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(Inq into better support for carers)

MS AUSTRALIA

Submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth

Better Support for Carers

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1. Executive Summary

This submission focuses on a range of carer issues faced by working age carers. MS is a condition of working age people, and many carers struggle with the integration of their working lives and normal family responsibilities with caring for a person with a chronic disabling condition. We are aware that the Committee will receive a lot of submissions about the caring role more generally, and we are keen not to duplicate this information, however we may raise common issues in the context of our main themes. Our submission will provide detail and practical recommendations on the following themes:

- Experience of caring for a person with MS
- Carers and employment
- Financial security for carers
- Carers Superannuation
- Improvements to the service system

1.1 Experience of caring for a person with MS

The experience of caring for a person with MS is complicated by the progressive nature of the disease, and the need to access multiple parts of the health and community care systems concurrently. The disabling effects of MS are lifelong, and individuals and their carers need and expect a lifetime support commitment from the service system. The burden of administration, organisation and accountability is one that presents one of the more frustrating elements of the caring role. Access to consistent and reliable information and continuity of services are key requirements of carers.

1.2 Caring and Employment

In order to improve the workforce participation across the community it is important to provide a range of assistance to carers and their employers. Carers who work value their employment and the accommodations they can negotiate with their employers.

There are a number of specific proposals to improve workplace flexibility such as workplace flexibility, advice and support, pooling sick leave and the provision of caring information in the workplace. Some creative and practical examples of accommodating working and caring exist in the community. These need to be showcased and encouragement needs to given to the employer sector to embrace these models as routine workplace arrangements.

1.3 Financial Security for Carers

Poverty is an issue for carers, and while working is important, many carers reduce or cease their work to accommodate the caring role. In the face of lower incomes carers and families must meet a range of costs of caring and disability support that are not funded or part funded. This includes aids, equipment and home modifications, health, transport and program co-payments. Too often income support payments for carers are spent co-funding disability services, further eroding carers' income and masking the endemic underfunding of the disability services system.

Carers also experience injuries and other health impacts of caring that need to be met, and looking after their own health, particularly treating physical injury is costly. Carers have expressed the need for an extension of workers compensation schemes to cover the costs of carer related injuries.

1.4 Carers Superannuation

Part of the financial security issue for carers is the poor retirement saving outcomes. Carers' ability to accumulate retirement savings is directly related to their ability to participate in the workforce. In many cases carers leaving employment access their superannuation balances early on compassionate grounds, and use these lump sums to settle debt, pay for equipment and home modification, and once this money is exhausted it does not grow back. Ageing carers need to contribute significant amounts each year to even manage a subsistence level of superannuation, and this is currently out of reach.

A way needs to be found to address this exclusion from the mainstream retirement savings system, and protect carers from the double disadvantage of losing income as well as their retirement savings.

1.5 Improvements to the Service System

Carers regularly raise issues about the operation of the service system. While it delivers substantial benefit and support to people with disabilities and their carers, it is complex and sometimes overly bureaucratic.

A range of measures are required as part of a reform process to simplify the operation of the system, provide complementary services and reduce the administrative burden on carers, which many see as a removable barrier.

1.6 Recommendations:

1. **Improvements to the service system**

    (a) Accelerate reforms to the community care system to enable simplified engagement, funding and accountability arrangements for people with disabilities and their carers.

    (b) Accelerate work to achieve the commitment made at the Community Services Ministers meeting in May 2008 to improve aids and equipment schemes across Australia. This work needs to include fully funding a range of items, and to introduce efficiencies and service standards.

    (c) As a first step in reforming the way disability services are funded in Australia, a national disability insurance scheme should be introduced to fund the lifetime care needs of people with high level disability to ensure that these needs are not ultimately underwritten by unpaid family carers

    (d) Expand the availability of skilled respite services for carers of people with MS and similar neurological conditions

    (e) Investigate options to improve the interaction between carers and Centrelink

2. **Provide for greater workplace flexibility for carers**

    (a) The Federal Government collaborate with community and employer organisations to implement a Workplace Flexibility Advisory Service to inform, assist and intervene to encourage the accommodation of workers with caring responsibilities and other needs for flexibility in the workplace.

    (b) A job retention service for carers and people with chronic illness be funded as part of the DEEWR suite of labour market programs to provide active workplace intervention and support to ensure people do not fall out of work prematurely.

(c) Investigate the feasibility of establishing industry sick leave pools to support people with chronic illness and carers through periods of extended leave from work, and

(d) Extend the eligibility for Centrelink Sickness Benefits to carers who leave work for periods of less than 6 months to provide full time care and who would not otherwise be ineligible for the Carer Payment

3. Financial Security for Carers

(a) Investigate options for funding ongoing superannuation contributions for carers who have reduced or ceased employment to ensure carers are not excluded from accumulating retirement savings while providing unpaid care to a person with a disability

(b) Extend taxation rebates for workers and self employed people who incur costs of care as part of their caring role, or who self-fund disability services (including aids, equipment, home and vehicle modifications, consumables and service co-payments), and allow salary sacrifice arrangements for these costs.

(c) Investigate the options for providing personal injury insurance for carers

2.0 Introduction

MS Australia congratulates the House Committee on Family, Community, Housing and Youth on conducting this Inquiry, and is pleased to be able to make a submission. MS is a disease of working age people with 87% of people with MS aged between 16-65, so the focus of the inquiry on economic and social participation is particularly welcome.

Family carers play a huge supportive role in the management of Multiple Sclerosis, and provide substantial amounts of physical and emotional support, as well as being advocates and administrators.

2.1 MS in Australia

MS currently affects 18,000 Australians directly, and indirectly hundreds of thousands of family members, friends and colleagues of those living with the disease.

While science continues to strive towards a cure for the medical effects, improved social and economic policy can also provide a 'cure' for many of the social effects of living with the disease. Keeping people in good health, maintained in the workforce, living with their families and making positive and productive contributions to the community will help reduce the burden of the disease and improve the quality of life of those affected.

There are substantial costs associated with having MS. Hendrie and colleagues (2005) found that the average annual cost to people with MS and their families in Australia was an extra $10,500 - a significant outcome of the disease for people on low incomes, many of whom are on partial and full government pensions. A large proportion of this cost is in the forgone income of family caregivers. The total estimated cost of MS to Australia is $2billion per annum, and will grow quickly unless we address the disease with increased research and more effective policy.

2.2 What is MS?

MS is a chronic, degenerative and incurable disease that randomly attacks the central nervous system (brain and spinal cord).The symptoms, disease course and outcome of MS are unpredictable and vary greatly from person to person and over time in the same person. They may include: extreme fatigue, tingling, numbness, impaired vision, loss of balance and muscle co-ordination, slurred speech, tremors, stiffness, bladder and bowel problems, difficultly waking, problems with memory and concentration, mood swings and in severe cases, partial or complete paralysis.[1] Depression is common and the incidence of suicide is 7 times higher than in the non-MS population.

We all know someone with multiple sclerosis (MS).

