A NEEDS ANALYSIS OF AUSTRALIANS WITH MS

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McCabe M. A Needs Analysis of Australians with MS, 2012. Prepared for MS Research Australia by Prof Marita McCabe, Deakin University, Melbourne, VIC.

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EXECUTIVE SUMMARY

This report summarises the findings from both an initial needs analysis, as well as a larger quantitative study of both the needs and services for people with MS in Australia.

Study 1

In total, 56 participants (28 clients, 18 staff) from Victoria, New South Wales, Queensland, South Australia, Tasmania and Western Australia participated in an interview study to identify the service needs of people with MS. The results from this study were used to inform on the major areas of need, the sub-components of these areas, and the extent to which these needs are currently being met. Local state MS agencies assisted with the recruitment of participants, and interviews were conducted face-to-face by the same researcher in order to reduce researcher bias.

The results demonstrated the major areas of need centred on: information and education needs (e.g., information about MS, information for family/children), environmental needs (e.g., equipment, housing, transport), employment and financial needs (e.g., employment support, financial support), psychosocial needs (e.g., peer support, counselling), broad service needs (e.g., home help, respite). Overall, the staff and clients were fairly congruent in their views on the needs of people with MS.

Obtaining information on treatment options, employment support services, fatigue management, exercise and diet were particularly emphasized. A need for better psychosocial support, including counselling and support from peers, was also highlighted. Unmet equipment needs, as well as long waiting periods for equipment, a need for greater access to physiotherapy and home help, as well as respite waiting lists being too long were also emphasized. Financial issues, particularly problems in dealing with Centrelink, were also highlighted.

Study 2

The above information, along with an analysis of both published and unpublished literature on the needs of people with MS, was used to develop a questionnaire designed to assess the needs of a broader sample of people with MS. This questionnaire was promoted through MS Societies throughout Australia and was sent to all participants in the Australian MS Longitudinal Study (AMSLS) (n=3,502 in April 2012), either as hard copy with reply paid envelope or via an emailed link to an online version.

In total, 2,808 AMSLS participants completed the questionnaire (80%) of which 2,676 (75%) were used in the present analysis. There were 2,053 females, 561 males (62 cases missing gender) from each of the states in Australia (ACT, n = 81; NSW, n = 816; QLD, n =

348; SA & NT, n = 237; Tas, n = 136; Vic, n = 716; WA, n = 292) (43 did not provide data on their state). The participants were drawn from urban, regional, rural and remote areas, which allowed the needs of people from all of these areas to be analysed. In addition, it was possible to determine the needs of people with MS from different age groups, different lengths of time since diagnosis, as well as different levels of severity of MS symptoms. The analyses that were completed provided detailed information on the needs of people with MS, and how these needs varied according to the above parameters. In particular, the following needs were explored: information, employment, transport, psychological services, peer support, equipment, other support services, and the need for respite.

The average age of participants was early 50s, they were mainly female, living in urban areas, and the average age since diagnoses was 11 years. The major symptoms experienced were fatigue, heat intolerance, walking difficulties and muscle weakness. The participants were mainly living in their own home with a partner. Very few of the participants identified as being unemployed, with the majority of the participants currently employed part-time or full-time or were retired (45% experienced mild symptoms, 35% experienced moderate symptoms and 20% experienced severe symptoms).

The participants expressed a need for more information and education around the following areas: understanding welfare and entitlements, Centrelink benefits information, information regarding the financial assistance people are eligible for, and information about superannuation. Participants also required more education and information for family and carers, particularly for children and teenagers living with someone with MS.

In terms of employment needs, participants indicated a need for more education around symptom management in the workplace, and advice about how the workplace can be adapted to meet their needs.

Transport was a significant problem for many of the participants. The reliability of taxis, as well as the expense of taxis, was noted by many participants. A number of participants indicated that wheelchair access on public transport was a problem, and so they lacked confidence in using public transport.

There was a need for a greater range of psychological services, as well as the accessibility of these services. In addition, participants highlighted the difficulty of paying for these services, and so the need to have discounted prices for psychological services. Associated with psychosocial support, participants indicated a need for a greater variety of peer support programs to meet their needs: a wider range of locations, a wider variety of meeting times and ensuring that the nature of the supports met the needs of the various sub-groups of people with MS.

Participants indicated that they required greater financial assistance to allow them to access equipment and/or modifications that they currently need. Further, the long waiting times for equipment frequently led to the equipment they received being no longer adequate once it became available. There were no significant differences between the states in the level of unmet need in relation to equipment and modifications.

Many of the participants required the services of dieticians, massage therapists, and psychiatrists, but felt dissatisfied with the quality and access to these services. People in remote areas were the group least satisfied with a wide range of services that were required.

More information about respite was required by participants. Many of them did not know about the availability of the different types of respite.

People with the greatest degree of symptom severity experienced the greatest number of unmet environmental needs, including access and affordability of equipment, transportation and assistance with tasks. The group with the most severe symptoms often required extra assistance with domestic duties, meal preparation, outdoor maintenance, shopping, social activities, and attending appointments. This group of participants also indicated the greatest unmet need in terms of mobility aids, home modifications, car modification and other equipment.

For those participants who had been newly diagnosed, the greatest unmet need was in terms of psychological services, with over 75% of this group expressing feelings of depression and anxiety in relation to their MS. This group also expressed a need for family and relationship counselling, as well as counselling for their own psychological problems. A greater variety of peer support was also a need among this group of participants.

There were no major differences between participants in different age groups, or those in different locations, except for the lack of access to services noted by those in remote locations that was mentioned earlier in this summary

There were many other needs identified by the participants that are not possible to include in the Executive Summary. We suggest that interested readers examine the tables, summaries and recommendations included at the end of the report. We hope and trust that the findings from this comprehensive analysis of the needs of people with MS leads to enhancements in the available services, and that these services are designed to meet the needs of the many sub-groups of people with MS.

1. BACKGROUND

Multiple Sclerosis (MS) presents unique challenges to patients and their significant others. The disorder can cause impairment and disruption in many areas including family roles, employment and daily functioning. It is important to have an understanding of the needs and priorities of people with MS to inform development, implementation and monitoring of services provided to such individuals and their family members. The planning of appropriate services for people with MS relies not only on epidemiological figures for the condition itself, but also requires a good understanding of the needs and priorities of the Australian MS population.

The MS Research Australia Needs Analysis Project was conducted in consultation with MS Societies nationally, to provide a strong base for the efficient and sustainable ongoing surveillance of the needs of Australians with MS, and to provide a baseline study upon which future needs analyses can be measured and national service strategies can be built and evaluated. The aim of this project was to determine the needs of the MS population, investigate the types of services currently available to people with MS, and assess the relative usefulness and satisfaction with these services.

2. INTRODUCTION

Multiple sclerosis is commonly characterised by an interference with the capacity of the cells in the spinal cord and brain to communicate with one another successfully (Buchanan & Huang, 2011a). Over time, this can result in scar tissue forming in the central nervous system and can ultimately lead to an impairment of cognitive, motor and/or sensory functions. The clinical course of MS is variable and generally unpredictable (Koopman, 2003). Although mortality is relatively unaltered by MS, walking aids and wheelchairs may be necessary later in the disease course (Koopan, 2003). While the experience of the disease varies greatly from individual to individual, some common symptoms include cognitive difficulties (e.g. judgement, concentration and memory), depressed mood, fatigue, muscle spasticity, difficulties walking, bladder and bowel dysfunction, sexual dysfunction and impaired vision (Buchanan & Huang, 2011).

MS is one of the most common acquired neurological diseases in young adults; the majority of people are diagnosed between 20 and 40 years of age (Mutch, 2005). The disease is estimated to affect over 23,000 people in Australia, of which approximately three quarters are female (Australian Bureau of Statistics, 2012; Multiple Sclerosis Society Australia, 2012). It can cause impairment and disruption in many facets of the individual's life including family roles, employment, and daily functioning, and presents a diverse range of challenges to patients, their carers, and their family members (Black, 1994). The costs associated with MS are extensive and include financial costs (medical treatment, hospitalisation, medications) and intangible costs (pain, anxiety, quality of life) (Khan, McPail, Brand, Turner, & Kilpatrick, 2006). It is thus important to have a thorough understanding of the needs of people with MS, in order to inform development of, and monitor, the services offered to people with MS. The following section will review the literature on the needs of people with MS.

2.1 LITERATURE REVIEW

In an analysis of the needs of 137 individuals with MS patients from five different European countries, Kresten et al. (2000) found a variety of needs. The authors grouped them into six general categories of needs: basic needs (e.g. food and clothing); equipment needs (e.g. walking canes, wheelchairs, hoists); service needs (e.g. a broad range of therapy and care including physiotherapy); information needs (e.g. information about the disease and prognosis); financial needs (e.g. the cost of therapies and care) and self-actualisation needs (e.g. social fulfilment and intellectual fulfilment).

In a literature analysis of 23 studies reporting the needs of people with MS, Forbes (2003) found that the needs of people with MS could also be separated into similar general categories. The groups of needs were as follows: psychological needs (e.g. support with adjustment to disease and management of psychological morbidity); social needs (e.g. management of stigma, relationships, financial and employment problems); physical needs (e.g., daily living and symptom management); knowledge about the disease (e.g., information needs); and contact with an expert health professional.

Koopman (2003) conducted a needs assessment of individuals with MS and their significant others using focus groups. The authors concluded that the needs of the individuals with MS could be grouped into: physical, health, psychological, financial, employment/meaningful daytime activity and leisure, accessibility, and information.

Koopman, Benbow, and Vandervoort, (2006) produced rankings of the ten most important needs of people with MS and their carers. Psychosocial and other personal needs (relationships with physicians, the MS healthcare team, family and friends) were ranked with high frequency. Information needs (information regarding MS or available support) and financial securities were also ranked as important.

In a similar study examining the importance of various needs in a sample of people with MS (N = 697) and their caregivers (N = 345), respondents ranked the services of a doctor, physical and occupational therapist, home modifications, and nursing care as important (Aronson, Cleghorm, & Goldenberg, 1996). This study also recommended awareness of the use of services and the assistance available to the population served.

MacLurg et al., (2005) examined the perceived needs of 168 individuals with MS. They found that physiotherapy was the most commonly identified need, irrespective of degree of disability, followed by respite care (for people with more severe physical disabilities) chiropody, and home-help services.

More recently, Forbes, Taylor, and White, (2007) conducted an analysis of the needs of people with MS (N = 435) who varied in level of disability, disease subtype, age and sex. The authors grouped the needs into seven key categories; medical treatment, socio-environmental support and adaptation, enhanced care provision, rehabilitation therapies, non-professional care, and psychological support.

Ytterberg and colleagues (2008) examined the perceived needs and satisfaction with care in 219 people with MS. The authors found that the majority of individuals perceived a need for rehabilitation, assistive devices, transportation services, psychological support/counselling and information on social and insurance/vocational rehabilitation at least sometimes.

