work). This year, I am studying fulltime to retrain, which already stretches my energy capabilities. (LW, 46, NSW)

I am able to drive, but only for short distances if I need to work afterwards. Can do longer if not expected to concentrate full on for next 6-8 hours then drive home again. Part time work is a necessary option given where I live and my health. (FR, 55, NSW)

The design of the package is based around traditional notions of disability and disability programs. People with MS and chronic neurological conditions need to be viewed as a different group, and treated differently.

4.3 The changing workplace

Sometimes people can be caught up in structural changes in the workplace and in many cases are most vulnerable to a poor employment outcome as a result. People regularly report company restructuring as a mechanism often used to move them out of the workplace.

The interaction between the Work Choices legislation and the Welfare to Work package may see a person go from a sustainable employment situation to the Newstart without proper recognition of their needs or status as a person with a chronic progressive illness.

I work every second day - with a day off to rest in between. I guess in my case I had to be up front about my disability. Luckily, I had a very understanding boss at the time. Unfortunately, she has recently left the company and there is talk of "re-classifying" my position, i.e. more responsibility. I will have to 're-apply' for this position as it will not be an automatic 'changeover'.

It has been indicated to me that I will not be successful in applying for this position. Sadly, after 6 years at the same company, it looks like I will end up unemployed again. (BR, Sydney, 34)

5. Capacity testing for people with MS

The nature of MS and its impact with health and employment means that each person and situation is unique. The complex interaction of disease symptoms, industry type and workplace dynamics all play a part.

Any move to improve employment outcomes for people with MS must be designed around individual situations. There is no simple model that will suit every situation. The course of MS is the single most significant variable that cannot be ignored. Proper capacity testing needs the detailed input of a person's treating Neurologist.

Where most significant gains can be made is in extending the working life of people in their current jobs by providing more comprehensive supports to employees and employers on the job.

This will also include a new incentive regime that recognises efforts made by both parties in changing and maintaining employment arrangements. . We would support a model that better shares the risk (currently borne by the individual) with providers and employers – as there is a lot for the individual to lose if their assessment is too ambitious or incompetent, or if employers fail to make reasonable accommodations.

In addition, the time period available to ‘test capacity’ being 2 years is much too long. The Comprehensive Work Capacity assessments appear to influence someone’s eligibility for the DSP for 2 years post, even if the person is assessed at having less than 15 hours per week capacity at the time of assessment.

The case study of Andrew used on p 18 of the Bill’s Explanatory Memorandum highlights the fact that a person can have to wait over 4 years to qualify for the pension, even though they meet all the tests – including not having a current capacity to work 15 hours.

If this case study is indicative of the type of guidelines that will be given to the CRS and Centrelink officers, then many people with disabilities, including those with MS risk being forced into false vocational programs and onto an ill fitting unemployment benefits regime for years, when they should be in receipt of the DSP.

In the case of someone with less than 15 hours per week capacity (such as case study Andrew), who meets the impairment test requirements, they should be eligible for the DSP immediately, and if and when they achieve the threshold, then be reassessed. The model proposed in this scenario in fact denies DSP to someone who in fact is eligible.

Already people with MS experience judgemental reactions from officials in a number of agencies because their impairments are not visible. Extreme fatigue and pain can be masked with make up and a smile, and legitimate claims can be thwarted by the gut reactions of people who should know better.

A capacity assessment regime must not allow this type of judgement to have such far reaching effects. In some cases the opposite reaction may be evinced by an assessor which errs on the side of compassion and recommends the DSP to someone on the margins.

Whichever way these judgements go, 2 year periods are too long if mistakes are made or if things change for the individual. The other problem with the testing regime in the context of MS is that labour market conditions are not a factor in deciding capacity. Reassessments may be possible, however many people with MS find such assessment with such far reaching consequences very stressful, and stress is a contributor to MS symptoms.

The system should not aim to over-assess, however this is likely to be a fact of life for people with variable illnesses.

For a person with MS the work environment, travel expectations, flexibility of duties and rosters, air conditioning, routines such as working from home are all critical to determining whether an individual can actually successfully work in that job. Capacity testing cannot be done in isolation from the environment in which the work is to be done.

These assessments cannot be done hypothetically, as the fit between an individual and a job must be tailored. A point in time assessment with such far reaching predictions is not an appropriate one for people with MS.

Given the course of the disease is unpredictable, and most people strive to maintain their productive capacity for as long as possible, capacity testing is a difficult concept due to matching skills, day to day health variability and finding and keeping a sustainable job.

Because of this, and the risks of variable interpretations in the assessment process, we strongly believe that the assessment itself should contain a separate appeals process. Currently, it is only the Centrelink decision that is appealable – however being able to sort out disputes over assessments before potentially bad decisions are made is a better option than the current position.