In supporting Australians with MS and their families, MS Australia is endeavouring to provide an integrated approach to managing the disease through service programs, a focused research effort and education.
To achieve this we are:

- facilitating Australian research that will accelerate the potential for prevention and better treatments
- providing direct services to individuals and families and working with the health sector to expand health services for all Australians with MS

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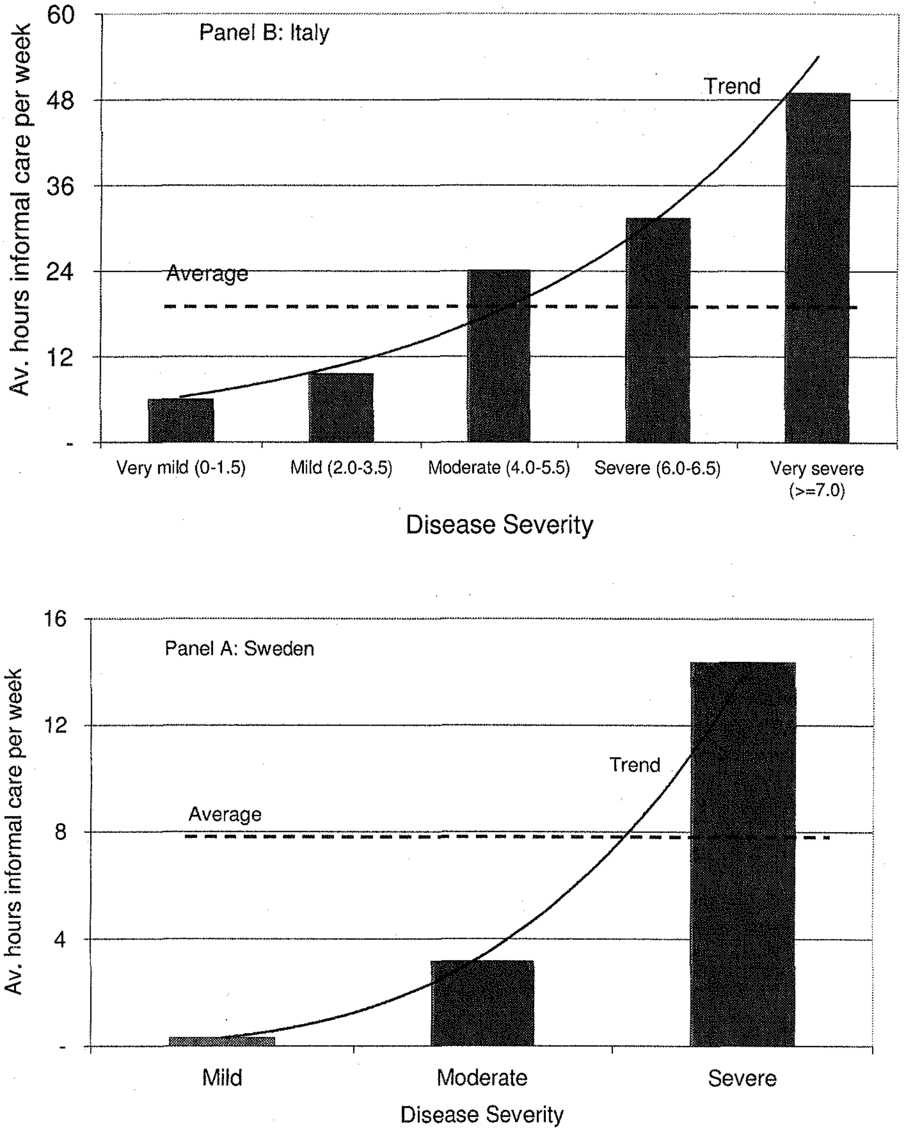
[1] Acting Positively: Strategic implications of the economic costs of multiple sclerosis in Australia. Report by Access Economics Pty Ltd for Multiple Sclerosis Australia. Winter 2005

- promoting early access to new and better treatments that will slow disease progress and reduce symptoms
- educating and informing the community and Governments to improve real life outcomes for those affected by the disease and to reduce discrimination against Australians with MS.

3. Experience of caring for a person with MS

MS is a progressive neurological condition, and consequently the need for assistance and care increases over time as the disease progresses (see the two graphs below in Figure 1). The experience for family caregivers is one of uncertainty in relation to how quickly it will progress, and what aspects of a person's life will be affected (Mobility? Blindness? Cognitive problems? Depression? Etc). However, as these two graphs illustrate (Italy & Sweden), better developed service systems and carer supports can reduce the demands on caregivers.

Figure 1: Informal care – Average hours per week, by level of disability



Source: Henriksson et al (2001) and Amato et al (2002)

Data from Australia shows that the average number of hours of unpaid care that people in the 2005 Australian MS Longitudinal Study survey received was 12.3 hours per week[2]. This care was listed as:

- assistance with activities of daily living
    - personal care
    - meal preparation
    - physical access to or within the home
- home and garden activities
- essential household tasks such as putting out the garbage bin, house maintenance and repairs
- managing bills and household paperwork
- other activities (essential transport, child care).

Applying these average care needs to the Australian MS population suggests that an annual total of almost 10.3m hours of informal care are provided to Australians with MS. This is values at over $260m per year

Data such as that presented above on what carers do to support people with MS is only part of the overall picture. In the rest of this section on the experience of carers we will focus on:

- Service system
- Employment and caring
- Financial Security

These issues are only a fraction of the whole-of-life impact that carers experience, and in their role as carers of people with MS the grief, uncertainty about the future and social isolation are markers of their role. Due to the fact that in Australia 75% of people with MS are women, carers in this group are often husbands and cases of children as carers are also common. We are focusing briefly on issues regarding the broader service system in relation to community care/disability/chronic illness because it was such a major feature of our consultations with carers. And similarly, employment and financial security were also dominant themes.

3.1 Carers' Experience and the Service System

One of the most common comments carers made during consultations in preparation of this submission was that if the service system worked better and was more effective in meeting the needs of a person with MS, their experience as a caregiver would be vastly improved. It also seems likely that the time and effort they must spend as caregivers would also be reduced, based on Figure 1 above.

The service system has become so layered and complex that it creates its own burden for carers as they try to figure out how to make it work effectively. The untangling of the matted bureaucracy of the formal care system is a major reform imperative that this inquiry can champion.

There are as many anecdotes about the seemingly irrational operation of services and programs as there are about how helpful they are. The following edited presentation by Robin Laird to the Senate Community Affairs Committee inquiry into the Commonwealth/State Disability Agreement in 2006 summarises this aspect of the carers' e experience particularly well:

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[2] The Australian MS Longitudinal Study is a social research initiative of MS Australia that has over 3,000 enrolled participants with MS.