For the purpose of this report, similar to the categories identified by other studies, the following subcategories will be used: Information and education needs, psychosocial needs, environmental needs, employment and financial needs, and finally, service needs. The following section will review these categories

2.2 INFORMATION AND EDUCATION NEEDS

The desire for information and education about the disease, treatment options, and symptom management has been shown to be universal across many needs analyses of people with MS (Kersten et al., 2000; Matti, McCarl, Klaer, Keane, & Chen, 2010; Miller, 1997; Robinson, 1991; Somerset, 2001). It has been suggested that information and education is a means of providing clients with a sense of empowerment over the disease and provides people with the tools and information that permits them to make informed decisions regarding their own welfare (Matti et al., 2010). This sense of patient empowerment is thought to play an integral role in the successful management of multiple sclerosis (Matti et al., 2010). Information and education for others is also seen as an important need of people with MS. It has been found that education for the family, carers and significant others are important in order to enhance their knowledge about the disease, the impact on the individual with MS and how to best manage it. Likewise, community education about the disease is another commonly identified need of people with MS.

2.3 PSYCHOSOCIAL NEEDS

The literature suggests that there are a number of important psychosocial needs of people with MS. These needs include: support from friends, peers, and family, as well as counselling, and psychological support for both the individual with MS and their carer/family members. For individuals diagnosed with MS, responding to the physical and psychological stresses of a condition with an unknown cause and no cure can be challenging (Koopman, 2006). The immediate stress caused by a traumatic injury or diagnosis of a life-threating illness can trigger symptoms of depression and anxiety (Dorstyn, Mathias, & Denson, 2011). However, people with the relapsing remitting forms of MS live in constant anxiety about new attacks, which usually come without warning. In contrast, people with the progressive forms of MS may experience feelings of hopelessness based on the knowledge that no fully effective therapies exist or are expected to exist in the near future (Holland et al., 2011) and have been found to require support in adjustment/coping (Campion, 1996a,b; Koopman & Schweitzer, 1999; Miller, 1997). Studies have also consistently found that individuals with MS perceive a need for social support (Halper & Holland, 1998; Miller, 1997; O'Hara et al., 2000a,b). For example, support from others with MS (Black et al., 1994) and support from family members (Aoun, 2008) are seen as integral in addressing the needs of people with MS.

2.4 EMPLOYMENT AND FINANCIAL NEEDS

Employment and financial needs are also important (Davies, 1979; Halper & Holland, 1998; Miller, 1997; Robinson et al., 1996; Robinson, 1991). MS has been found to impact on an individual's ability to work (McCabe et al., 2008a). Vocational support to assist the individuals retaining their employment, or seeking alternate employment, up-skilling or transitioning are important needs that are consistently identified as needs of people with MS (McCabe et al., 2008a; Tribe, 2006; Kersten, 2000). Also, information pertaining to financial support (e.g. disability payments), grants (for equipment, home modifications), eligibility for financial assistance, and availability of various assistance have all been highlighted as important needs. Palmer (2011) examined the economic impact of MS in 2010 among an Australian sample with MS and found that MS imposes a substantial financial and economic burden, which becomes substantially greater as the condition becomes more severe. Further, Simmons, Tribe, and McDonald (2010) found that many people with MS lost employment, primarily due to the ineffective management of symptoms in the workplace.

2.5 ENVIRONMENTAL NEEDS

A number of studies suggest that there are equipment needs of people with MS. Equipment needs range from smaller items such as walking canes to larger items including wheelchairs. Likewise, transport (e.g., wheelchair accessible, discounted transport), home modifications (ramps, railings, hoists etc.) have all been seen as important needs of people with MS.

2.6 SERVICE NEEDS

There are a number of service needs of people with MS. These may include general services, including domestic duties such as help with cleaning, meal preparation and other domestic duties, gardening services and shopping. Professional service needs include rehabilitation, physiotherapy, neurologists, general practitioners, psychologist, respite, speech pathologists, and occupational therapists (e.g., McCabe et al., 2008). Of the various services, physiotherapy, neurology and general practitioners are consistently highlighted as important service needs of people with MS, irrespective of disease severity. For example, in a study of 1143 people with MS, participants were asked to rate the relative importance of health professionals in the management of their illness (Black et al., 1994). Respondents rated their family physician, followed by their neurologist, physiotherapists and finally their urologists as the most important. McCabe et al. (2008b) obtained similar findings in a sample of individuals with a neurological disorder. The authors found that physiotherapy, occupational therapy and rehabilitation were important professional service needs of people with MS and other neurological disorders.

In addition to these needs, there are a number of factors that may impact on the level of requirements by different groups of people with MS. These include disease severity, and the time since a person w*as* first diagnosed. These two factors are discussed below.

2.7 DISEASE SEVERITY

It has generally been recognised that people with MS are not a homogenous population, and their needs vary according to the individual experiences of the disease and its symptoms. For example, Forbes et al. (2007) found that the most severely affected individuals with MS had a significantly reduced quality of life and increased carer burden compared to those with milder disability. Forbes (2007), found socio-environmental support, rehabilitation and non-professional care needs, were more frequently identified by those with greater disease impact, while information was identified as a stronger need for those in lower disease impact groups. It is thus important to consider variations in disease severity when examining the needs of people with MS.

2.8 NEWLY DIAGNOSED

Newly diagnosed participants are thought to have specific needs relevant to their recent diagnosis. For example, in a qualitative study of people with MS, Khan et al. (2006) found that a recurring theme in participant responses was the inability of both family and friends to be sympathetic to someone with a disease in its initial stages when it manifests itself as overwhelming fatigue but shows few external signs of physical disability. As such, education for family was seen as an important need of people with MS. In order to identify service and information gaps at the time of diagnosis of the disease, respondents were asked about help they would have liked to have had when the disease was confirmed. Over half identified “better information about MS” while “more informed medical treatment” was recognised by just under half of the participants. The psychological and physical impact of the disease*,* the changes in the roles, loss of financial security and loss of dreams places stress on the family unit. As such, psychological support was seen to be an important service requirement.

Mood disorders and problems have been shown to affect people at varying stages of their disease course. Newly diagnosed participants have been shown to be vulnerable to psychological distress. The early days and weeks after diagnosis has been shown to be characterised by a state of disbelief and devastation felt by both the person with MS and their family members. This early stage involved adjustment to changes in roles, loss of financial security and loss of dreams (Jassens et al., 2003). These changes may lead to psychological distress, including depression and anxiety. Jassens et al. (2003) found that 50% of a sample of newly diagnosed people with MS, had clinically significant levels of anxiety, distress, or depression in the early phases after diagnosis.

2.9 UNMET NEEDS

A number of studies have examined the unmet needs of people with MS. Table 1 summarises some of the more commonly identified unmet needs of people with MS.

Table 1. The unmet needs of people with MS and their family members/carers

AUTHOR	PARTICIPANTS	UNMET NEEDS
Black et al. (1994)	N = 1143	Respite care Family support Support from others with MS Education and counselling for family.
Aoun et al. (2006)	503 patients with either (MS, Neurone Disease, Huntington's Disease, and Parkinson's disease) > 30% people with MS 373 carers	Financial support in terms of pension Equipment and home modification Transport Access to allied health services Regular contact with society especially in rural areas Info about condition and treatment Improved public understanding and awareness *Carers* Respite and home support for carers
Tribe et al. (2006)	N = 2618	Essential medical care and personal support needs were mostly met, but less reliably so for the most severely disabled respondents and those living farther away from major cities Breaks from home Employment services
Kersten et al. (2000)	N =137 individuals with MS N = 125 carers N = 111 professionals	The most common unmet needs were service needs (e.g. medical care, different types of therapy, other services such as incontinence and sexual advice), followed by equipment and self-actualisation needs (e.g. employment, education, and social activities). *Carers* The most pressing unmet needs for carers included increase for finances, service and information, and in the United Kingdom and Belgium, carers identified respite as an unmet need.
Kristjanson et al. (2006)	503 patients with a neurodegenerative disease of which 162 had MS 373 carers of which 71 cared for someone with MS.	*Clients* More community education regarding neurodegenerative diseases, delays in access equipment, increased respite required, more access to home services, increased transport access and improved services for rural client. *Carers* Increased public awareness (about neurodegenerative diseases) and community education, increased access to providers and association, more information about conditions, availability of services, and treatment. More assistance in the home for caregiver, and more funding for organisations (e.g. MS Australia).
Ytterberg et al. (2008)	N = 219	The participants were least satisfied with psychosocial support; counselling; and information about social insurance/vocational rehabilitation, and the availability of rehabilitation.

3. STUDY 1: QUALITATIVE STUDY

3.1 AIM

The aim of study one was to conduct a qualitative study of the needs of people with MS. A research assistant visited each of the states to conduct interviews with clients/carers and staff members. The staff members were included to ensure that a broad spectrum of client needs was identified. Previous literature suggests that in some cases clients may underestimate their own care needs (Donobue et al., 1996), and looking solely at access to community services may bear little relationship to need (Freeman & Thomson, 2000).

3.2 METHODS

3.2.1 PARTICIPANTS

Fifty-six participants between the ages of 23 years and 71 years (mean age 51 years) took part in study one. The participants were recruited by their local state MS Australia office. The participants were divided into two groups: clients (individuals with MS and carers and family members of individuals with MS) and staff (unpaid volunteers and paid employees of MS Australia).

3.2.2 MATERIALS

Interview Questions

Recent empirical literature was used to develop a series of questions relating to the needs of individuals with MS. The questions aimed to determine the current needs, unmet needs and service requirements of individuals with MS and their carers/family members. A variety of areas of needs were assessed including employment, psychosocial, environmental and information and education, and service needs.

The participants in the client group were asked a series of questions relating to their current needs (in the case of family members and carers they were asked about the needs of the individual with MS and also any specific needs that they may have; see Appendix A). Participants in the staff group were asked a similar set of questions, but were asked to answer based on their interpretation of the needs of people with MS as a whole (see Appendix B). Depending on the nature of the responses, further questions were asked of the participants to probe for further information.

Needs Checklist

A 25 item checklist was administered to the participants in order to identify the most important needs, and identify if those needs were currently met. A synthesis of published literature was used to identify the most commonly identified needs of people with MS. Twenty-five of the most commonly identified needs were included on the checklist. The needs included various physical, transportation and psychosocial needs (see Appendix C). The participants were instructed to select the ten needs out of the 25 available options that they felt were most important. The participants were required to indicated if they believed each of the 10 identified needs were: 'currently met', 'somewhat met', or 'not met at all'.

Services Checklist

A 28 item checklist of services and support needs was administered to participants in order to assess the important service and support needs of people with MS. The 28 items included service/support needs derived from a synthesis of the literature, that were deemed important (see Appendix D). For example, physiotherapists, occupational therapists, neurologists and general practitioners were included in the list. The participants were instructed to select the ten most important needs out of the 28 available options. The participants were required to indicate if they believed each of the 10 identified service/support needs were: 'currently met', 'somewhat met', or 'not met at all'.

3.2.3 Procedure

This study was approved by the Ethics Committee of Deakin University. The local state MS agencies were responsible for the recruitment of participants from their respective state. A total of 56 face-to-face interviews were conducted. In order to reduce interviewer bias, the same interviewer conducted all of the interviews. The interviews were conducted in a private room and ranged in duration from 45 minutes to 1 hour. The participants were firstly asked some basic demographic information followed by the interview questions. After the interview questions had been administered, the participants completed the checklists. The checklists were given to participants at the completion of the interview questions in order to prevent any prompting effects that the checklists may have had on participants' answers to the interview questions.

