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Seeking the Cure.
Providing the Care.

Multiple Sclerosis Australia

Submission to

The Senate Employment, Workplace Relation and Education Committee

Inquiry into the Workplace Relations Amendment (Work Choices) Bill 2005

9 November 2005

1. Introduction

MS Australia has a vital interest in this area of inquiry, as employment and financial security are major life issues for people with MS and their families. Because of the onset of MS generally in early adulthood a significant number of people with MS are working or studying, or starting families. The maintenance of employment is a critical factor in people retaining maximum independence and normality in the face of a progressive disease.

Workforce participation is a critical part of life for a person with MS and their families, as it is for all Australian families. MS Australia welcomes the initiatives of the Government in promoting the employment of people with disabilities, and believes that there is great potential to change employer attitudes to the value of people with disabilities in the workforce.

Employment makes a positive contribution to many aspects of wellbeing, and unemployment comes at great cost to the individual, their family, and wider society. Multiple sclerosis (MS) is the most frequent neurological disease in young and middle-aged adults in developed countries, with diagnosis usually occurring in a person’s 20s or 30s.

Many people with MS may leave employment prematurely, and the likelihood of being re-employed is poor. Unemployment rates are high, despite people with MS as a group having a positive work history, a strong work ethic, and a desire to resume employment.

Current opinion 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.

This stance regarding “job retention intervention,” rather than finding “new” jobs for the unemployed, is consistent with arguments in the current literature on disability and employment, although this is not reflected in the current suite of labour market programs funded by Government, or evident in the substance of the Work Choices Bill, with its reduction of general workplace protections.

One of the main points we want to make with this submission is to highlight the need for high levels of integration with legislation dealing with industrial relations, welfare to work, and discrimination protection.

The Work Choices Bill potentially risks the effectiveness of the Government’s stated intention to get people with disabilities (and carers) in the workforce and keep them there over the long term. The Government has recognised that major cultural change needs to occur in the world of employment (particularly in the attitudes of employers) for workforce participation to rise for people with disabilities, and it needs to promote expectations and protections at every opportunity. This Bill misses this opportunity.

2. 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 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).

3. The Value of Employment

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).

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).

People with MS work part time in greater numbers (29%) than the general Australian population (21%), and many receive income support via the partial Disability Support Pension.

For the employer, also, experience and skills are lost, and there are costs and risks involved in hiring a new employee (Habeck, 1999; Robinson, 2000). 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).

4. The Scope of the problem for people with MS

The recent Access Economics Report (2005), drawing on data from the Australian Multiple Sclerosis Longitudinal Study (AMSLS), indicates that over 16,000 people in Australia have MS, of whom 74% are women and 87% are of working age. People with MS also tend to be in higher skilled jobs than the general population.

Employment, however, is precarious. The AMSLS Economic Impact Study (Simmons et al., 2004) found that almost half the study sample had left paid employment due to MS and another third felt their current employment was at risk. Consistent with overseas evidence regarding early loss of employment (e.g., O'Day, 1998), AMSLS data indicate 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 the workforce (Access Economics, 2005). Due to its association with loss of income and impaired quality of life, the impact of unemployment on people with MS and their families is profound (Metz, 2003).

Premature retirement also takes a significant economic toll on society (Johnson, Amtmann, et al., 2004; Metz, 2003). The financial and disease burden of MS in Australia is estimated at nearly $2 billion per annum, including total financial costs in 2005 of over $600m or 0.7% of GDP. Production losses of around $158.6m, due to reduced work hours, temporary absences, early retirement, and premature death, account for just over a quarter of financial costs, while losses arising from taxation revenue foregone and welfare payment transfers are estimated at a further $13.5m (Access Economics, 2005).

However, it is now recognised that many people with MS retire prematurely (Johnson, Amtmann, et al., 2004). Not surprisingly, the Access Economics Report (2005) identifies as one of the areas of greatest challenge, "using health management, employment policy and responsive welfare to keep people well, working and with their families for as long as possible" (Access Economics Report in MS in Australia Fact Sheet). Access Economics (2005) identifies the "first best solution," from an economic and equity perspective, as involving 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.

5. Policy imperatives

Societal or programmatic factors, which include policies and the knowledge and attitudes of the public and employers, as well as health professionals, also need to be systematically addressed (Johnson, Amtmann, et al., 2004).

Clearly, employers need to be educated about the nature and symptoms of MS and the wide range of accommodations and adaptations that can often allow people with MS to remain productive employees for many years.