Figure 2: One Carers' Experience of the Service System

Senate Thursday 28 September 2006

Mr Laird—My wife has both MS and Graves' disease. The MS will not get her but the Graves' disease will. The services that I use on a very regular basis include UnitingCare Community Options based in Boroondara; Australian Home Care Services; the Royal District Nursing Service; and St Vincent's At Home, who do Mary's bowel regime. We use the appliance and equipment funding, CAS funding, the local council and of course the mercurial Centrelink. We also use Bethlehem Health Care for respite. We are regular visitors to St Vincent's Hospital and use taxi and ambulance services.

One of the major problems which I have mentioned to a number of people over many years is that it is bad enough managing at home with Mary's MS and her Graves' disease but the administration I find equally onerous.

One of the real problems that I have is what I would term the lunacy of bureaucracies—for instance, I have two documents here from our carers service. This is one of the problems with our funding—that it comes from various sources.
I am not crying poor mouth at all: we have an enormous amount of equipment; we have an enormous amount of hours. The problem with the hours is that they come from several sources.

I will give you one example. We have a carer who does the eight-to-three shift on Fridays. The first four hours of that are funded by Boroondara council. The next half-hour is funded by DHS, and the next 2½ hours are funded by UnitingCare Community Options. One of our problems with the way it is funded is that a number of organisations now have a no-wheelchair policy, so Mary cannot be wheeled in a wheelchair. We have to be careful that Mary's time for being in a wheelchair is when we are not being funded by the local council.

The second thing that amuses me is particularly related to our home-care people. I have here a roster for a woman who works for us on a Saturday between 10 and 12. Her roster starts at seven in the morning for her first shift, and finishes at 10, her second shift starts at nine and finishes at 10.30 and her third shift starts at 10 and finishes at 12. As a carer, these are some of the inconsistencies and lunacies that I—and I will say 'I' and 'we' where it is appropriate; Mary cannot converse, so quite often I will say 'I'—have to deal with on a daily basis.

There are other problems across a whole range of issues, but I want to concentrate on two. The first one is about equipment. In 1999, my wife spent nine days in a large public hospital which did not have a pressure mattress and was so understaffed that the turning of Mary, which has to be done on a four-hourly basis, was not available. She spent nine days in that hospital and then 18 months in respite curing a bedsore. For the sake of a small amount of money, 18 months of hospital care could have been saved. That is the first thing.

The second thing is that I am a co-facilitator of a carers group. We are an ageing group; I would be probably the third youngest person in the group. It is interesting to me that a number of the members are now going through the same situation that I went through seven years ago, when Mary's chronic progressive MS suddenly deteriorated. Whilst I know that people all over the country will be asking you for money left, right and centre, one of the things that has to be looked at is the ageing—and we are ageing, us carers are ageing—of carers. These people are going to go through a situation where financially they are going to need more and more help.

> Another thing I would like to say is that we need equipment for carers. One of the older members of our carers group is a physical wreck. He could not get a hoist, so he had to do all of the turning of his wife. He now has arthritis in his elbows, his wrists are in very poor condition, his knees are gone.
>
> I could spend hours talking to you, but the next thing I really want to talk to you about is training. In my household, it is interesting that when we do get a new carer, they will do what is called a shadow shift. They come in with an experienced carer and will do a day, maybe less, and after that it is me who does the training. To me, that is a worry. I want to refer to point 10.1 of the MS Society's submission, which talks about a skilled workforce. There is a shortage in allied health. I know that in the eastern suburbs of Melbourne it is particularly difficult; it is an ageing population with much greater needs for support and care, but it is made up of a population of people who find the pay and conditions in that sort of work inappropriate.
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> In my opinion, there is an appalling lack of education for carers who come to my home. I have had a carer who would be lucky to be 45 kilos wringing wet trying to move someone around in a bed who weighs 65 kilos. There is a very important role in training. The agency that provides our carers talks to me all the time about having div 3 and div 4 people in aged care et cetera, but it is blackboard stuff. None of them have come to visit my wife.
>
> The thing that carers want is some consistency of policy across the board. We do not want one council having a particular policy about wheelchairs whilst another does not. We do not want one council having a policy about disabled parking while another council does not. Carers want consistency, but, more importantly, carers want recognition for the work they do and for the money they save both state and federal governments. They do not want just lip-service.
>
> I could go on forever, but I will not.

In consultations with carers to develop this submission, a major theme has been to streamline the service system, reduce the sheer number of funding programs and requirements for administration. Carers of people with MS fear loss of service through disease transitions where additional support is required, and cannot generally reconcile conflicting eligibility, divisions between Carer Services HACC and Disability Services.

This is a high level objective that is not only supported by carers, but people with disabilities and service providers. No one suggestion will deliver a simpler system, however the Committee will receive many individual suggestions, so a recommendation along these lines is consistent with the Terms of Reference of the Inquiry.

One suggestion coming out of a carer consultation was that a one-stop-shop for income support and service provision could be set up through Centrelink for all Commonwealth programs. This was in response to the regular and repeated information requests from Centrelink about the status of the carer when it is information already known to Centrelink and numerous other commonwealth programs.

4.0 Carers' Experience of Employment and Caring

Caring often has a significant impact on their ability to undertake paid work, or to avail themselves of training and education opportunities. It also has major impacts on their relationships with other employees and their employer. Not surprisingly, these impacts on work flow on to other major impacts in relation to being able to pay for the extensive range of goods and services associated with providing care at home, living costs more generally, and short and long-term financial security.

The 2008 survey of the economic impact study of the AMSLS surveyed participants about the employment experience of their carers.

Figure 3 below summarises the impact on changes to employment status for carers of people with MS

Of the 1,329 people with MS who completed the Economic Impact Survey's Baseline Questionnaire, 174 people or **13.1% indicated that someone had CHANGED their employment situation to help them.**

If translated to the population of Australians with MS, (estimated at 18,000), 2,358 Australian carers in this position. This 13% includes all types of changes, including stopping and changing hours, and was broken down as follows:

* 16 (9.2%) that increased hours
* 6 (3.4) that kept the same hours but changed employment in another way
* 99 (56.9%) decreased hours
* 53 (30.5%) didn't report hours

And for the 121 who reported hours:
* 51 (42.1%) Stopped work for someone with MS
* 70 (57.9%) Changed (increased or decreased hours) for someone with MS.

Put another way, at least 99 people or **7.45% of all Australians with MS have a carer who has REDUCED OR STOPPED employment to help them**, and with 18,000 people with MS this means 1,341 carers in this position.

Source: Simmons, RD et al. Preliminary data from the Australian MS Longitudinal Study, National Economic Impact of Multiple Sclerosis Survey 2007-2008, in preparation for publication 2008.

The experiences of trying to combine work and care are described well in the two case studies presented below in Figures 4 and 5. As you can see, Dianne (Figure 4) has had a relatively positive experience with a supportive employer, whereas Jennifer (Figure 5) had what is unfortunately the more common experience of an unsupportive employer. As you might expect, their different experiences have had a tremendous impact on their lives far beyond the simple notion of being or not being employed. Maintaining employment is important to many carers, and carers have expressed that it can provides its own form of respite and normality in addition to financial benefits. It is also clear that the levels of understanding and flexibility within the workplace have a huge influence on the ability of the carer to juggle their roles.