3.3 RESULTS

3.3.1 Demographic characteristics

Demographics

The demographic characteristics of all of the participants are summarised in Table 2. The participants in the client group were aged between 23 and 71 years (mean age of 54 years). There were 21 females and 7 males in the client group. This sex imbalance may reflect, in part, epidemiologic data that show that 74% of all Australians with MS are female (Palmer, 2011). The participants in the staff group were between the ages of 28-61 years (mean age = 47).The staff participants included physiotherapists, MS nurses, MS service managers, employment specialists, occupational therapists, social workers, counsellors, case managers and unpaid volunteers.

Table 2. Demographic characteristics of the study participants

		RANGE	**MEAN**	**STATE OF RESIDENCE**					
	N	**Age**	**Age**	**Victoria**	**New South Wales**	**Queensland**	**South Australia**	**Tasmania**	**Western Australia**
		Years	Years	n	n	n	n	n	n
STAFF									
Female	25		47	4	5	4	4	3	5
Male	3		47	1	0	1	1	0	0
Total	28	28-61	47	5	5	5	5	3	5
CLIENTS									
Female	22		54	3	5	4	3	3	3
Male	7		54	2	0	1	2	0	2
Total	28	23-71	54	5	5	5	5	3	5
TOTAL	**56**	**23-71**	**51**	**10**	**10**	**10**	**10**	**6**	**10**

The needs were divided into five general categories: Information and Education needs, Environmental needs, Psycho-social needs, Employment and Financial needs and Service needs. The following section reviews the results of each of these general categories.

3.3.2 Information and Education Needs

A number of Information and educational needs were identified by both the staff members and clients. Table 3 provides a summary of the most common information and education needs identified by the staff and clients.

Table 3. The information and education needs of people with MS identified by participants

Information	Education
The disease	Children's/teens education
Treatment	Family education
Symptom management	Community education
Eligibility to services/grants	Carer's education
Navigating services	Education for health professionals
Variety of information	Symptom management
Sharing information across states	Planning for future
Stance against poor information	Online education
Information for family	
Information for children	

Similarities between clients and staff: Both the clients and the staff members identified education for the family and community as areas of educational needs that could be improved.

> *"We need to educate the community about MS." (Staff)*
> *"My wife needs to know I'm not being grumpy or lazy. I'm just so tired." (Client)*

A large number of staff members, and a smaller number of clients, suggested that there needs to be more variety of information and education formats.

Clients: A common theme among the clients, but not the staff was that available information was often confusing and hard to locate. A number of the clients expressed the desire for a 'one-stop shop' where all of the information pertaining to financial grants, services, treatment and disease information was clear and accessible. For example, one client stated:

> *"The information is there if you are prepared to spend a while looking for it."*
> *"It's very hard navigating through the [MS Australia] website."*
> *"I want to find out things, such as schemes, home help eligibility."*
> *"I want information about financial assistance, dealing with Centrelink is a nightmare."*

Staff: A number of the staff members, suggested information and education about planning for the future are an important need of people with MS. The staff generally suggested that clients often leave things too late before they take action and consequently find themselves in a worse position because of a lack of planning. For example, one staff member suggested that:

> *"They [individual's with MS] may go and buy a house with stairs, but not realise that as the disease progresses in two years time those stairs are going to be a problem,*

> *whereas if they had of planned for the future or at least had some education around possible future encounters before this, they would have been more prepared*." *(staff).*

3.3.3 Environmental Needs

The socio-environmental category included the following subcategories of needs; equipment/mobility aids, accommodation, house adapations, and transport. Table 4 outlines some of the more common socio-environmental needs identified by clients and staff members.

Table 4. The socio-environmental needs identified by staff and clients

EQUIPMENT	ACCOMMODATION	HOUSE ADAPTATIONS	TRANSPORT
Scooters Wheelchairs (manual and electric) Walkers Walking canes Assistive technology	Specialised residential care Supported accommodation Suitable housing	Hoists Ramps Rails Bathroom adaptation Lifts	Transportation to get to appointments, social activities, shopping etc. Public transport (buses, trains, trams) Taxis Vehicle modification Private transport

a) Equipment

The need for a variety of pieces of equipment were identified by the participants. The types of equipment included canes for walkers, manual wheelchairs, electric wheelchairs, portable ramps, hoists, showering, assistive technology and bedrails. These needs varied greatly depending on a person's degree of disability.

Clients and Staff

The most common theme among both clients and staff was that equipment is expensive to purchase and maintain.

> *"I could only afford equipment because I'm self-funded… I know of others that were not able to afford equipment that they needed as they could not finance it." (Client)*
>
> *"I received the equipment I needed, but the maintenance of equipment is extremely expensive*". *(Client)*
>
> *"The minute you mention 'disability', the prices go through the roof. The prices of my tyres for my wheelchair are the same price as car tyres, yet they are only bike tyres." (Client)*
>
> *"The need for equipment is huge." (Staff)*

The participants acknowledged that there was some assistance available to people to obtain equipment, but this was capped at one item. As such, many of the items that would contribute to an increased quality of life were often not able to be received due to insufficient funds.

Both of the groups identified problems with waiting lists for equipment. However, this was seen more frequently in the responses of the staff members. As the required equipment became more complex, and larger items were required, a number of participants often noted that the "*waiting lists are extremely long*" and the "*funding for the equipment was minimal if any at all*".

"*There are major gaps in the timeliness of equipmen*t". *(Staff)*

A lack of access to equipment was seen by both groups of participants to be a possible barrier to people being able to get out and socialise, as without the required equipment, some participants were confined to their own houses.

Clients: A common need seen among the clients but not the staff was the desire for more information pertaining to the access, and means of obtaining funding for equipment. One client stated

> *"I only have access to the equipment I require because I know the system, however others that don't seem to constantly miss out."*

Staff: A common theme among the staff was a problem with funding available to people, with a number of staff suggesting the delivery of funding was unequal.

> *"Clients were not always able to get the equipment they needed [through grants]."*

For example, one staff member stated

> *"Self-funded retirees have to buy their own equipment while others don't; this is not fair."*

b) Housing/Accommodation

This category included needs relating to an individual's access to appropriate accommodation and an individual's current housing, including the addition of hand railings in the bathroom, the widening of corridors and the addition of ramps or elevators. Housing also included moving to new housing that better suited the person's level of disability. Finally, for the more severely disabled participants, there was a need for specialised and more appropriate residential care.

A number of the more physically disabled clients noted a need for adaptations to their current homes to assist them with getting around at home. A few of these clients suggested that such adaptations were too expensive, or inappropriate, due to them residing in a rental property or public housing. For example, one participant said:

> *“I had to adapt my bathroom in order to allow room for my wheelchair; this was an expensive process. I need hand rails installed for when I become fatigued, but I can’t start making changes to my rental property; I don’t own it.” (Client)*
>
> *“Clients can wait up to 5-10 years for purpose built housing.” (Staff)*

A common theme among both the clients and staff participants was the need for specialised and supported accommodation for the more severely disabled individuals. Both the staff and clients often expressed their concern over the housing of severely disabled young people with MS in nursing homes. For example, one participant stated

> *“A young person is at the prime of their life, they don’t want to be living with older people”. (Staff)*

In addition, a number of clients with more severe disabilities voiced their desire for more appropriate accommodation that was tailored to meet the needs of clients. The need for more assistance in the home was seen as unmet needs by many of the participants. Even the participants with no obvious signs of physical disability often struggled with fatigue and were thus not able to fulfil basic domestic duties, including cooking, cleaning and basic domestic functions.

c)Transport

Transport was commonly identified as an important need. Transport was a means of attending important appointments, social events, shopping for essentials and getting away from home. Public transport needs included buses, trams (Victoria only), and trains. Taxis were also seen as an important need.

Clients and Staff: A common theme that emerged from the interviews with both the clients and the staff was the need for public transport to be accessible. Accessing public transport was often a problem for a number of reasons, including stations being too far away. One client stated,

> *“If I didn’t live across the road from the train station, I wouldn’t be able to catch the train as fatigue would deter me from walking to the station”*.

A staff member suggested that:

"Even if an individual is willing to take public transport, it's hard for someone to walk or get to a bus station in the first place".

This was seen as especially relevant to rural and semi-rural clients, who were deemed to be somewhat disadvantaged due to their limited access to public transport.

Another problem identified by both participant groups was the lack of wheelchair access on buses for individuals confined to a wheelchair. For example, one client stated:

"I have to call 24 hours in advance to ensure a wheelchair accessible bus would be there, and that doesn't mean it will actually turn up".

Staff members and a small proportion of the clients confined to wheelchairs, suggested that taxis were often too expensive even at the discounted rate. For example, one client noted that going to the gym was important to physical and mental health. However, the client stated:

"While my gym membership only costs me approximately $5 per week, a round trip [in a taxi] to the gym costs me $28."

A staff member also stated:

"People can get up to 50% off for a taxi trip, but that doesn't help when they need to use a taxi up to half a dozen times a day."

Finally, one client suggested that many taxi drivers will refuse short trips despite this being illegal. Going down the street for a coffee with friends was not possible as many taxi drivers refused the short trip.

Clients: An additional theme identified by some of the clients was that a lack of transport was a reason why people may cease employment.

Staff: A common theme among the staff members was the unreliability and lack of availability of maxi taxis for transportation of more disabled clients. Staff members often noted that many clients had to wait a long time for a maxi taxi to arrive. One staff member stated:

"It is not uncommon for clients to wait up to 2 hours after calling a taxi before one comes".

A client stated that:

> *"Calling a taxi during the school drop off and pick up times was a "no go zone" as "they [taxis] won't come*".

Another common problem area identified by staff members was the lack of knowledge of some drivers about transportation of the physically disabled. For example, one staff member stated:

> *"Driving erratically while someone is strapped into the taxi can mean that they slowly slip down and are unable to physically lift themselves back up.*

Among a number of staff and clients, a common theme was that the unmet transportation needs had a rippling effect on social and leisure activities as well as mental health. A frequent consequence of unmet transportation needs was isolation of clients. A number of staff members suggested that the lack of access to, and unreliability of, transport for disabled people meant that many individuals were left isolated and consequently missed vital appointments and lacked social interaction. This social isolation was a particular concern among staff members for people living in rural areas when access to public transport was scarce.

3.3.4 Psychosocial Needs

The psychosocial needs identified by the participants are summarised in Table 5.

Table 5. The psychosocial needs of people with MS

PSYCHOSOCIAL NEEDS	
Peer support programs for client	Client counselling
Peer support programs for families	Psychological services
Peer support programs for carers	Family counselling
Teenage support groups	Carer counselling
Wellness programs	Relationship counselling
Variety of peer support groups	Motivational counselling
Variety of peer support delivery	
Kids day/support	
Variety of regions for peer support	
Support from friends and family	

Clients and Staff: The staff members and the clients for whom peer support was relevant, suggested that peer support groups could be improved in the following ways: more variety of peer support groups, more age/disability appropriate peer support group options, more session times including after hours, a larger variety of peer support group formats (e.g., email, Skype, person-to-person) and better promotion of the peer support groups.

Peer support was noted as being important among many of the participants across each of the states. It was suggested that peer support is a means of obtaining information, socialising, and sharing problems and concerns.