These include part-time work, additional breaks in the work day, working only mornings, reducing the room temperature, changing work tasks, telecommuting, reducing travel, and providing offices near restrooms (Multiple Sclerosis International Federation, 2005).

It is also clear that the knowledge and attitudes of significant others impacts on employment. Thus, well-intentioned support networks, and even health professionals, advise people with MS to leave work as a way of dealing with stress, fatigue or pain, without appropriate consideration of the consequences of unemployment.

Also, if work colleagues have an understanding of MS symptoms and appropriate accommodations, especially in relation to "hidden" symptoms, damaging misinterpretations are less likely to occur, e.g., misinterpreting MS fatigue as "faking" or being "stupid" (Johnson, Amtmann, et al., 2004; Johnson, Yorkston, et al., 2004).

Government action and policies are also important in facilitating workplace accommodations. Thus, small workplace modifications, such as those funded through the federal Workplace Modification Scheme or Work Based Personal Assistance measures, can make enormous differences if targeted and widely promoted.

6. Interaction with the Welfare system

The high number of people with MS working part time and receiving income support means there are a number of points of interaction with the welfare system.

Because the legislation for this latter package has not yet been released, we cannot be definitive about the effects, but from what has been released in policy, the following points can be made:

MS Australia is concerned that the complexities of the disease process will be missed in a system that is largely designed for people who are either well, mainly engaged in the workforce, or not working.

There are a number of risks that need to be managed with the complementary design of these two packages that will no doubt be the subject of other submissions to this inquiry.

7. Issues of relevance

The following are the main issues of relevance to MS Australia’s reading of the Bill. The case studies included in this submission have been collected through consultations throughout 2005 with people with MS on their experiences in the workplace.

7.1 The definition of disability in the Bill

MS Australia believes that the definition of disability used in the Act is too narrow, and needs to be defined much more clearly for the purposes of protection from discrimination.

S 90(b) of the Bill defines disability as being

employee with a disability means an employee who is qualified for a disability support pension as set out in section 94 or 95 of the S*ocial Security Act 1991*, or who would be so qualified but for paragraph 94(1)(e) or 95(1)(c) of that Act.

In this definition is used in reference to the operation of key sections of the Act, particularly the Australian Fair Pay Commission and references to discrimination in employment.

This definition is problematic on three fronts for people with MS

- Due to the progressive nature of MS, disease symptoms begin to have an impact on health and employment long before the person would ever become eligible for the Disability Support Pension

- The disclosure of diagnosis is a fraught area for people with chronic illness, and the decision to disclose to an employer is a personal one dictated by the dynamics of the workplace and the relationship with the employer and co workers. Disclosure is something that can precipitate workplace discrimination, so people are advised to be very careful about disclosure.

  The narrowing of the definition of disability in the Bill may inappropriately force the hand of a person with MS to either disclose or not. Disclosure should not be something that is done purely to create a protection through disability discrimination. There needs to be more systemic protections in place.

- Discrimination occurs frequently in employment at the point of disease disclosure – mostly when there are no or only minimal symptoms present

- Other more functional definitions of disability exist in Commonwealth legislation

Recommendation 1
MS Australia recommends that for the purposes of increased protection from discrimination and consistency, the definition of disability used in the Disability Discrimination Act be used in this Bill.

7.2 Wage Setting and incomes of people with MS

MS Australia is concerned that the wage setting provisions of the Bill have the potential to impact negatively on people with MS.

Section 90 contains sub-sections that could potentially lead to wages outcomes being determined by disability status rather than skills, industry wage levels or historical factors.

Section 90 (P) defines the Federal Minimum Wage (FMW), and refers to a FMW for people with a disability:

3) There is an FMW for an employee with a disability (other than an APCS piece rate employee) if the AFPC has determined a special FMW that applies to all employees with a disability, or to a class of employees with a disability that includes the employee. The FMW for the employee is that special FMW.

Section 90 (D) 2 also refers

(1) For the purposes of this Division, a ***classification*** *of employees is a classification or category of employees, however described in the pre-reform wage instrument or APCS concerned.*

2. A classification or category of employees may be described by reference to matters including (but not limited to) any of the following, or any combination of any of the following:
(a) the nature of work performed by employees;
(b) the skills or qualifications or employees;
(c) the level of responsibility or experience of employees;
(d) whether employees are junior employees, or a particular class of junior employees;
(e) whether employees are employees with a disability, or are a particular class of employees with a disability;

Section 90ZR *Anti-discrimination considerations*

(1) Without limiting sections 90 and 90A, in exercising any of its 22 powers under this Division, the AFPC is to:

b) have regard to the need to provide pro-rata disability pay methods for employees with disabilities;

Access Economics found that people with MS are generally more skilled than the general workforce. The course of MS leads people to move from full to part time work, and the majority of people with MS work in the area of their pre diagnosis employment.