Importantly, these two case studies also emphasise the interconnectedness between employment, caring, other family responsibilities and the service system.

Figure 4: Dianne – A Working Carer

Dianne has been a carer for her husband since they were married. They have 2 school age children and live in Perth. In more recent years his needs have grown and after 9 prior attempts, he has now received funding for a care package that has allowed him to stay at home with the family.

Like many carers Dianne provides the coordination and administration for her husband's care in addition to personal care and household tasks. Her husband has care for around 50 hours per week (when there are carers to fill shifts) and Dianne covers the rest of the week, including overnight care. Her mother is a secondary carer who fills the gaps with Bob and the children when Dianne is tied up. Finding cover for the school holidays is an issue as there is no additional paid time off for those weeks.

Dianne has worked for her current employer for 26 years, and has an employer that allows her the flexibility she needs to take time off when needed. She job shares with another worker with young children. This longevity has had its rewards for both parties and is something that she believes is a consequence of having a good working relationship with her employer.

Dianne uses her formal leave to take time off and can coordinate care workers and other services while at work. When she has run out of leave then she will take leave without pay.

'My work has been fantastic over the years and it's only fair that if I don't work I don't get paid. It hasn't happened very often so it's OK. They are good to me so I like to hold up my end of the bargain. I have thought of trying to get a job closer to home to cut down on travel time, but I doubt that I would get anywhere with the flexibility I have where I am, and that is the most important thing.' I rely on all the people and systems in my life to be helpful and flexible, particularly because MS is so changeable. Life is at its most difficult when at any point I can't get that.

She began working 4 days per week, but over time has reduced to 17 hours because of the difficulty in managing everything. This has reduced the family income, which is a combination of her part time wage, part carer payment and part disability pension. The family has a mortgage and regular other expenses.

I couldn't say how many times I've nearly given up work. So many times after being up half the night I'd come to work exhausted and wonder if it was worth it. But then things would settle and I'd be fine. If I did stop who would pay the bills?

Like many carers Dianne finds the coordination of funded services one of the most frustrating and burdensome elements of caring. Getting the system to respond when necessary, finding carers, going to meetings and chasing case managers and bureaucrats are all time consuming. Bob was rejected 9times for in-home funding by the State Government before finally getting a care package through the COAG Young People in Nursing Homes program.

In addition, the additional costs of disability and co-payments take their toll on the family budget. Some programs charge a contribution, and non funded consumables are expensive.

Bob needs a calorie supplement that costs $75 per month, and a round trip by taxi to medical appointments is $50 even with the half price taxi card. His annual continence allowance runs out after 7 months, so we have to pay for the rest of the year. Then we are expected to pay a top up for the care services.'

The caring itself is one thing, and I'll always do that, but it takes so much effort to make the system work, and even then it falls short. We have to fill all the gaps that really shouldn't be there.

A major difficulty faced by Dianne and her family is the shortage of attendant carers. It is a regular occurrence that workers cannot be found to fill shifts and increasingly there is little notice with workers calling in at the last minute to say they can't work. It is a source of great frustration and uncertainty, particularly after the long battle they had to get an adequate funding package. It has proved to be a cruel irony that now the funding is there, the workers cannot be found.

In the end it will always come down to me. I've got more confidence in my ability to provide what Bob needs than anyone else, but we can't manage without the services either. With all the workers coming and going the house is like a station. Sometimes we just need our privacy so we tell them all to stay away'

When asked what she wanted to tell the Committee, she said there were many things, but the things that would make the most difference would be better financial support for carers (including removing co-payments and short funding of consumables) and for the Government to take action to improve the attendant care workforce.

She wants to keep working and has a supportive workplace, but she believes that the thing that will force her to leave work is most likely to be service provision failure.

Figure 5: Jennifer's Care and Work Journey Employed → Unemployed → Employed

Jennifer is in her early 40's and until recently worked for a State Government Disability Services Division as a case manager. She provides care for Emma, her 18 year old daughter with MS who was diagnosed and age 14. Emma has an aggressive relapsing/remitting form of MS, and the amount of time she needs to dedicate to her daughter's care fluctuates with the course of the disease, which increases during relapses. Until recently Emma was experiencing a relapse once per month which would dramatically affect her balance, walking and vision for one to two weeks.

The additional support she provides for Emma includes educational support due to time off school, supervision and personal care, attending appointments.

Jennifer initially used leave provisions to manage appointments and caring duties. At the time of her disclosure and request for more flexibility in her work, Jennifer's section manager was on secondment, and her replacement negotiated an arrangement where she worked from home 2 days per week and could juggle her other hours accordingly depending on Emma's needs. This allowed a good balance and Jennifer managed both roles well, something backed up by a very good performance review that was completed in this period.

When her section manager returned from secondment, she told Jennifer that she would never have approved the flexible arrangement as she believed that staff should be at work to do their work. She pressured Jennifer to return to 5 days in the office which at the time was not possible. This pressure intensified over time, creating additional stress for Jennifer. This manager did not appreciate her caring responsibility was an issue, saying that everyone has to manage their lives around their work and that her case was no different to anyone else.

"My temp manager was far more supportive than my regular boss; she had been very understanding as she is in a caring role her self (with an ageing parent). My boss is not married and has no children. I did not feel comfortable discussing or disclosing my caring responsibilities to her – I felt that I had to justify my position constantly. Each time Emma recovered from one of her relapses, I would be pressured to get back to work. She must have thought MS was like having a cold.'

I found my colleagues pretty reasonable and compassionate initially. My previous manager did tell me that people had been querying the hours I kept at work once I started working from home, but I'm not sure where this came from as people were OK towards me directly.

Generally I felt fine about discussing my caring responsibilities with my colleagues, although I really only discuss my private life with people I consider to be friends at work. I would never discuss personal topics with people I feel are only colleagues."

There was little organizational support for Jennifer to renegotiate her position, with little interest being shown by senior management in the Division, making her feel particularly vulnerable. Working 5 days was not possible at the time so Jennifer took extended sick leave and was suffering anxiety. She consulted legal advisers and considered taking action but decided she did not have the energy to take on another fight and was sure that formal action was the wrong way to bring about a workable routine.

Late in 2007 Jennifer resigned from her job after a short period working back in the office. She was convinced that any work/caring balance would not be accommodated within the Division

'I got sick of my legitimate caring responsibilities being seen as excuses to leave work, and I was angry that this was happening within a Disability Services environment. I mean if the people running the system don't get the reality of disability within families who will? I really expected better and I think that made it worse. They should have been more sensitive to the caring role overall and not allowed an individual manager to set the tone.'

Emma's MS has been stabilised through a new drug regime, and has been well for most of 2008, and is in the middle of her VCE. Jennifer is working full time in the non-government sector, but is planning on going down to 4 days to help Emma with the VCE year.