Both clients and staff highlighted the importance of having peer support sessions for newly diagnosed patients. However, many staff members and clients suggested that having peer support groups with highly disabled people acted as a deterrent for non-disabled people seeking the support of peers. It was thought that being exposed to such an image straight after being diagnosed often brought about anxiety about the future. As such, many staff highlighted the need for more tailored support groups. Furthermore, many staff suggested the need for age appropriate support programs, including those aimed at teenagers and children of a parent with MS. Both staff and clients also supported the need for counselling and a focus on psychological health for newly diagnosed clients. Staff suggested that with a diagnosis comes “anxiety about the future”, “grief”, “denial” and “adjustment”. Many staff suggested that psychological help in the first few years acts as a buffer for the future development of depression and anxiety for clients when they reach the latter stages of their journey.

As the disease progressed, the participants commonly suggested that ongoing counselling is important. One participant, for example, who had the relapsing-remitting subtype of MS, stated:

> *“Relapsing is like being first diagnosed, with the same rollercoaster consequences". (Client)*

A common theme among the clients was that there wasn’t enough access to counselling. While some participants acknowledged that their respective state agencies offered counselling, they indicated that this counselling was often limited and difficult to get a booking. Private counselling was often deemed to be too expensive. A number of clients also suggested that private counsellors *“lacked insight into the illness, thus making it difficult for the counsellor to relate”*. The importance of counselling for newly diagnosed clients was a common theme identified in the interview responses. Some of the participants suggested that the first diagnosis was particularly difficult, as it can cause anxiety and depression about the future.

A number of clients also highlighted the need for specialised counsellor/psychologist who had an understanding of MS.

> *“I want to see someone who has experience with MS. The one (Counsellor) I’ve seen without experience can’t relate.” (Client)*

"Psychologists in the community lack an understanding of MS." (Staff)

The importance of family and career counselling was recognised as being highly important among many staff members. Families need help adjusting to such a life change and accepting and acknowledging the disease. In addition, children require counselling to assist with understanding

3.3.5 Employment and Financial Needs

Employment needs were identified as an important for people with MS. Table 6 illustrates some of the common employment needs.

Clients and Staff: There were a number of common themes among both the clients and the staff members. Both groups agreed on the need for specialised employment services. The participants highlighted the idea that it is important for such agencies to have a good understanding of MS.

Both the staff and the clients identified flexible workplaces as a need of many people with MS. Not having a flexible workplace was seen as a reason people with MS cease employment, as was the ignorance of the employer, with one participant suggesting "*employer education"* as a means of rectifying this issue.

In addition, a small number of the clients and a large number of the staff suggested that there exist inconsistencies in funding entitlements. Some of the quotes from participants relating to unmet financial needs are listed below.

"There's an inconsistency in funding between people." (Client)

"*At Centrelink you have to jump through hoops [to get help with finances], you wait and they lack understanding; they need to lift their game and not treat everyone like a dole bludger". (Client)*

"Disability funding at state level is not enough." (Staff)

Clients: The clients suggested a need for employment programs and better guidance and vocational support were a need that was presently not met. While one of the states had a specialised employment program the remaining states did not have this information.

"I want to work, but Centrelink is a nightmare. I tried to access an employment agency, but I couldn't get through the corridor [of the agency] with my wheelchair. They've got no idea."

> *"They're insensitive, there's no support. Finding a job is like hitting a brick wall, even volunteering is hard."*

Staff: A strong theme in the staff interviews, was the need for people with MS to know their rights as an employee. It was suggested that by not knowing their rights, many people with MS cease employment because they are not aware of what can be done for them.

The staff highlighted the need for appropriate workplace environments. This included things such as having a desk close to the toilet, lifts to assist with fatigue, wide corridors for wheelchairs, or walkers. A non-environmental friendly workplace was provided as a possible reason why people cease employment. For example, one staff member provided the following example:

> *"if the toilets were on the other side of the room a person with fatigue would struggle, not only due to the fatigue and the inability to walk across the room, but also as incontinence and bladder and bowel dysfunctional are common symptoms of MS the number of times per day the persons would be required to get up would also make working in that office difficult".*

Another suggested need posed by a number of staff members was the need for skills reassessment (e.g., builder to account keeper), as physically a person can no longer be a builder, but may be able to work as an account manager at a building business. Many of the participants suggested that they did not know what they were entitled in terms of financial support and grants (for equipment, heating/cooling/home modification).

Table 6. The employment and financial needs of people with MS

EMPLOYMENT	FINANCIAL
Information around disclosure	Grants for equipment/home adaptations
Support options	Financial support for carers
Specialised employment Agency that understands MS	Financial help for services
Flexibility	Air-conditioning rebates
Symptom management in workplace	Assistance dealing with Centrelink
Don't want to disclose	Information around superannuation
Employee rights	Knowledge around accessibility to financial assistance
Workplace environment	

3.3.6 Service Needs

There was a variety of different service needs identified by the participants. Table 7 illustrates some of the more common service needs identified by participants. The service needs of individuals varied greatly depending on the participants' state of residence, their level of disability and where the individual was along their journey (e.g. newly diagnosed).

A need for more physiotherapy was a common service need across all states, and independent of severity of illness. This need was identified by both the clients and the staff. A common need across the board was contact with a neurologist and general practitioner.

Table 7. The service and support needs of people with MS

GENERAL	PROFESSIONAL	
Home help	Neurology	MS nursing
Personal care (bathing, showering etc.)	General practitioner	Occupational therapy
Domestic help (cook, cleaning, ironing)	Physiotherapy	Social worker
Outdoor maintenance (gardening)	Neuropsychology	Hydrotherapy
Access to community services	Respite	Optometry
Advocacy	Urology	
Exercise and wellbeing	Psychology	
	Counselling	

Home help

There was also a need for more home help especially among the more disabled clients. This need was identified by both the staff and the clients as both beneficial to the individual and/or their carers. Of note, a number of participants with moderate to severe disability identified a need for more outdoor assistance. This included help with personal care for the severely disabled, help with domestic duties, assistance with outdoor maintenance, and administering medications.

Respite

Overall, respite was seen as more of a need for carers. A small number of the participants identified a need for respite. However, a large majority of the staff highlighted the importance of respite for the carer. A common theme among the staff was there that is a limited amount of respite, the waiting lists are too long, and there needs to be more variety. The staff suggested that respite options, and the benefits of respite for some carers needs to be further promoted. However, the staff noted carer guilt as a barrier to many carers seeking respite.

Clients: Some of the quotes by clients included:

"The camps [for carers] are all good, but it would be nice to go together"

"The waiting lists are too long, and the same people seem to get priority".

"It's political and doesn't meet the needs of the individual; just the respite needs the society [MS Australia] thinks are needed".

> *“The carers need it. Sometimes they need a break.”*
>
> *“There’s always room for more [respite].”*
>
> *“It’s there but it’s not easy to access.”*
>
> *“Sometimes I need a break from looking after my daughter; the stress makes my symptoms worse.”*

3.4 CHECKLISTS

The number of completed legible checklists was less than the total number of participants. This was due to a number of factors, including participant fatigue and time restraints. The information from the qualitative portion of the interview was deemed to be of more importance and thus priority was given to the interview questions. In addition, with a number of the checklists, the participants found it difficult to rank their selected ten most important needs from most important to least important, and thus the participants instead just picked their top ten needs, and then decided whether those needs were met, somewhat met or not met at all. The results using the top ten identified needs have been reported instead of the top ten and their rankings. The limitations of this exercise were thus taken into consideration when designing the larger questionnaire. The results of this exercise are summarized in Tables 8 and 9 below.

Table 8. The top ten most frequently selected needs identified by staff members

Percentages over 50% in bold

Rank	Needs	Met %	Somewhat met %	Unmet %
1	Coping with feelings	27	**73**	0
2	Info disease	**69**	31	0
3	Info services	**62**	31	7
4	Fatigue management	38	**62**	0
5	Equipment	33	**77**	0
6	Personal care	38	**62**	0
7	Respite	23	**69**	8
8	Employment	40	**50**	10
9	Home modification	0	**88**	12
10	Education for family	**89**	11	0

Table 9. The top ten most frequently selected needs identified by clients

Rank	Needs	Met %	Somewhat met %	Unmet %
1	Home Modifications	33	42	25
2	Info services	25	**50**	25
3	Equipment	40	**60**	0
4	Bladder control	**55**	45	0

5	Coping with feelings	25	**63**	13
6	Outdoor maintenance	0	33	**66**
7	Fatigue management	17	**66**	17
8	Info on the disease	50	50	0
9	Meet others with MS	**71**	29	0
10	Community Education	0	**66**	33

The staff and clients had six needs in common that were part of the top ten most frequently identified needs. These needs included: information about services, information about the disease, fatigue management, home modifications and coping with feelings as well as equipment needs.

Both the staff and the clients generally felt that equipment needs of people with MS were only somewhat met (77% and 60%, respectively). Sixty-two percent of the staff felt that information about the disease was met, while 50% of the clients felt that this need was met. Of the staff who identified information about services as important, 62% felt that this need was met, while only 25% of the clients felt that this need was met. Both the majority of staff members (73%) and majority of the clients (63%) felt that the coping with feelings need was only somewhat met. Finally, home modifications needs were identified by the majority of staff and clients to be only somewhat met or not met (see Table 8 and 9).

The remaining top 10 needs identified by the staff included respite, education for family, personal care, and employment. Of these needs, only education for the family was identified by the majority of the staff to be met. The respite needs, personal care, and employment needs were identified by most of the staff members to be only somewhat met or not met (see Table 8).

The remaining top 10 needs identified by both clients and staff were bladder control, need to meet other people with MS, outdoor maintenance and community education. Of these needs, only the bladder control need and need to meet others with MS were considered to be met by the majority of clients, while outdoor maintenance, and community education were seen by the majority of participants to be only somewhat met or unmet (see Table 9).

Table 10. The top ten most frequently selected support and service needs identified by staff

Rank	Services	Met %	Somewhat met %	Unmet %
1	Neurologist	**61**	33	6
2	General Practitioner	46	46	8
3	Counselling	40	40	20
4	Physiotherapist	38	46	16
5	Support while in work	31	45	24
6	Transport	0	**75**	25
7	Specialised Nurse	**69**	23	8
8	Occupational Therapist	36	**64**	0
9	MS Society	**70**	30	0
10	a) Support for Family	33	**56**	11
	b) Specialised Employment Service	**67**	22	11

Table 11. The client top ten most frequently selected support and services needs identified by people with MS

Rank	Services	Met %	Somewhat met %	Unmet %
1	Neurologist	58	42	0
2	General Practitioner	**82**	9	9
3	MS Society	**70**	30	0
4	Physiotherapist	**50**	25	25
5	Transport	17	**50**	33
6	Adapting a Vehicle	40	40	20
7	Home help	13	25	**63**
8	Specialised Nurse	**75**	0	25
9	Dietician	0	25	**75**
10	Specialised Employment	**50**	25	25

For the clients and the staff, neurologists, general practitioners, the MS society, transport services, specialised employment services, specialised nurses, and physiotherapists were frequently identified service and support needs. Half of the client participants felt that their physiotherapy service needs were met, while the remaining half felt that they were somewhat met or unmet. The majority of staff felt that this need was unmet. The psychosocial needs illustrated a need for more variety of peer support groups, formats, and additional classes. In addition, a consistent finding was the desire for more access to counselling (see Table 10 and 11). Percentages over 50% are in bold.