The Supported Wage System is rarely used for people with MS, because with the right accommodations, people can be fully productive in the time they work.

The prospect of wages for people with MS in a range of industries and professions being influenced or set by the AFPC's decisions of the Federal Minimum wage is a major concern.

While the AFPC may only use this for certain groups (such as disabilities in supported employment), no room can be allowed for this section to be used to dictate wages in the wider workforce on the basis of disability or impairment, however defined.

Recommendation 2

That the Bill be amended to not categorize all people with disabilities (however defined) for the purposes of AFPC deliberations and decisions.

The Bill to be made clearer as to its intention for wage setting for people with disabilities.

7.3 Advocacy and Bargaining in the workplace

Success factors for retaining employment
A number of factors support the retention for people with MS in the workplace, including:

- A positive relationship between employee and employer
- Basic employer knowledge of MS and sensitivity to the employee's needs
- Workers knowledge of employment rights frameworks
- Good workplace modification and job modification and flexibility
- Effective management of symptoms by the individual. This includes the use of the MS medications that allows suppression of symptoms to facilitate longevity in work
- Availability of responsive support services into workplaces to assist in workplace accommodation, information provision and disclosure issues
- Alternative work arrangements such as part time work, work from home, flexible rostering, disability leave, carer leave etc

Conversely, the absence of these factors will contribute to poor workplace outcomes for people with MS. In many cases poor information is just as powerful as a negative employer attitude as a contributor to early exit from the workforce of a person with MS.

Many people with MS state that planning for the future is difficult. Many people want to stay in work but do not have great confidence in their ability or the support from their employers (current or future). The uncertainty of their health makes forward planning extremely difficult, and many expressed the need for the DSP to be available if and when required.

> I have been with my current employer for over 5 years. I was already working there when I got MS over 4 years ago. I was a casual and now will never be offered a permanent position because of my MS. No employer will knowingly employ person who has a chronic illness.
>
> As a casual it is much easier to get rid of me when I can no longer fulfil my duties. I actually work in Human Resources so know how the system works. Although I currently do not get a DSP if I was to lose my job it would be almost impossible to get another one because of both my age and illness.
>
> MS being so unpredictable makes me an unreliable employee. You can't be relied upon to do something tomorrow let alone next week or next month because you can't guarantee that you will be there. My current employer is understanding but there it a limit. I would need a pension to compensate as I have no other source of income and my husband does not earn a lot. (PG, 46, Sydney)

The reduction of the minimum conditions in the Bill to just 5 means that a person with MS or similar condition who requires a range of accommodations in their workplace will need a much more complex workplace agreement than the norm.

This may relate to variable hours and days, working from home, third party support (from an attendant or from notoriously unreliable taxi transport) and flexibility around duties.

The minimum conditions leave a lot that needs to be negotiated, so it is essential that free access be available to specialist bargaining assistance for both the employer and the employee.

Recommendation 3
Workers with chronic illnesses such as MS need legislated access to skilled advocates in negotiations with employers to ensure that the full range of individual needs (not just wages) can be expressed in individual contracts.

Likewise, employers have access to specialist HR and clinical advice when setting up the workplace and workplace agreements

7.4 Adequacy of Job Protections

Schedule 1 of the Bill contains a worthy objective

Section 3
Principal object…
The principal object of this Act is to provide a framework for cooperative workplace relations which promotes the economic prosperity and welfare of the people of Australia by:

(m) respecting and valuing the diversity of the work force by helping to prevent and eliminate discrimination on the basis of race, colour, sex, sexual preference, age, physical or mental disability, marital status, family responsibilities, pregnancy, religion, political opinion, national extraction or social origin;…

There appears to be little in the Bill that directly acts on the prevention or elimination of discrimination. Workplace discrimination of people with MS is likely to increase because of the removal of the unfair dismissal provisions of the current Workplace Relations Act.

In removing unfair dismissal protections in firms with less than 100 employees, the Work Choices Bill removes a key protection for people with MS and other disabilities. It is well recognised that people with disabilities need protections in the workforce against discrimination, as well as ensuring the provision of workplace accommodations that allow them to be fully productive.