The research locally and internationally makes it clear that the experiences of Dianne and Jennifer are 'normal'. In the workplace, particularly difficult issues for carers include:

- Disclosure (usually underpinned by a lack of confidence in their employer's and fellow employees' responses, and stigma) (Davey et al, 2004; Bernard et al 2002; Artcraft Research)
- Difficulties juggling caring and work responsibilities (Davey et al 2004; Bernard et al 2002)
- Reduced earnings and career impact (Greene 2001)
- Caring for more than one person (TOCC 2006)
- Unpredictability of caring needs, short and long term
- Failure to self-identify as a carer, and forgone assistance, support, services and income support as a consequence (Artcraft Research)

Additionally many are endeavouring to care for their own family; partners and children. Task Force on Care Costs latest report noted that of the 10 million Australians with caring responsibilities, 13% of care recipients have a disability as opposed to 12% being elderly. Care for the disability cohort is generally provided by a partner or child and the capacity of these Carers to engage in paid employment is limited. There appear to be significant gaps in both the data and effective strategies or approaches used by society to address the needs of this particular sub group of carers.

Carers have expressed to us the need to reduce work hours or work from home should their caring responsibilities increase in intensity. Some expressed that their work was ultimately expendable if their caring role escalated, as it was not an option to give up caring.

The MS Society in Victoria conducted a small research project (The Working Futures Project) with 2 large employers in Victoria looking at the experience of employed carers from personal and employer policy viewpoints.

81% of carer received some level of support in their caring role. 71% receive informal support from other family members or friends. 29% use a combination of informal and formal support systems. The vast majority of secondary carers provide support in the areas of transport, supervision, attending appointments. Only 19% of participants are recipients of government benefits or allowance; information provided in their responses suggests that a number of other would meet eligibility criteria. [3]

4.1 Disclosure

Disclosure of caring status at work, like disclosure of a medical diagnosis or disability is a difficult issue, and is the trigger for the negotiation and introduction of workplace flexibility measures.

It is at this time when carers and employers may require support and information. Carers are driven very much by perceptions of both understanding of the carer role and quality of the workplace relationships with their Managers and colleagues. Quotes obtained through the Working Futures Project are presented in Figure 6 below.

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[3] Thomas, L The Working Futures Project, MS Society of NSW/Vic 2007

Figure 6: Carer Disclosure and Employment

I have recently commenced work with a new Manager who is extremely supportive of my caring responsibilities. Prior to that I was … discriminated against on the basis of carer status (in a performance review I was told that because my son has a disability I had to attend sessions in a psychiatric facility one afternoon per week – I was not committed to the job. **Mary, Carer of 10 year old disabled son**

I did not feel comfortable at all disclosing my caring responsibilities to either my manager or colleagues. I do not find either my Manager or colleagues to understand at all. **Nicole, Carer of 39 year of partner.**

I do not feel comfortable about discussing my caring responsibilities, as I can be vulnerable if people want to talk. **(Carer of disabled child)**

Both are understanding and treat my concerns with sympathy and dignity. We have set clear boundaries on this issue over the years, and have all worked together well over the years. One of my managers is also the carer of a disabled husband, so we sometimes share our experiences. **Georgette, Carer of 57 year old partner**

Not really comfortable in sharing my personal life with my Manager. **Carer of frail aged relative**

My work environment is completely hostile and inflexible. I feel totally uncomfortable discussing my caring responsibilities with either my Manager or Colleagues. **Megan, carer of 80 year old relative**

Don't feel comfortable discussing my sons caring needs with my Manager. When it comes to my colleagues it depends on whom. **David, Carer of 25 year old disabled son**

Source: MS Society Working Futures Project 2007

5.0 Carers' Experience Regarding Financial Security

Poverty is closely associated with caregiving, and is a result of both the short and long-term impacts of caring on employment, as well as the extra costs of caring at home. Often the person being cared for also represents another 'lost income' earner for the family. Over 25% of all primary carers reported to the 2003 Survey of Disability, Ageing and Carers, gross household income in the lowest quintile. (Access Economics, 2005)

People with disabilities and carers have significantly lower incomes and less workforce participation than the Australian average (ABS 2004).

Two income households become 'no-income households' as MS progresses so the issues around financial security are acute. Although 87% of people with MS are of working age, and most people with MS are employed when first diagnosed, 80% are not employed 10 years after diagnosis. Likewise, as the disease progresses many carers are often forced to give up work either as a result of the lack of flexible employment arrangements, or the overwhelming need for care of the person with MS – combined with an often inadequate service system.

There are significant costs associated with having MS. As stated earlier, the average annual costs to people with MS and their families in Australia $10,500 ($3,893 out-of-pocket and $6,593 for informal care) (Access Economics 2005).

Reduced levels of employment and reduced levels of income while employed (via reduced hours, unpaid leave and career impacts) combined with the additional costs of caring at home also have substantial impacts on the ability of families to save, invest and put funds into superannuation. This in turn leads to considerable financial insecurity, concerns about retirement, and concerns about how the person with MS will be cared for in the event of the death of the carer.

Carers who have been employed often dip into their superannuation funds early in order to fund equipment, modifications to the house and vehicle. Many carers are also unable to accumulate significant superannuation due to leaving the workforce early and/or reduce earnings overall as a result of working fewer hours, taking unpaid leave and seeking less demanding (and lower paying work) that is more flexible in relation to caring responsibilities. Additionally, as most carers are women, their overall lower incomes also contribute to this problem.

Figure 7: Using Superannuation Funds to Purchase Home Care Equipment

George, a 60 year old NSW man, caring for his wife with MS was able to retire at 60 as he had served in Vietnam. Prior to this he had successively reduced his employment to be able to provide care to his wife with MS, and he was receiving the Carer's Payment. Prior to retirement he accessed his superannuation to fund the purchase of a wheelchair-friendly vehicle for $55,000. This was a relatively inexpensive purchase as the vehicle was second-hand (he had priced an identical new vehicle with modifications at almost $90,000).

George did not see this as a problem – just something that needed to be done, and was quick to acknowledge that the NSW aids and equipment program has provided wheel chairs, a hospital bed, hoists and other equipment over many year at only a modest cost to the family.

6.0 Carers' Experience on a Range of Other Issues

As indicated earlier, the caring role is pervasive, and interaction with the service system can be problematic. In the process of consultation carers consistently raised issues that relate to overall financial security and recognition of the real experience of caring. Below is a brief summary of these issues.

6.1 Continuity of carer support after residential placement

Carers noted that the system devalues their role once their family member goes into permanent residential care. The caring role does not recede completely in this situation, it changes. They still have to provide many of the same tasks as before, with shopping, transport, attendance at appointments and administration, but the advocacy and safeguarding roles tend to increase for many carers. Access to carer payment and carer allowance ceases when the care recipient goes into residential care, which is seen as unfair.
Carers who maintain an active caring role in this situation are clear about needing the financial support to recognise their continuing carer status.

6.2 Costs of caring

A universal issue is the personal costs of caring. As well as the loss of income due to reduction or cessation of employment, carers of people with MS are also faced with having to purchase (or co-purchase) aids and equipment, fund sometimes expensive home modifications to accommodate physical disability, and the cost of consumables such as continence aids, dietary supplements and medications. The rising costs of transport are also impacting heavily on carers.