3.5 SUMMARY

The needs identified by the participants were consistent with those identified in the literature. Similar to previous studies (Forbes, 2007; Forbes, 2003; Kersten, 2000), the needs identified by the participants could be divided into a number of general categories. The categories included: information and educational needs, environmental needs, employment and financial needs, psycho-social needs and service needs.

Overall, both the clients and staff were fairly congruent in their views on the needs of people with MS. The staff generally provided an overview of all levels of disability in their responses, thus in some instances the staff responses were more detailed. This is consistent with previous research in which patients may underestimate their own care needs (Donohue et al., 1996).

The participants expressed a perceived need for more information pertaining to treatment. These findings are consistent with those of the previous literature. For example, an Australian study conducted by Matti et al. (2010) found that people with MS desired more information about treatment. These needs and unmet needs are congruent with a recent report conducted by the MS Society of Tasmania (2011; N=196) titled 'Raise Your Voice – We're Listening: Client Survey'. The report found that clients were most interested in receiving information on research, treatment options, fatigue management ideas, exercise and MS, eating for good health, and tips and strategies for coping with MS. Interestingly, the report found that only 24% of participants were very interested in receiving information about employment issues. However, given the overwhelming response of the participants in the present study indicating a need of information pertaining to employment, this category was included in the final needs analysis questionnaire. The topics in which the majority of participants were very interested included information on research, treatment and financial assistance. These areas were considered when developing the final MS needs analysis questionnaire. Similar to the findings of the present study, the Tasmania study found that participants were interested in a wide variety of means of receiving information, including online forums, talking to staff at clinics, text messages and support meetings.

Similar to the findings of the present study and previous needs analyses (Aoun et al., 2006; Kristjanson et al., 2006), the Tasmanian study also found that there was a need for increased community education about MS. Other types of information/topics suggested by participants to be of interest included research/treatment/clinical issues/therapies, dealing with change/emotions, access (e.g., access to public areas, wheelchair accessibility), aids/equipment/home, financial and other practical issues, and suggestions for recreational activities. Although they found that overall the MS Society was providing good information in regards to MS in general, more information was desired in regards to MS symptoms, prognosis, and management (Matti et al., 2010)

Consistent with findings from previous research (e.g., Ytterberg et al., 2008), the participants in the present study? identified a need for greater psychosocial support, including counselling and support from peers. In addition, the participants acknowledged that there was a need for a variety of peer support formats and times (e.g., online, after hours).

There was a need for more access to equipment, reduced waiting periods for access to equipment, and for equipment to be more affordable. Other studies have found similar results regarding unmet equipment needs. Kristjanson et al. (2006) in a sample of Australians with a neurodegenerative disease (N=503) including MS (162), found similar themes emerged, including delays in access to equipment, a need for more access to home services, and a need for increased transport access. Likewise, another Australian study of the needs of people with neurological illness by Aoun et al. (2006) found transport was an unmet need. Kersten et al. (2000) found that among other things, equipment needs were common unmet needs. Notably, equipment and transport needs were more applicable to those more severely disabled.

There was a range of service needs. Physiotherapy was seen as an important unmet need. This is consistent with findings from other studies. For example, despite the fact that most of the people in the sample had mild symptoms, Ytterberg (2008) found that a high proportion of people with MS perceived a need for physiotherapy (61%) and rehabilitation at special rehabilitation units in a day care. However, more than one third of those who perceived a need were not satisfied with these areas of rehabilitation.

Other services, including home help, were seen as an important but unmet need. Wollin et al. (1999) found that people with MS reported that help with personal care, home duties and children, were the most valued resources. These resources have also been found to be important for carers.

Respite care was seen as an unmet need by a number of the participants. Some common themes included: a need for more variety, more options, more locations (e.g., rural). Problems with respite included the waiting lists being too long, and not enough availability. Respite has also been found to be an unmet need in previous literature (e.g., Black et al., 1994; McCabe et al., 2008) and is thought to play an integral role in preventing carer burnout in those looking after the most severely disabled individuals. Given the importance of respite for some carers, especially those who are looking after the more severely disabled individuals, respite was included as a separate category in the final MS Needs Analysis questionnaire.

Information about and access to financial assistance, grants (e.g., for equipment, housing adaptations), as well as dealing with Centrelink were all seen as important unmet needs. Information about financial support in terms of the pension (Black et al. 1994), social insurance and vocational rehabilitation (Ytterberg et al., 2008) were also seen to be important. Participants, especially the staff participants, highlighted a need for more information regarding employment and employment services. This is consistent with the findings of a study conducted by Tribe et al. (2006) in which a need for more employment services was found.

4. STUDY 2: QUANTITATIVE STUDY

4.1 DEVELOPMENT OF THE QUESTIONNAIRE

The needs identified by participants in study one were consistent with the needs identified by previous needs analyses. The questions, methods, and results of previous needs analyses of people with MS (Kersten et al., 2000; Matti et al., 2010; Tribe, 2006), the unpublished findings of the needs of people with MS (e.g., MS Society Tasmania), and the results from study one were collated and were used to develop the needs analysis questionnaire.

A notable consideration was the differing needs of people depending on the state of residency and/or locations (e.g., rural, metro). As such, while some needs may have been met in one location, the same needs were not necessarily being met in another location. For that reason, areas of needs identified in the literature and interviews were included to ensure that the final questionnaire gained an insight into the needs of a wide spectrum of people with MS in Australia. Finally, by including a wide spectrum of needs and sub categories of needs, it was possible to also determine unmet needs relevant to each of the states. For example, if the transport needs of a particular state are not being met, this may be an area of further exploration and finer detail for that respective state, but not so for another state where the need is being met.

4.2 METHOD

A meeting was held with the research team to review the questionnaire developed by the Deakin University team from the material outlined above, and make adjustments where appropriate. The research assistant then made the required adjustments and a final copy was sent to each of the MS State service leaders for final comments. Further adjustments were made on the basis of these comments.

Pilot Trial

A pilot study was undertaken to test the questionnaire. Nine participants with MS volunteered to take part in the trial after being approached by MS Research Australia. The participants were sent a copy of the draft questionnaire and asked to provide feedback pertaining to the types of questions and format of the proposed questionnaire. The questionnaires were promptly returned. The comments from each questionnaire were then collated and reviewed. Minor adjustments were made to the questionnaire, including slight amendments to the wording of some of the questions. A copy of the final questionnaire can be located in Appendix E. This questionnaire was then either sent to AMSLS participants throughout Australia as paper copy with reply paid envelope, or made available to them online via emailed links (total n= 3,502). A total of 2,808 responded (80%) of which 2,676 (75%) were used in the present analysis..

4.3 RESULTS

4.3.1 NATIONAL SNAPSHOT

4.3.1.1 BASIC DEMOGRAPHICS

N= 2676

AGE

Table 1. The average participant age nationally and in each state

	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	NATIONAL
Mean	51	52	53	53	55	51	52	52

GENDER

Table 2. The percentage of female and male participants

SEX	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	NATIONAL
Female	79	78	84	76	79	77	79	79
Male	21	22	16	24	21	23	21	21

Table 3. The average age of participants by females and males in each state

SEX	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	NATIONAL
Female	52	52	53	51	55	51	52	51
Male	50	54	53	54	55	53	52	52

REGION

Table 4. The percentage of participants living in metro, regional, rural, and remote areas, in each state

AREA	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Metro	90	49	47	68	37	64	72	57
Regional	8	37	37	16	34	21	18	27
Rural	2	14	14	16	28	14	9	14
Remote	0	<1	2	0	1	<1	<1	1

DIAGNOSIS

Table 5. The average years since the participants first experienced symptoms, and were first diagnosed (nationally, and in each state)

	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Years since first diagnosis	10	11	11	11	12	11	11	11
Years since first symptoms	14	16	15	16	17	15	15	15

DEMOGRAPHIC SUMMARY

The average age of participants was early fifties, with about 80% of the participants being female. The majority of participants lived in metropolitan areas, followed by regional areas. On average, participants had been diagnosed for a period of 11 years, generally by a neurologist. There were no major differences in these demographic characteristics between the different States.

Table 6. The percentage of participants diagnosed by various specialists

Diagnosed by	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Neurologist	98	93	91	90	81	90	93	91
Ophthalmologist	0	2	2	2	3	3	1	2
Consultant Physician	0	1	3	2	9	2	2	2
General Practitioner, Local Doctor	1	3	2	4	3	3	3	3
Other	1	1	1	2	4	2	1	1

4.3.1.1.1 SYMPTOMS

Table 7. The percentage of participants who experience various symptoms; not at all, sometimes, or often

Symptom type	Not at all	Sometimes	Often
Concentration Problems	29	55	16
Memory Difficulties	24	56	20
Judgement Difficulties	51	41	8
Planning Difficulties	55	36	9
Visual Problems	44	41	15
Ringing in the ears	66	22	12
Sleep Disturbances	30	42	28
Speech Difficulties	38	45	17
Fatigue	7	38	55
Mood Changes	31	54	15
Depression	39	45	17
Heat Intolerance	15	35	50
Balance Problems	43	37	21
Bowel Problems	43	37	21
Bladder Problems	34	37	30
Muscle Weakness	22	46	33
Muscle Spasticity	40	40	20
Numbness	23	37	24
Pain	39	37	24
Sexual Dysfunction	49	28	23
Twitching	49	40	11
Walking Difficulties	31	32	37

SYMPTOM SEVERITY

Table 8. The percentage of participants experiencing varying degrees of symptom severity

SYMPTOM								
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
22	18	19	9	9	7	7	1	8

KEY

1. I may have some mild symptoms, mostly sensory, due to MS but they do not limit my activity or lifestyle.

2. I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle**.**

3. MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need to use a walking stick [cane] or other walking aid, but I might during an MS attack.

4. I can walk about 8 metres [or 25 feet] without using a walking stick or other walking aid such as a splint, brace or crutch, but I may use a walking aid for greater distances.

5. To be able to walk 8 metres [or 25 feet], I have to have a walking stick, single crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

6. To walk 8 metres [or 25 feet], I must have two walking sticks, two crutches or a walking frame [walker]. I may use a scooter or wheelchair for greater distances.

7. My main form of mobility is a wheelchair. I may be able to stand and or take one or two steps, but I can't walk 8 metres [or 25 feet], even with crutches or a walking frame.

8. I am unable to sit in a wheelchair for more than one hour, and I spend most of my time in bed.

9. None of the above options describes my MS. I don't have any mobility problems, but I do have other kinds of MS symptoms such as eyesight or memory problems that significantly interfere with my activities and lifestyle.

SYMPTOMS SUMMARY

The most common symptoms experienced by participants were fatigue, heat intolerance, bladder problems, muscle weakness and walking problems. The majority of participants experienced mild to moderate symptoms of MS.