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

I have been sacked from a job specifically because I have MS, I sued and won a pittance of a payment. I am nervous about trying to work fulltime again as I don't trust my body, MS or the employer. I have a large number of qualifications that I can not use any more and MS is not my only disability anymore. (RD, Adelaide, 39)

The allowance for employers to terminate employees for operational reasons codifies a poor practice used by employers to remove a person with MS and/or similar conditions from their workplace. This now allows the disguise outright discrimination as operational management, and leave little protection for the employee.

While this practice has been used by some employers, many people with MS have told us that the unfair dismissal provisions currently in place have acted as a deterrent from their employer sacking them. In many of these consultations the point has been made that these are a more effective deterrent than the anti discrimination law.

These people are now seriously concerned that they will lose their jobs as soon as the Work Choices Bill becomes law.

When I informed my employers about MS I was at first told that it was "OUR PROBLEM" and that we would work through it together. 2 weeks later I was given a redundancy offer. This was a one off so I took it (46years old). If I'd stayed I may of been given a lower paid job which would of dropped the amount of super I was able to claim.

My job was a very physical one so I would not have the strength to do it any more and at 52 am not a very good re-training prospect. (AR, 52, TAS)

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)

MS Australia believes it is very likely that people with MS and other chronic illnesses will be terminated from their employment is much greater numbers once these provisions become effective. This is especially a concern for those people who acquire a disability while in employment.

There are a number of labour market support programs available through the Department of Employment and Workplace Relations that can make it easier for employers to accommodate workers with chronic illness and disability (Workplace Modification Scheme and Work Based Personal Assistance Program).

There is a risk in this Bill that allows an employer to decide that for operational reasons, it would be easier to replace the person who requires accommodations at work with one without a disability rather than access these worthy programs, and there is no redress for the displaced worker.

I was 38 when I was diagnosed with MS in 1999 I worked as a real estate agent with the same office for 9 years when it was taken over by a group of my sales colleagues. At the time I was the longest serving member of the team, but I was sacked due to my MS, (and the concern of the agency about their image having an agent with a physical disability), despite my strong sales performance. I subsequently got a job with a sister office and worked for a further 2 years before 'retiring'.

This proved I had more work left in me than my other employer recognised.

I did take a discrimination action but withdrew it because it was going to be costly and futile after the fact- it was not going to get my job back. The Anti Discrimination legislation is inadequate protection against bad employer behaviour. I was a victim of discrimination borne out of the need for education and information to counter the mythology around MS in the workplace. (RM, 43, Melbourne)

I was diagnosed at 47 when working as a senor executive in the printing industry. I suffered through months of systematic discrimination at work until being made redundant. I have not worked since.

After I disclosed my illness, I was forced to work in an office that was up stairs and nor air conditioned, was not allowed to perform my production management duties on the factory floor because of perceived ‘risks’. I also lost my work car, making productive work impossible. All I needed was to modify my work slightly. I had not lost my skills, just some energy.

It was the fear and ignorance of a chronic illness that contributed my loss of employment, all made to look like a legitimate redundancy. With a young family I was left with no choices and no job, just to suit the company. (RP 54, Melbourne)

Recommendation 4

The Government must urgently increase the legislative protections available people with chronic illness and disability in the workforce in the current Bill and related legislation.

The overall legislative protections in this and other related Acts must have a more present deterrent effect to cover for the loss of protection afforded by the unfair dismissal provisions.

The policy imperatives of the Government to get people with disabilities into the workforce are put at risk of being inadvertently neutralised by the effect of the operation of the Work Choices legislation.

8. Conclusion

The current reforms under consideration in this Bill and the Welfare/employment issue must be cognisant of the realities of the progressive and unpredictable disease that MS is for people and their families.

What is required by people with MS are things also required in the system for older workers and carers – 2 other priority groups in the community that the Government wants to keep engaged in the workplace.

The Government's promotion of this Bill has often referred to the need to modernise Australia's industrial Relations system. A truly modern system would be multifaceted and sensitive to the needs of priority groups in the community, and well integrated.

Because MS is a lifelong disease that has impacts in every area of life, the effects of policy change in this area will also be felt in other areas, including health, superannuation and others.

The bottom line outcomes of the workforce participation reforms in this and the Welfare/Work package that are required by people with MS are to

- Maximise employment protections to enable people to stay at work as long as possible,
- Legislative provisions that are able to encourage and support people working part time with part DSP
- Stricter obligations on employers to provide more supportive and flexible workplaces
- targeted labour market programs
- Strong links between Workplace Relations legislation and welfare to provide adequate income and health supports for those that can no longer work.

MS Australia is happy to present to the Committee and provide more detail than time allowed in this written submission. For further contact:

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