The short funding of aids, equipment and home modifications by State/Territory programs, and the lack of any tax deductibility for individuals and families is a real problem. There is a pressing need to reform funding and service delivery in this area – not only for carers but as a significant part of the overall support to people with disabilities and those who are ageing. In our submission to the CSTDA Senate Inquiry, MS Australia called for the introduction of a nationally consistent and fully funded aids and equipment scheme that would reduce costs, improve buying power and rationalise the myriad ineffective programs.

The physical burden of caring also has its costs. Many carers believe there should be an extension to Workers Compensation schemes to include cover for carers who sustain injuries as a direct consequence of caring. With the contraction of allowable physical care tasks performed by care workers due to Occupational Health and Safety rules, carers are the ones who undertake a range of lifting, transferring and household tasks deemed unsafe because they have to be done. The treatment of soft tissue injuries through long term lifting is not covered by any scheme. This treatment is most often sought from private physiotherapists and chiropractors.

6.3 Better respite care system

Respite is a critical service area for carers, and demand for in-home and out-of-home respite is far outstripping supply. It is a major area of unmet demand in disability services. Carers of people with MS have stressed the need for respite services to be highly capable in providing the complex care required by people with MS, and that these are all too rare. A significant contributor to the resistance to using respite services (particularly those offered in hospital or in aged care) is that care regimes and preferences do not get observed, and that staff are not trained in care of people with neurological conditions.

Availability and quality of respite services needs to be greatly improved, and investment in more specialised services is required. This needs additional government funding, but also includes addressing the longstanding shortage of care workers in disability services.

6.4 Centrelink

Another universal theme in carer consultations has been the negative aspects of dealing with Centrelink. While people appreciate it is a complex and difficult task they have, the repeated administrative mistakes and poor behaviours and work practices of the organisation continually confuse and frustrate carers. The most common complaints raised have been:

- Duplicate requests for information and multiple mail outs
- Poor understanding of the carer role and general lack of respect
- Unexplained instances of being 'cut-off' from carers benefits
- Demands to come to the office to fill out forms that could have been done by phone or mail

Carers want better training for Centrelink staff to help them understand the position and role of carers, and improved business operations.

6.5 Labour Market Programs for Carers

There is currently no labour market program for carers (or their employers) to assist them to manage their need for flexibility at work. While large companies may have well developed programs and information, the vast majority of carers and employers trade on goodwill. Carers are often vulnerable in these situations, and the achievement of sustainable workforce outcomes will rely on more than goodwill.

The research shows that carers need similar supports to people with chronic illness and disability. From the time of disclosure, carers and their employers need information and advice about managing the ongoing relationship and the post-disclosure issues. From redesigning job expectations, legal requirements, performance management, conditions and communication, there are requirements for specialised information and intervention.

7.0 Ways of supporting carers in the workplace

The MS Society Working Futures Project found that carers do best in workplaces with a positive culture and overt support mechanisms, where fear of disclosure is minimised, and role models and support programs are visible.

One example that was presented to the project was the 'Jugglers Network' that exists within the Law firm of Stephen Jacques Mallesons that promotes work life balance and employee education and support. This is the kind of model that will promote a positive and accepting culture for carers.

http://www.eowa.gov.au/EOWA_Employer_Of_Choice_For_Women/2007/Documents/Mallesons.pdf

7.1 Flexible Employment Practices

Flexible employment practices are central to improving the capacity of carers to find and maintain employment.

A focus on flexibility for both employees and employers has the potential to provide many benefits – providing employers with a vital source of often highly skilled labour in the context of a national skilled labour shortage, and to provide family caregivers (as well as people with chronic illnesses and disabilities) increased capacity to participate in the workforce as much as possible while balancing complex interplay of: disability/illness – family – community – family caregiving – work.

Real flexibility is required to meet the rapidly changing workforce demographics in relation to the nexus of: (a) the ageing of the population; (b) increasing levels of disability and chronic illness; (c) increasing dependency ratio; (d) increased workforce participation of women; (e) low levels of unemployment, (f) reduction in the availability of family caregivers into the future; and (g) deeply entrenched employment practices and cultures that continue to disadvantage and to discourage carers (and people with disabilities and chronic illnesses) from maximising their participation in paid work.

The need for flexibility covers the inevitably broad spectrum of human experience, and the particular cases presently being put for things like child care and parental leave are relevant for carers and people with chronic illness. The need for flexibility in the current economic environment has general community acceptance, however the debate seem to be taking one issue at a time rather than looking at how the frameworks and structures can serve a range of employee and business needs.

Some employees will need a small amount of flexibility over a long period of time, others will need episodic flexibility where they need a few days or a few weeks several times a year, and a small number will need large chunks of time such as 3-4 months or 12-24 months of unpaid leave to deal with particularly demanding caring situations that have a clear endpoint such as death or residential care.

In many ways caring for someone with a chronic illness or disability requires the same intensity and time commitment as looking after a child under school age. Approximately 13% of people living in households are carers, and approximately 20% of these are primary carers: 55% of primary carers report providing 20 or more hours of care each week. In relation to those of working age, there is a gradual increase over time with 9% of 18-24 year olds reported as carers gradually increasing to 22% of 55-64 year olds. (ABS 2004)

More flexibility in workplaces would increase these participation rates, and provide employers with access to additional skills and labour.

In particular there needs to be increased capacity for employers and employees to enter into dialogue and negotiations in relation to:

(a) requests for flexible working arrangements
(b) flexible leave arrangements
(c) personal/carer's leave.

All of these arrangements need to be negotiated, and need to be workable for both employers and employees. The recently announced National Employment Standards by the Government for comment are a good starting point for many of these issues, but need to be extended to more adequately cover the needs of people with chronic illnesses and/or disabilities and family caregivers.

Requests for flexible working arrangements should enable employees and employers to find workable week-to-week arrangements in relation to working hours, shiftwork and so forth.

Flexible leave arrangements must enable the negotiation of paid and unpaid leave to cover both expected and unexpected contingencies that arise. Some of these arrangements will need to be in relation to a few hours a week, or perhaps a couple of days here and there. Some people may need 6-12 months of unpaid leave to care for a family member who is going through a particularly difficult time, or even dying. Someone with a disability or chronic illness may need a period of 6-12 weeks of paid or unpaid leave to recover from an episode of illness, a disruption in housing arrangements or in other contextual issues that impact on their health and/or capacity to work.

Whatever the details of arrangements are, they need to cover the continuum of needs for employees, and be viable for employers. And as much of this is beyond current employment entitlements arrangements, they key is that employees are supported and encouraged to enter into discussions, and that employers are able to turn requests down on 'reasonable business grounds.'

Importantly, if progress is not made on flexible employment arrangements, employers will continue to miss out on engaging many skilled and willing potential employees, carers will miss out on much needed income, government will miss out on an increased tax base, and government will but up for the additional costs associated supporting poverty-stricken caregivers and those that they care for.