4.3.1.1.2 ACCOMMODATION

Table 9. The percentage of participants in each state residing in various forms of accommodation

TYPE	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Self/family owned property	87	81	80	84	91	85	88	84
A private rental	5	12	11	10	7	10	6	10
Public housing	3	3	4	4	2	2	3	3
Residential Aged care facility	4	2	3	1	0	1	1	2
Supported accommodation	0	1	<1	0	0	0	1	<1
Other	1	1	1	1	0	1	1	1

Table 10. The living arrangements of the participants

LIVING ARRANGEMENTS	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Alone	16	15	14	20	16	13	14	15
Spouse/partner/children	80	75	77	76	78	76	80	77
Parent(s)	2	5	3	1	5	5	2	3
Friend/housemate(s)	2	2	2	1	3	3	1	2
Other	0	3	4	2	3	3	2	3

CARER

Table 11. The percentage of people who have a carer per state, and the relation of that carer

CARER	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
Yes	30	29	36	32	35	28	19	29
No	70	71	64	68	65	72	81	71
CARER RELATION								
Spouse/partner	74	78	86	75	85	83	76	80
Child	4	2	2	3	9	3	6	2
Parent	4	10	2	6	0	5	2	6
Other family member	0	1	1	3	2	2	2	1
Friend/housemate	4	2	4	4	2	3	4	3
Paid carer	13	7	5	9	2	4	10	7

ACCOMMODATION/CARERS SUMMARY

Most participants lived in their own home without a carer. If they had a carer, that person was most likely to be their spouse/partner.

4.3.1.1.3 EDUCATION

Table 12. The highest levels of education attained by the participants in each state

	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	TOTAL
EDUCATION	%	%	%	%	%	%	%	%
Primary school	1	<1	1	<1	1	1	1	1
Secondary school	19	31	39	35	36	33	37	33
Occupational certificate or diploma	23	35	29	35	34	29	32	32
University bachelor’s degree	35	20	20	17	16	20	20	20
University postgraduate degree	21	12	8	12	10	15	9	12
Other	1	2	3	1	2	2	2	2

EDUCATION SUMMARY

Virtually all participants had completed secondary school, with many of them having also completed an occupational certificate or university degree.

4.3.1.1.4 EMPLOYMENT

PAID/UNPAID EMPLOYMENT

Table 13. The participants’ average number of paid and unpaid hours of employment per week

	ACT	NSW	QLD	SA/NT	TAS	VIC	WA	NATIONAL
Paid work hours	16	14	11	15	9	14	15	13
Unpaid work hours	4	4	3	4	2	4	3	3

FATIGUE AND EMPLOYMENT

Level of fatigue experience by participants

Not at all: n = 162, mean age: 51, male 25% female 75%

Sometimes: n = 986, mean age 53; male 22%, female 78%

Often: n = 1423, mean age 52; male 21%, female 79%

Table 13a. The employment status of people experiencing fatigue symptoms not at all, sometimes, and often

	Not at all %	Sometimes %	Often %
Self employed	13	10	7
Full time	32	23	13

Part time	19	23	20
Unemployed seeking full time	1	1	<1
Unemployed seeking part time	2	2	2
Unemployed not seeking employment	4	6	15
Retired	19	23	26
Homemaker	7	7	10
Student	2	1	1
Volunteer	1	3	5

Table 13b. Hours of work undertaken by participants experiencing fatigue not at all, sometimes and often

	Not at all	Sometimes	Often
Paid hours per week	20	17	11
Unpaid hours per week	4	4	3

Fifty eight percent of the clients not experiencing fatigue had disclosed their MS to their employer, while 74% of people experiencing fatigue sometimes and 77% of people experiencing fatigue often had disclosed their MS to their employer. Participants not experiencing fatigue worked on average 20 hours per week paid employment, those experiencing fatigue sometimes worked 17 hours per week and those who often experienced fatigue worked 11 hours per week. There was a negative correlation between the frequency of fatigue symptoms and hours of paid employment per week $r = -.203$, $p = \underline{\leq}$ .001. Fatigue was not correlated with the number of unpaid hours. Age was also not significantly correlated to frequency of fatigue symptoms. Likewise, the average age of people often experiencing fatigue was about the same as those sometimes experiencing fatigue.

INFORMATION NEEDS RELATED TO EMPLOYMENT

Table 14. The participants views regarding various statements, and the availability of information and resources pertaining to employment

Topic	Not required	Unavailable	Sometimes available	Often available
Your rightS as an employee	25	19	29	27
Employer education	31	28	25	16
Flexibility in the workplace	29	17	29	26
Specialised employment services	25	19	28	27
education about symptom management	34	27	26	14
Advice about workplace adaptations/equipment	39	22	24	15
Access to transport to get to employment	48	23	17	12
Information about superannuation	33	27	25	15

Table 15. The percentage of participants in each type of work status

Work Status	
Self-employed	8
Full-time	19
Part-time	20
Unemployed looking for full-time work	1
Unemployed looking for part-time work	2
Unemployed not looking for work	11
Retired	25
Homemaker	9
Student	1
Volunteer	4

EMPLOYMENT SUMMARY

The majority of the participants were either presently employed full-time or part-time, or were retired, with very few being unemployed. They indicated that the information that was most frequently not available related to how to manage their symptoms, education for their employers and access to information about superannuation.

4.3.1.1.5 INFORMATION

Table 16. The percentage satisfaction of the availability of information and resources pertaining to employment

Bold percentages only include the participants who required each form of education.

Type	Not required	Not satisfied	Slightly satisfied	Very satisfied
Location of education sessions	33	18	25	24
		27	**37**	**36**
Education sessions about MS for people with MS	31	13	24	32
		18	**35**	**46**
Education sessions about MS for carer/spouse/partner	47	14	19	20
		26	**37**	**38**
Education about MS aimed at teenagers with MS	84	6	5	5
		35	**33**	**31**
Education about MS for teenagers living with someone with MS	78	10	7	6
		43	**31**	**26**
Education about MS for young children with MS	85	6	4	4
		41	**30**	**29**
Education about MS for young children living with someone with MS	77	10	7	6
		45	**30**	**26**
Education sessions about symptom management (e.g. nutrition, fatigue)	29	23	29	20
		32	**40**	**28**
Education sessions around financial management	22	28	35	15
		36	**45**	**20**

Online education sessions	25	20	30	25
		26	**40**	**34**

Table 17. The percentage level of satisfaction with various forms of available information to them

Bold percentages only include the participants who required each form of information.

Type	Not required	Not satisfied	Slightly satisfied	Very satisfied
Up-to-date information about current Ms research	10	11	33	46
		13	**36**	**51**
What services the State-based MS organisations provide	12	15	32	40
		17	**37**	**46**
What services you are eligible for from government or local council services	20	39	27	14
		48	**34**	**18**
Information regarding what financial assistance you are eligible for	25	42	22	11
		56	**30**	**14**
Understanding welfare and benefit entitlements	27	39	23	11
		53	**31**	**15**
Centrelink benefits information	40	36	22	12
		51	**32**	**17**
Information about superannuation	41	31	18	11
		52	**30**	**18**

INFORMATION SUMMARY

Many of the types of information were not required. However, for those who did need it, there was a desire for more information for teenagers and young children to cope with either their own or a family member with MS, as well as sessions on financial management and online education sessions. More information was required on government services, financial assistance for which the person with MS may be eligible, as well as information on Centrelink benefits and superannuation.

4.3.1.1.6 TRANSPORT

Table 18. The percentage responses regarding transport statements relevant to participants.

Bold percentages exclude participants in which the statement was not applicable

Statements	Responses			
	Not applicable%	**Not at all %**	**Sometimes%**	**Quite Often%**
Wheelchair access on PT is poor	83	4	6	7
		23	**36**	**41**
Can't attend appointments/miss appointments because of lack of transport	68	21	9	2
		66	**27**	**7**
Can't get to PT stop due to lack of mobility	68	15	8	9
		46	**25**	**29**
Lack confidence using PT	56	17	13	14
		38	**29**	**33**
Limit social activities due to lack of transport	63	20	10	7
		55	**27**	**18**
The reliability of PT is poor	60	12	17	10
		31	**43**	**26**
The reliability of taxis is poor	63	16	15	6
		44	**40**	**16**
Taxi drivers do not understand needs	72	16	9	3
		56	**33**	**11**
Taxis too expensive	66	20	10	5
		57	**29**	**15**
Public transport takes too long	70	9	9	11
		31	**32**	**37**

TRANSPORT SUMMARY

Approximately one third of the participants (for whom the statement was relevant) responded that they can't get to public transport due to a lack of mobility. While only 17% of participants indicated that the statement about wheelchair access on public transport is poor was relevant to them, of those participants to whom it was relevant, 41% agreed that this was a problem quite often. Finally, for those who saw public transport as relevant to them, approximately one third of the participants indicated that they lacked confidence in public transport or felt that public transport took too long. Of the participants for whom the statement was relevant, 43% and 40% respectively felt that the reliability of public transport and the reliability of taxis were poor.

4.3.1.1.7 SERVICES

Table 19. The percentage level of satisfaction with the quality and access to different services

Bold percentages only include the participants who required the relevant service

Services	Not Required	Not Satisfied	Slightly satisfied	Very satisfied	Don’t know
Case Worker	61	8	7	13	11
		30	**25**	**45**	
Counsellor	59	10	8	12	11
		33	**26**	**41**	
Dietician	64	11	7	7	12
		44	**27**	**29**	
General Practitioners	10	5	20	63	2
		6	**23**	**71**	
Physical activity/exercise	29	14	21	28	9
		22	**33**	**45**	
Incontinence Nurse	60	7	9	15	10
		22	**28**	**50**	
Advice about MS treatments	14	14	29	38	5
		17	**36**	**47**	
Massage Therapist	49	14	9	17	12
		35	**22**	**42**	
Neurologist	8	8	19	61	4
		9	**22**	**69**	
Occupational Therapist	61	6	8	14	11
		23	**41**	**48**	
Physiotherapist	47	9	12	23	10
		20	**27**	**53**	
Psychologist	67	7	6	9	11
		32	**26**	**42**	
Psychiatrist	76	5	3	4	11
		40	**25**	**35**	
Specialised Nurse	63	5	6	18	9
		17	**21**	**62**	
Speech Pathologist	80	4	3	4	10
		34	**26**	**40**	
Accurate information about MS services	12	13	29	41	5
		16	**35**	**49**	
Information about MS Australia	11	8	26	50	5
		10	**30**	**60**	
Peer Support	40	10	15	26	9
		20	**30**	**50**	

SERVICES SUMMARY

Of the participants who required the service, the participants were mostly satisfied with the availability of and access to the following services: General Practitioner, Specialised Nurse, Physiotherapist and Neurologist. Just under one third of participants required access to a Dietician, a Psychiatrist, a Massage Therapist, a Counsellor, and a Speech Pathologist.

4.3.1.1.8 PSYCHO-SOCIAL

PSYCHOLOGICAL SERVICES

Table 20. The percentage level of satisfaction with access to psychological services

Bold percentages include only participants that required the relevant psycho-social services.