A model that is more useful for people with conditions like MS is that used in many Workers Compensation jurisdictions. The linking of managing chronic illness with the workers compensation management of workplace injuries is something that should be investigated. The methodology involved in modifying duties and workplaces for injured workers returning to work is one that would very much apply to workers with chronic illnesses.

Employers are usually well acquainted with their obligations towards injured workers, and have systems to guide them through the procedures, however if a worker develops a major illness, those same guidelines would be most useful, but are not applicable.

We have the anomalous situation where injured workers are taken back because of a statutory obligation, but employers are in no way bound to make any provision for an existing employee who develops a health problem.

The other thing that Workers Compensation schemes have to teach the model described in this Bill is that capacity can be measured in real time in gradients for benefit changes are at 13, 26 and 52 weeks. They manage to link voc rehab with job search, placement and post placement support. These shorter gradients are much more realistic in managing marginal capacity than the Bill's 2 year timeframe.

5.1 'Independent of a Program of support'

Another difficult area in the Bill in the addition of subsection 94(2) and 94(2)(a) that include the consideration of whether a person can do a job 'independently of a program of support'. The Explanatory Memorandum says at page 17:

There are three circumstances when a person will be treated as doing work independently of a program of support. These are if the Secretary is satisfied that to do the work the person is:

- unlikely to need a program of support to do the work;
- likely to need a program of support but only occasionally; or
- likely to need a program of support but the provision of the program of support is not ongoing.

For the purposes of the reference to 'program of support', new subparagraph 94(4)(a)(ii) provides that the program of support must be a program that is funded (wholly or partly) by the Commonwealth; or a type that the Secretary considers is similar to such a program. Subparagraph 94(4)(a)(ii) specifically contemplates the types of support that have been formally acknowledged and recognised by the Department as being programs that assist people in preparing for, obtaining or doing work. Such programs may or may not have been specifically designed for people with disabilities. These programs include the Disability Open Employment Service and Post Placement Support from a Job Network Service.

The types of support required by a person with MS may not be of the kind intended by these sections. It appears that the Bill intends ‘a program of support’ to include services currently offered by the Department of Employment and Workplace Relations, or complementary state disability programs.

A person with MS may require irregular or intermittent support that may in fact come from medical professionals, counselling, peer support or the provision of advice to them or their employer. Sustaining employment for a person with MS requires a range of available supports that are not funded by the Commonwealth or through the Commonwealth State/Territory Disability Agreement – and may not even be required at the time of assessment – but may be needed on any day within a 2 year period.

Given that the work capacity assessment has the potential to lock a person in for 2 years to life on Newstart, it is essential that the working definition of a program of support is broad and flexible and well understood by assessors and Centrelink staff. The definition of continuing inability to work in this section does not encompass the important scenario of increasing or variable inability to work.

It is also not appropriate to design a system that relies on the existence of funded programs to define capacity and assume successful engagement – capacity should be able to be assessed independently in was similar to the medico legal system for injured workers.

5.1.1 Work based attendant care

The Explanatory Memorandum refers to attendant care in the workplace as an example of ‘a program of support’. In concept this is a good notion, however the current eligibility guidelines of the WBPA program are so narrow as to be ineffective.

Many people with MS and similar conditions could use support but cannot access it because of program limitations. Currently eligibility is limited to those people who need personal hygiene assistance, feeding, tube feeding or nursing services.

Many people could use assistance with mobility, environmental control, note taking, and with tasks they are unable to do on their own.

6. Other Elements of the Bill

6.1 Mobility Allowance

Basically the extension of this is a good thing as it recognises the additional costs and burdens of participation in the labour market. The ability of part time workers (> 15 hours) to access this will be a boon to their overall support.

This is a positive provision because it recognises the relatively high cost of transport to and from work for someone on a low or fluctuating income

6.2 The definition of disability

Throughout the Bill, the definition of disability does not include neurological disability or chronic illness. It is limited to physical, intellectual or psychiatric impairment. Unless people with Chronic Illness are to be exempted from the coverage of this Bill, the definition needs to be broader.

6.3 Incentives/penalties

Due to the context of MS being an adult onset condition, people will generally be in the career and family building phase of life when the disease begins to progress. The incentives to stay at work are intrinsic to the lives of these people and their families. People cannot work more than their disease and workplace conditions allow, regardless of marginal incentives.

Where people have had to reduce work to part time due to reduced capacity, no amount of incentive will enable them to do more work – and no penalty for the same can be justified. The financial incentive and penalty regime attached to Newstart is totally misdirected and irrelevant to this group of Australians.

It is in fact personally and socially destructive.

The policy imperative in the welfare and work domains for people with MS and similar chronic illnesses is to provide all support possible to retain employment, and provide an income support regime that can allow families to stay viable and also make healthcare affordable. This is not served at all by forcing people into situations where they cannot meet requirements.