In addition to the flexible leave arrangements outlined above, there are a number of initiatives that would provide vital support to employers in relation to ensuring the viability of flexible workplace arrangements. These include:

- Sick leave/carer leave pooling
- Government 'gap' funding for extensive unpaid leave from employment
- Information and support services for employers
- Supported labour market programs for carers

These initiatives are briefly outlined below.

7.2 Sick Leave Pooling

Some major Australian companies have introduced extended leave coverage for people with chronic illness and carers through the corporate pooling of sick leave. This allows companies to offer additional paid leave to staff who because of their health or caring status will exhaust their regular annual entitlement, and need additional leave in order to manage their lives.

It is a relatively simple concept where the employer uses the entire sick leave liability to provide a degree of flexibility for people needing extended leave. It is a simple idea that is based on the fact that for the employer, sick leave is a liability on the balance sheet for the entire organisation, and it does not cost the organisation to draw down that liability in order to support those valued employees who would normally run out of leave and have to consider leaving work. Traditionally sick leave for employees it is an individual entitlement, and when it is exhausted, it presents a major problem. Having a pool of leave it means that people with a genuine need for flexibility can be supported through periods of illness or crisis without suffering an unaffordable loss if income or losing their job altogether. As many employees never even go close to exhausting sick leave entitlements it comes at no additional cost to the employer, assuming they value the employee.

This model has bee implemented by the National Australia Bank and the Transport Accident Commission in Victoria. Both organisations have clear policies and procedures around its operation, and it has been a powerful tool in building a positive culture for employees.

These are successful programs within larger organisations, but for small and medium enterprises community or industry leave pools could be created to support additional disability and carers leave. Depending on the size and operation of the pools it may also be viable to extend to other kinds of leave where flexibility is required, such as maternity leave.

7.3 Centrelink Sickness Benefits

When people need time off for caring, but have no opportunity to extend their paid leave through their employer, it is important to ensure there are ways to prevent any income gaps for carers through other means, and to ensure that carers will **still have their job to return to**. Currently Centrelink offers nothing to people who need to leave work (without leave entitlements) to provide care for someone for less than 6 months. To qualify for the Carer Payment, the person being cared for must require constant care for a minimum period of 6 months.

As a way of filling this gap for carers of people with short term or episodic conditions such as MS, Sickness Allowance should made available where they:

- have no further **sick leave** available
- need time limited (less than 6 months) benefits to overcome illness/caring related obligations
- can demonstrate medical, allied health and employer endorsement for leave period
- can demonstrate proof of a permanent and sustainable job to return to after the caring episode.

7.4 A Flexible Workplace Advisory service

An advisory service for employers is required and would target job retention and support through mutually agreed flexible arrangements entered into by the employer and employee.

Employers need technical and legal advice about how to accommodate a worker needing additional flexibility; a worker needs that as well as links to specialist support and advice about illness management. Currently no single agency holds all the necessary information for all parties concerned.

While information exists on diverse websites and within chronic illness organisations, small to medium employers can't be expected to search it out. Such information is often general, and not related to Australian conditions, may be inaccurate or gloss over the hard questions, such as performance management, disclosure and managing co-workers.

Across a range of needs, but particularly in the carer and disability area, freely available advice and consultancy needs to be mane available for employers. This service is best placed within the employer peaks, and would have strong links to health, disability and carer organisations that could provide workplace interventions and consultation to employers and employees.

While there is a lot of talk and media about the need for flexibility in the workplace there is little dynamic expert advice available for either carers or employers. Website information is available, but is inert and must be found first. Setting up such a service is feasible and relatively simple to set up, and when put in the context of wider community needs for flexibility at work, should have been implemented some time ago.

8.0 Financial Security for Carers

Improving the capacity of carers (and those they care for) to actively participate in the workforce to the fullest extent that is possible and realistic for them will in itself go a long ways in assisting with improving their financial security. Likewise, if the service system could be improved this would increase carers' capacity to participate in the workforce and also reduce the extent to which they are plugging gaps and fixing problems in the service system by purchasing equipment and services that are generally already supposed to be provided through government funding. Additional ways of helping to provide a much needed greater degree of financial security for caregivers would include:

- A superannuation system for carers
- Support through the taxation system
- Lifetime disability insurance

8.1 Sharing the Care – Can the Taxation System Help?

The costs of caring have been well documented, and are regularly raised as a major issue by carers of people with MS. Aids and equipment, transport, out of pocket medical expenses, non PBS medications, co-payments and other expenses.

A number of options have been canvassed, however there is no one size fits all solution as some carers work, some have private income and some rely on welfare payments. For employed carers, there are opportunities to utilise the taxation system to provide relief for these costs of care.

The Task Force on Care Costs (TOCC) has recently released their key findings from a study into care costs. They found that 75% of Australians with carer responsibilities surveyed believe their care costs should be equally shared with the government and 93% believe the child care tax rebate should be extended to cover elder and disability care costs.

77% of those surveyed want choice as to how the reimbursement of carer costs will be paid, e.g. directly to them, to the care provider or via their employer (salary sacrifice). The Salary Sacrifice model is offered in the UK by County Hertfordshire's CareWISE program. In this scheme care vouchers are deducted before tax so that both the employee and employer save money. (Clare, 2005) As a formal program, it provides an additional incentive to disclosure for carers.

TOCC went onto explain that the Child Care Tax Rebate (CCTR) has had a direct and positive impact on Government income tax revenue. The same outcome is predicted if the CCTR is extended to include care costs. They expect that this may produce improved rates of workforce participation. The initial cost to Government for this initiative will be lower than for childcare as fewer Australians have elder or disability care responsibilities (23%) than those with childcare responsibilities (77%).

Tax deductibility for aids and equipment is also an issue raised regularly by carers and people with MS. Many people purchase items privately, or co-fund equipment with State and Territory schemes, and it is this that could be made tax deductible.

8.2 Disability (Lifetime Care) Insurance

The introduction of a lifetime care disability insurance scheme is an important part of increasing the resources available to people with disabilities and their families, and to improve the service system.

Much of the policy in disability services is driven by the imperative to ration services, so is not entirely focused on meeting individual needs. In this environment, funding programs will develop eligibility criteria that are primarily focused on the sustainability of the program, and are often written in isolation from similar policy efforts in other programs.

People with MS have lifetime care requirements, and yet there is no pathway to provide that care to an agreed standard in Australia. People with neurological conditions are said to be around a third of all young people living in aged care facilities across the country, and most are there through the failure of the community care system to deliver an adequate and timely response. A national disability insurance scheme was recommended at the 2020 Summit, and is something that would greatly assist the efficiency of the health and community care systems for people with complex disability.

Disability in Australia is an unfunded liability, and as need increases with the ageing of family carers, funding from the budget will become more difficult to meet these needs into the future. People with acquired disabilities like MS are competing for scarce budget resources for their services, and long waiting lists are the norm. Progressive diseases do not respect waiting lists, and the lack of service can exacerbate symptoms and/or result in aged care placement.