PSYCHOLOGICAL SUPPORT	Not Required%	Unavailable%	Sometimes available%	Easily available%
Counselling (for client)	39	17 **28**	20 **34**	24 **38**
Psychological assistance when first diagnosed (for client)	37	31 **50**	13 **21**	19 **29**
Family counselling	55	26 **58**	9 **20**	10 **22**
Relationship counselling	58	25 **59**	8 **19**	9 **22**
Counselling for child/children	71	18 **62**	5 **18**	6 **20**
Psychological support to assist mental illness	67	15 **46**	9 **28**	8 **26**

PSYCHOLOGICAL SERVICES SUMMARY

About two thirds of the participants indicated that they required psychosocial services, but many of the participants indicated that the service was not easily available. Just under half of the participants indicated that they required family counselling and relationship counselling, but of the participants required it, 50% indicated that the service was unavailable.

4.3.1.1.9 PEER SUPPORT

Table 21. Requirement for peer support provided by MS Australia

Bold percentages include only participants that required the relevant peer support services.

Peer support	Not required %	Agree%	Disagree%
More variety to meet your particular needs (e.g. younger peer support)	59	28 **68**	13 **32**
Meeting are too far away	40	36 **60**	24 **40**
More variety with times	49	34 **67**	17 **33**
More variety in mode of communication	45	34 **61**	21 **39**

PEER SUPPORT SUMMARY

Approximately half of the participants required peer support. Of the people who required peer support, 60% agreed that the variety of peer support needs to increase as does the locations, the times, and the mode of communication of peer support.

4.3.1.1.10 EQUIPMENT

Table 22. The percentage of people who require various types of equipment that they do not currently have, and the percentage of those people who cannot afford it

	Need but don't have	Can't afford
Mobility aids	10	53
Computer-related aids	6	53
Continence aids	8	20
Home modifications to assist with mobility	11	48
Home modifications to assist with personal care	10	46
Car modifications	5	61
Other equipment (e.g. lifting aids, special beds)	5	51
Heating or cooling	21	48

EQUIPMENT SUMMARY

There was a wide range of equipment that participants indicated that they needed, but did not have (most particularly, heating and cooling), as well as equipment that they could not afford (e.g., car modifications).

4.3.1.1.11 ASSISTANCE

Table 23. The percentage of people with MS who need assistance with various tasks, and of those that require assistance, the percentage who need more help

Need more help column include only the participants that sometimes or quite often required each service.

Required Assistance	Never	Sometimes	Quite Often	Need more help
Administering medications	74	17	9	**16**
Assistance with managing finances	75	18	8	**26**
Communication	78	16	6	**16**
Domestic duties	38	29	32	**48**
Meal preparation/cooking	50	29	21	**30**
Moving around in-home	73	21	6	**11**
Outdoor maintenance	37	26	37	**51**
Personal care	78	14	8	**18**
Shopping	52	25	23	**36**
Social activities	60	25	15	**21**
Attending/making appointments	64	22	14	**26**

ASSISTANCE SUMMARY

Participants needed more help with a large number of activities. Highly rated activities were domestic duties, outdoor maintenance and shopping. Clearly more services are needed in these areas.

4.3.1.1.12 RESPITE

Table 24. The percentage level of agreement with various respite statements for participants who require respite

	Disagree	Agree a little	Strongly agree	Don't Know
It would be nice to go into respite with child/spouse/partner	27	25	33	15
Respite accommodation isn't age appropriate	17	18	32	33
Respite accommodation is too expensive	12	26	24	39
Respite accommodation is too far away	23	19	23	35
The permitted length of stay is too short	24	15	11	50
The waiting lists for respite are too long	11	13	27	48
There is not enough respite available	8	12	40	40
There is not enough variety of respite	7	16	35	41
I am able to get to respite accommodation	15	23	25	36
I am able to get in home day respite	13	17	12	58
I am able to get out of home day respite	15	13	8	63
I am able to get in home overnight respite	21	11	7	61

RESPITE SUMMARY

Ten percent of the participants required respite, while the remaining participants either answered that they did not require it, or that respite did not apply. As the participant symptom severity increased, so too did the likelihood of the participant requiring respite. Interestingly, a large number of participants responded to the various statements with “Don't Know”. Perhaps a large portion of the participants did not have a good understanding of Respite and this may reflect an area of information need. An alternative explanation may be that respite is generally more of a carer need. As such, if this question was put to carers instead, perhaps different results may have been obtained.

4.3.1.2 SYMPTOM SEVERITY

4.3.1.2.1 SYMPTOM GROUPS

The participants' responses were divided into four groups based on the severity their symptoms relating to mobility. This was done in order to examine how the needs of people with MS differ depending on their symptom severity. The participants were allocated to a group on the basis of their score onto the Symptom Severity Scale (question 14). The four groups included the following:

Mild (MILD)

1. I may have some mild symptoms, mostly sensory, due to MS but they do not limit my activity or lifestyle.
2. I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.
9. None of the above options describes my MS. I don't have any mobility problems, but I do have other kinds of MS symptoms such as eyesight or memory problems that significantly interfere with my activities and lifestyle.

Moderate (MOD)

3. MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need to use a walking stick [cane] or other walking aid, but I might during an MS attack.
4. I can walk about 8 metres [or 25 feet] without using a walking stick or other walking aid such as a splint, brace or crutch, but I may use a walking aid for greater distances.
5. To be able to walk 8 metres [or 25 feet], I have to have a walking stick, single crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

Severe (SEV)

6. To walk 8 metres [or 25 feet], I must have two walking sticks, two crutches or a walking frame [walker]. I may use a scooter or wheelchair for greater distances.
7. My main form of mobility is a wheelchair. I may be able to stand and or take one or two steps, but I can't walk 8 metres [or 25 feet], even with crutches or a walking frame.
8. I am unable to sit in a wheelchair for more than one hour, and I spend most of my time in bed.

Table 25. The number of participants in each symptom group in each state

STATE	MILD	MODERATE	SEVERE
ACT	46	32	8
NSW	394	287	123
QLD	134	136	71
SA/NT	110	82	42
TAS	58	56	21
VIC	333	273	96
WA	166	84	39

SEVERITY OF SYMPTOMS SUMMARY

The majority of the participants fell into the mild to moderate categories of symptom severity. The average age of the participants, and the number of years since first diagnosed increased with symptom severity.

4.3.1.2.2 DEMOGRAPHICS

AGE

Table 26. The age of participants by symptom group

	MILD	MODERATE	SEVERE
Number of participants	1246	960	404
Range of age (years)	18-91	20-90	25-82
Mean	51	53	54
No of years since first symptoms	15	16	19
Years diagnosed	10	11	14

ACCOMMODATION

Table 27. The percentage of participants living in various accommodations, and with whom, by symptom group

ACCOMODATION	MILD	MODERATE	SEVERE
Self/family owned property	85	84	77
A private rental	11	10	7
Public housing	2	4	5
Residential Aged care facility	1	<1	7
Supported accommodation	<1	<1	2
Other	<1	1	2
LIVING ARRANGEMENTS	**MILD**	**MODERATE**	**SEVERE**
Alone	13	15	20
Spouse/partner/children	80	76	66
Parent(s)	4	3	4
Friend/housemate(s)	2	2	2
Other	1	4	7

DEMOGRAPHIC SUMMARY

The largest number of participants were in the mild symptom group (47%), followed by the moderate symptom group (37%), with the least number of participants in the severe symptom group (15%). The average age of the mild group of participants was 51 years, the moderate group was 53 years and the severe group was 54 years. The years since first experiencing symptoms of MS and formal diagnosis increased with the severity of symptoms.

4.3.1.2.3 CARER

Table 28. The percentage of participants who have a carer by symptom group

CARER	MILD	MODERATE	SEVERE
Yes	12	34	72
No	88	66	28
CARER RELATION			
Spouse/partner	81	85	75
Child	4	2	2
Parent	10	5	6
Other family member	3	2	<1
Friend/housemate	1	4	3
Paid carer	1	2	14
CARER CHANGED WORK			
Yes	8	21	40
No	65	50	26
Not applicable	27	29	34

CARER SUMMARY

The participants in the severe symptom category were approximately twice as likely and six times more likely to have a carer compared to participants in the moderate and mild group respectively. The carer was most often a spouse or partner. 40% of carers of people with severe symptoms had changed their employment as a result of their caring role.

4.3.1.2.4 EMPLOYMENT

Table 29. The following table lists the average number of paid and unpaid hours of work for each symptom group

	MILD	MODERATE	SEVERE
Paid work	19	10	2
Unpaid work	4	4	2

Table 30. The percentage of employment status of participants by symptom group

EMPLOYMENT	MILD	MODERATE	SEVERE
Self-employed	10	8	3
Employed, full time (>35 hours)	28	13	2
Employed, part time, casual or seasonal	28	18	4
Unemployed, seeking full time employment	1	1	<1
Unemployed, seeking part time employment	3	2	<1
Unemployed, not seeking employment	6	12	26
Retired	13	28	53
Home and/or family management	8	11	5
Student	1	2	<1
Volunteer	2	5	6

Table 31. The percentage of participants who have disclosed their MS to their employee by symptom group

DISCLOSED YOUR MS TO EMPLOYER	MILD	MODERATE	SEVERE
Yes	71	81	84
No	24	8	0
Not applicable (e.g., seeking work)	5	11	16

Table 32. The percentage of responses to the availability of information and resources regarding various aspects of employment

Key: NR = Not Required; U = Unavailable; S = Sometimes available; O = Often available
*Includes only participants who work are currently employed or are seeking employment

	MILD				MODERATE				SEVERE			
	NR	U	S	O	NR	U	S	O	NR	U	S	O
Your rights as an employee	30	17	30	24	15	24	29	32	12	9	27	51
Education about MS for employers	37	26	23	14	20	34	27	19	24	24	21	30
Flexibility in the workplace to accommodate your MS (e.g. hours, leave)	33	16	27	24	21	19	31	29	15	12	32	41
Specialised Employment Services	48	23	19	9	31	28	22	18	25	16	34	25
Education about symptom management in the workplace	39	25	24	12	22	33	27	18	18	18	33	30
Advice about workplace adaptations and equipment	45	21	22	12	27	27	26	20	15	9	36	39
Access to transport to get to employment	54	20	15	11	38	31	18	13	25	22	25	28
Information about superannuation/moving out of employment	38	24	24	14	23	32	27	17	22	25	22	31

EMPLOYMENT NEEDS SUMMARY

The participants in the mild symptom group on average reported higher hours of paid work (19 hours) compared to participants in the moderate (10 hours) or severe symptom groups (2 hours). Over half of the participants in the mild group were employed either full time or part time. The participants in the moderate group were most commonly employed part time or were retired, while over half of the participants in the severe group were retired. This is despite the mean age of people in the moderate and severe groups being only slightly older than those in the mild group. Of the participants who were employed, most had disclosed their MS to their employer. When asked about the availability of employment information and resources, the participants in the mild and moderate groups felt that specialised employment services, education about symptom management in the workplace and advice about workplace adaptations and equipment were often not available. All three groups indicated a need for more availability of information about superannuation.