7. Recommendations

7.1 Retain the Disability Support Pension for people with a disability working part time. The Senate amend the Bill to retain the DSP for people who:

- meet the impairment criteria and/or
- have a chronic illness that results in changeable or broken continuity of employment and/or
- are working more than 15 hours per week (and who cannot achieve full time employment) and require income support with current DSP concessions and allowances.
- are assessed as being unlikely to achieve an employment outcome
- meet the above criteria and are transitional DSP recipients and new applicants after 1 July 2006

This would mean that the legislation recognises the true cost and labour market reality of progressive chronic illness, and remove the myriad problems associated with the Newstart compliance regime for those people who are in the wrong benefit regime.

7.2 Change the work capacity assessment regime to make it more accurate and more responsive to the needs of people with MS and chronic illness

- Amend section 94 of the Social Security Act to better define partial capacity to work to give better guidance to assessing officers in streaming people with MS into the correct benefit type
- Amend the sections of the Bill that allow the prospective decision making that says that a person will not be eligible for the DSP because of predicted achievement of a 15 hour capacity in the future despite having less than 15 hour per week capacity at assessment. These provisions need to be replaced with those that grant the DSP at assessment in those cases, and will utilise future reviews to judge capacity based on rehabilitation, labour market experience and health.
- Amend the Bill to include a separate appeals mechanism of the Comprehensive Work Capacity Assessment.

7.3 Amend the definition of disability in the Bill to include neurological impairment where appropriate

- Taking into account recommendation 7.1, and the need to restructure the eligibility for DSP, the Bill needs to have a better definition of disability

7.4 The provision of employment services and other assistance

- With reference to recommendation 7.1, amend the definition of ‘programs of support’ in 94 (2)(a) to include and define the suite of services and supports other than those provided by DEWR or State disability services that are essential to supporting a person with MS or chronic illness in the workplace.
- The Committee investigate the current limitations to the Work Based Personal Assistance Program and recommend its broadening to enable more people who be properly supported in the workplace
- The Committee investigate the potentially negative interactions between this Bill and the Workchoices Bill (in particular the removal of general employment protections, and the future ability of people with disabilities to negotiate complex arrangements in their workplace) and recommend appropriate amendments to promote improved opportunities for this group.

Further contact

For further contact in regard to this submission, please contact

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References

- Access Economics. (2005). *Acting positively: Strategic implications of the economic costs of multiple sclerosis in Australia*. Report for Multiple Sclerosis Australia,
- Allaire, S. H., Niu, J., & LaValley, M. P. (2005). Employment and satisfaction outcomes from a job retention intervention delivered to persons with chronic diseases. *Rehabilitation Counseling Bulletin*, 48, 100-109.
- British Society of Rehabilitation Medicine. (2003). *Vocational rehabilitation: The way forward*. London: British Society of Rehabilitation Medicine.
- Walker, C, Tamlyn J. (2004) The Cost of Chronic Illnesses for Rural and Regional Victorians, Chronic Illness Alliance, Victoria p26
- Disler, P. B., & Pallant, J. F. (2001). Vocational rehabilitation: Everybody gains if *economic impact of multiple sclerosis in Australia: Summary statement of preliminary results from the Australian MS Longitudinal Study*. 26 November,
- Feagan, B. G., Bala, B. M., Yan, S., Olson, A., & Hanauer, S. (2005). Unemployment and disability with moderately to severely active Crohn's disease. *Journal of Clinical Gastroenterology*, 39, 390-395.
- Habeck, R. V. (1999). Job retention through disability management *Rehabilitation Counseling Bulletin*, 42, 317-328.
- 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.
- Johnson, K.L., Yorkston, K. M., Klasner, E. R., Kuehn, C. M., Johnson, E., & Amtmann, D. (2004). The cost and benefits of employment: A qualitative study of experiences of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 85, 201-209.
- 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.
- Multiple Sclerosis International Federation. (2005). *Principles to promote the quality of life of people with multiple sclerosis*. Multiple Sclerosis International
- O' Day, B. (1998). Barriers for people with multiple sclerosis who want to work: A qualitative study. *Journal of Neurological Rehabilitation*, 12, 139-146.
- Polman, C. H., Thompson, A. J., Murray, T. J., & McDonald, W. I. (2001). *Multiple Sclerosis: The Guide to Treatment and Management* (5th ed.). New York: Demos.
- Simmons, R., Hendrie, D., McDonald, E., Tribe, K., & Vowels, L. (2004). *The economic impact of multiple sclerosis in Australia: Summary statement of preliminary results from the Australian MS Longitudinal Study*. 26 November, Canberra Hospital.
- Victorian Council of Social Service. (2005). *27,900 Victorians could be worse off if Federal welfare law is passed. 25 July* (Media release). Melbourne: VCOSS.