The model for such a scheme needs to be designed carefully, requiring the Commonwealth and States to work together to achieve a workable scheme. A disability insurance scheme with a capacity to fund rehabilitation and lifetime care is a necessity for Australia's health system from both a financing and service delivery perspective.

We support the recommendation from the 2020 Summit and urge it to be considered as a major reform agenda item.

8.3___Superannuation for carers

It has been well recognised that as well as foregoing income because of caring responsibilities the accumulation of retirement incomes are severely compromised.

By its very nature, superannuation is designed for earners. The compulsory system we have in Australia is relies on the contributions from employers and a range of measures have been adopted by Government to provide incentives to people to make their own contributions and increase the overall level of super savings in the community.

Where people are forced to reduce their participation in the workforce due to caring, it results in a reduction or curtailment of their superannuation accumulation. This is a major issue for carers of people with MS due to the working age profile of those living with the disease. People living with MS and carers follow a similar trajectory in employment, with a reduction of hours or early retirement (see figure 3). In cases where both the individual with MS and their carer both reduce hours or give up work completely, then the retirement savings for the family suffer accordingly.

The fact that MS is a progressive disease means that it gets more expensive as it progresses. While there are advantages in a person with MS dropping income and moving into the concessional income band to reduce the cost of medications, the downside comes with the increasing costs of the disease over time and the reduced capacity to meet these costs out of a fixed income.

The superannuation issue expresses itself in two main ways.

- Lack of accumulation of superannuation
- Using saved balances for funding of disability supports

While people can get access to their super by way of compassion, they often spend it on reducing debt or on disability related items such as aids and equipment or home modifications.

8.3.1 Superannuation adequacy and shortfalls for carers

There is no definitive measure of adequacy of superannuation however the following table shows one that has been adopted by the Australian Superannuation Federation of Australia.

It describes moderate and comfortable retirement incomes.

Figure 8 Estimates of Retirement income adequacy [4]

	Modest lifestyle-single	**Modest lifestyle couple**	**Comfortable lifestyle single**	**Comfortable lifestyle couple**
Total per year	$18,742	$26,339	$36,319	$48,648

We know from carers that superannuation shortfall is a major cost of caring. Trying to estimate the opportunity cost in retirement savings for carers is difficult due to the wide range of caring situations, ages and incomes.

However the table below has been constructed to illustrate the overall shortfall that carers are exposed to by leaving employment. It also shows the annual contribution that would be required at various stages to maintain a subsistence income in retirement.

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[4] **Westpac ASFA Retirement Standard**

The Westpac ASFA Retirement Standard benchmarks the annual budget needed by Australians to fund either a comfortable or modest standard of living in the post-work years. It is updated quarterly to reflect inflation, and provides detailed budgets of what singles and couples would need to spend to support their chosen lifestyle.

- **Modest lifestyle in retirement**
  Better than the Age Pension, but still only able to afford fairly basic activities.
- **Comfortable retirement lifestyle**
  Enabling an older, healthy retiree to be involved in a broad range of leisure and recreational activities and to have a good standard of living through the purchase of such things as household goods; private health insurance; a reasonable car; good clothes; a range of electronic equipment; and domestic and occasionally international holiday travel.

Figure 9: Superannuation shortfalls for carers leaving the workforce to deliver an annual income of $15,600[5]

Age at onset of caring and cessation of employment	**30**	**40**	**45**	**50**	**55**
Existing Super	0	0	54,822**	0	75,221**
Years to fund in retirement	15	15	20	15	20
Total assets needed at retirement **(in today's dollars)**	$542.718	$403,833	$434,893	$300,490	$375,142
Asset shortfall	$542, 718	$403,833	$259, 071	$300,490	$188, 892
Years to fund in retirement	15	15	20	15	20
Annual contributions needed	**$4,870**	**$7,361**	**$7,043**	**12,190**	**14,331**

* Assumed CPI rate 3%
* Retirement Age 65
** Average Superannuation Balances at 2004[6]

This table shows that the annual amount needed per year to sustain what would be described as subsistence level retirement income. It shows the shortfall in cases where no starting superannuation savings,

The gap each year remains the same and the amount required to maintain this level widens over time, and carers do not have the means to make these kinds of contributions.

The Government has invested heavily in incentivising earners to contribute more to their superannuation. The two initiatives that stand out are the superannuation co-contribution (costing $1.9B in 2006/7).and the tax free window provided in 2007 for people to top up their super with large lump sums.

These both have proved to be effective strategies in raising personal contribution levels, and not surprisingly have been targeted at people with the capacity to contribute.

There is an equity issue that emerges when reviewing these incentives for carers who are locked out of the workforce, and who do not have spare dollars to commit to savings because they are spending spare cash on disability consumables and equipment.

MS Australia is fully expecting the Future Tax system Review to examine this issue and we will participate in the review process

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[5] Calculated from a superannuation model supplied by Synchron Business Services Pty Ltd
[6] http://www.rojay.com.au/whkgroup/pdfs/SEPT_07/WHKHORWATH.pdf,

9.0 Recommendations:

1. Improvements to the service system

(a) Accelerate reforms to the community care system to enable simplified engagement, funding and accountability arrangements for people with disabilities and their carers.
(b) Accelerate work to achieve the commitment made at the Community Services Ministers meeting in May 2008 to improve aids and equipment schemes across Australia. This work needs to include fully funding a range of items, and to introduce efficiencies and service standards.
(c) As a first step in reforming the way disability services are funded in Australia, a national disability insurance scheme should be introduced to fund the lifetime care needs of people with high level disability to ensure that these needs are not ultimately underwritten by unpaid family carers
(d) Expand the availability of skilled respite services for carers of people with MS and similar neurological conditions
(e) Investigate options to improve the interaction between carers and Centrelink

2. Provide for greater workplace flexibility for carers

(a) The Federal Government collaborate with community and employer organisations to implement a Workplace Flexibility Advisory Service to inform, assist and intervene to encourage the accommodation of workers with caring responsibilities and other needs for flexibility in the workplace.

(b) A job retention service for carers and people with chronic illness be funded as part of the DEEWR suite of labour market programs to provide active workplace intervention and support to ensure people do not fall out of work prematurely.

(c) Investigate the feasibility of establishing industry sick leave pools to support people with chronic illness and carers through periods of extended leave from work, and

(d) Extend the eligibility for Centrelink Sickness Benefits to carers who leave work for periods of less than 6 months to provide full time care and who would not otherwise be ineligible for the Carer Payment

3. Financial Security for Carers

(a) Investigate options for funding ongoing superannuation contributions for carers who have reduced or ceased employment to ensure carers are not excluded from accumulating retirement savings while providing unpaid care to a person with a disability

(b) Extend taxation rebates for workers and self employed people who incur costs of care as part of their caring role, or who self-fund disability services (including aids, equipment, home and vehicle modifications, consumables and service co-payments), and allow salary sacrifice arrangements for these costs.

(c) Investigate the options for providing personal injury insurance for carers

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