4.3.1.2.5 PSYCHO-SOCIAL NEEDS

PSYCHOLOGICAL

Table 33. The percentage responses on how the participants feel about access to the following services by symptom group

Key: NR = Not Required; U = Unavailable; S = Sometimes available; E = Easily available

	MILD				**MODERATE**				**SEVERE**			
Psychological services	**NR**	**U**	**S**	**E**	**NR**	**U**	**S**	**E**	**NR**	**U**	**S**	**E**
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	42	14	19	25	32	20	24	24	47	18	18	17
Psychological assistance when you were first diagnosed	39	26	13	22	31	37	15	16	41	34	12	13
Family counselling	61	22	7	10	48	31	11	10	54	27	10	9
Relationship counselling	63	21	6	10	52	30	10	9	59	24	10	7
Counselling for child/children	75	15	4	6	66	21	7	6	72	19	5	4
Psychological support to assist with mental illness	71	12	8	9	61	19	12	9	72	17	6	5

PSYCHOLOGICAL SUMMARY

Participants in all three symptom groups who required family counselling and relationship counselling when they were first diagnosed, indicated that it was unavailable or only sometimes available. While less than half of the participants required counselling for child/children, of those participants who did require it, the majority felt that it was unavailable or only sometimes available. In general, there were no differences between the symptom severity groups in the extent to which the participants required psychological services.

4.3.1.2.6 PEER SUPPORT

Table 34. The percentage of participants who require various forms of peer support and of those participants those who agree or disagree with the following statements

Key: NR = Not Required; RQ = Required (A = Agree; D= Disagree)

	MILD			**MODERATE**			**SEVERE**		
	NR	**RQ**		**NR**	**RQ**		**NR**	**RQ**	
	NR	**A**	**D**	NR	**A**	**D**	NR	**A**	**D**
Need more variety to meet your particular needs (e.g. younger peer support)	60	71	29	54	66	44	68	67	33
The meetings are too far away	46	57	43	31	62	38	42	64	36
Need more variety with times (e.g. after work hours, weekends etc.)	49	70	30	42	66	44	63	58	42
Need more variety in mode of communication (e.g. phone, email, Skype etc.)	47	61	39	38	62	38	52	62	38

PEER SUPPORT SUMMARY

Over half of the participants in each symptom group felt that the peer support meetings were too far away, although a higher percentage of participants in the moderate and severe symptom groups felt this way.

4.3.1.2.7 ASSISTANCE NEEDS

Table 35. Percentage responses regarding assistance by symptom group

Key: N = Never; S = Sometimes; Q= Quite Often

	MILD			MODERATE			SEVERE		
	N	S	Q	N	S	Q	N	S	Q
Administering medications	79	15	6	73	18	8	59	19	22
Assistance with managing finances	83	13	4	69	23	8	61	19	20
Communication- reading or writing tasks	89	10	1	74	20	6	56	23	21
Domestic duties (e.g. cleaning, ironing)	59	30	11	22	37	41	11	7	82
Meal preparation/cooking	69	25	6	38	39	23	18	15	67
Moving around in-home	94	6	0	64	32	4	29	41	30
Outdoor maintenance (e.g. gardening)	58	28	14	18	31	51	14	7	79
Personal care (e.g. showering, bathing)	95	5	0	75	22	3	33	23	44
Shopping	76	19	5	35	37	28	14	17	69
Social activities	83	14	2	44	38	18	22	27	51
Attending/making appointments	85	13	2	53	32	15	24	26	50

Table 36. The percentage of participants who require assistance with a task, but need more help, by symptom group

	MILD	MODERATE	SEVERE
Administering medications	18	14	18
Assistance with managing finances	27	29	21
Communication- reading or writing tasks	15	17	20
Domestic duties (e.g. cleaning, ironing)	44	50	48
Meal preparation/cooking	25	27	41
Moving around in-home	7	9	16
Outdoor maintenance (e.g. gardening)	41	50	50
Personal care (e.g. showering, bathing)	5	13	27
Shopping	23	33	38
Social activities	15	18	28
Attending/making appointments	21	24	31

ASSISTANCE SUMMARY

As the severity of the symptoms increased so too did the level of assistance required. The mild and moderate group most often needed assistance with domestic duties and outdoor maintenance. Of those participants, just under half of the mild group required more assistance with domestic duties and outdoor maintenance, while approximately fifty percent of the moderate severity participants required more assistance with these areas. Fifty percent or more of the participants in the severe group often needed assistance with domestic duties, meal preparation, outdoor maintenance, and shopping, social activities, and attending appointments. Of those people, half required more assistance with outdoor maintenance, and just under half required more assistance with domestic duties, meal preparation, and shopping.

4.3.1.2.8 EDUCATION

Table 37. The percentage level of satisfaction with education sessions by symptom group

KEY- NR = Not required; NS = Not satisfied; SS = slightly satisfied; VS = Very satisfied

	MILD				MODERATE				SEVERE			
Education	NR	NS	SS	VS	NR	NS	SS	VS	NR	NS	SS	VS
Location of education sessions	34	15	25	26	27	23	24	26	40	20	24	16
Education sessions about MS for people with MS	33	9	21	36	26	16	28	30	38	15	24	23
Education sessions about MS for carer/spouse/partner	50	10	18	22	44	16	21	19	46	18	19	16
Education about MS aimed at teenagers with MS	84	5	5	6	83	7	6	4	85	5	5	5
Education about MS for teenagers living with someone with MS	78	9	7	6	76	11	7	5	83	7	5	4
Education sessions about MS for young children with MS	85	6	4	5	84	7	4	4	88	4	5	3
Education sessions about MS for young children living with someone with MS	75	11	7	7	76	12	7	6	85	6	5	4
Education sessions about various treatments	33	17	27	23	23	28	31	19	31	27	26	16
Community awareness of MS	26	23	33	18	17	34	36	14	22	30	37	11
Education sessions about symptom management (e.g. nutrition, exercise, fatigue, and continence)	27	18	27	28	20	22	33	25	27	20	35	18
Education sessions around financial management	49	21	19	11	43	28	20	8	55	21	18	6
Education session online	45	17	22	16	41	24	23	12	53	19	19	9

EDUCATION SUMMARY

The moderate and severe groups more frequently reported being unsatisfied or only slightly satisfied with education sessions around various treatment options, compared to the participants in the mild group. Of the participants in the severe group who required education sessions, a large portion reported that they were either not satisfied or slightly satisfied with the location of education sessions. All three groups generally reported being not satisfied or only slightly satisfied with community awareness of MS.

4.3.1.2.9 INFORMATION

Table 38. The percentage level of satisfaction with education sessions by symptom group

KEY- NR = Not required; NS = Not satisfied; SS = slightly satisfied; VS = Very satisfied

	MILD				MODERATE				SEVERE			
INFORMATION (printed and online)												
	NR	NS	SS	VS	NR	NS	SS	VS	NR	NS	SS	VS
Up-to-date information about current MS research	11	8	30	51	7	14	35	45	12	16	36	37
What services the MS Society provides	16	11	30	44	8	19	35	38	10	21	34	35
What services you are eligible for (government, local councils services etc.)	28	35	24	13	13	45	28	14	11	35	34	20
Information regarding what financial assistance you are eligible for	33	38	18	10	17	49	25	10	16	38	30	16
Understanding welfare and benefit entitlements	38	35	17	10	18	45	26	10	14	34	32	19
Centrelink benefits information	41	33	16	10	20	43	26	11	16	29	34	22
Information about superannuation	38	30	17	11	38	34	17	10	51	18	20	11

INFORMATION SUMMARY

The three symptom groups were fairly consistent with their level of satisfaction with their access to and availability of various forms of information. The key areas participants were likely to be unsatisfied with included information about eligibility for services and financial assistance, understanding welfare and benefit entitlements, and information about superannuation.

4.3.1.2.10 EQUIPMENT

Table 39. The percentage of participants from each symptom group who need but do not currently have equipment, and the percentage of those participants who cannot afford such equipment

KEY: N = Need; X = Cannot afford

	MILD		MODERATE		SEVERE	
	N	**X**	N	**X**	N	**X**
Mobility aids (e.g. scooter, electric wheelchair, etc.)	1	**54**	15	**50**	23	**58**
Computer-related aids (e.g. for vision, manual difficulties, or other assistive technology)	3	**55**	9	**52**	11	**55**
Continence aids	4	**19**	11	**21**	14	**21**
Home modifications to assist your mobility (e.g. ramps, railings, remote control equipment)	2	**48**	18	**52**	24	**40**
Home modifications to assist your personal care (e.g. toileting, showering)	3	**56**	16	**45**	18	**42**
Car modifications	1	**30**	7	**63**	19	**63**
Other equipment (e.g. lifting aids, special beds, etc.)	1	**22**	4	**49**	22	**55**
Heating or cooling (e.g. an air-conditioning unit)	18	**46**	26	**57**	21	**44**

EQUIPMENT SUMMARY

As the symptom severity increased so too did the need for equipment. Irrespective of the severity of symptoms, heating and cooling was considered an equipment need that is currently unmet as a result of not being able to afford it. Just under a quarter of the participants in the severe group, and to a lesser degree the moderate group, did not currently have, but needed, mobility aids, home modifications, car modifications, and other equipment. Yet, nearly half of those participants could not afford such equipment.

4.3.1.2.11 RESPITE

Table 40. The percentage of participants that required respite per symptom group

NEED	MILD	MODERATE	SEVERE
Yes	4	10	33
No	47	53	41
Not Applicable	49	38	26

Table 41. The percentage agreement or disagreement with the various statements regarding respite, by symptom level

Key: D = Disagree; AL = Agree a Little; SA = strongly Agree; DN = Don't Know

Note: The following table includes only participants that need or would like respite

	MILD				MODERATE				SEVERE			
	D	AL	SA	DK	D	AL	SA	DK	D	AL	SA	DK
It would be nice to go into respite with children/spouse/partner	11	30	46	13	25	26	41	8	36	21	21	22
Respite accommodation is not age appropriate	22	13	20	45	11	18	39	32	20	18	32	30
Respite accommodation is too expensive	13	24	15	58	7	18	29	47	14	33	23	30
Respite accommodation is too far away	26	15	17	41	12	17	23	48	29	24	24	23
The permitted length of stay is too short	22	11	15	52	15	12	11	62	30	19	10	41
The waiting lists for respite are too long	11	13	20	57	6	6	27	61	15	18	30	38
There is not enough respite available	7	11	24	59	4	6	37	53	10	15	50	26
There is not enough variety of respite	13	9	22	56	6	11	28	56	7	21	44	27
I am able to get to respite accommodation	13	25	19	43	14	14	18	54	17	26	34	22
I am able to get in home day respite	20	9	2	69	14	10	3	72	11	24	21	44
I am able to get out of home day respite	13	11	4	72	14	7	3	76	18	17	13	52
I am able to get in home overnight respite	18	9	0	73	15	3	5	77	26	14	11	48

RESPITE SUMMARY

Approximately one third of the severe symptom group required respite whereas only a small portion of participants in the mild and moderate groups required respite. In general, there were no obvious differences between the groups in the agreement or disagreement with the various respite statements. Overall, the participants in the mild group and the moderate group reported 'don't know' in response to the respite statements more frequently than the severe group. These findings suggest a lack of information about the nature of respite and the potential help that this service can provide.

4.3.1.2.12 TRANSPORT

Table 42. Percentage agreement of transport requirement by symptom group

Key- NA = Not Applicable; N = Not at all; S= Sometimes, Q = Quite Often

	MILD				MODERATE				SEVERE			
	NA	**N**	**S**	**A**	**NA**	**N**	**S**	**A**	**NA**	**N**	**S**	**A**
Wheelchair access on public transport is poor.	93	3	2	2	82	3	7	8	51	9	17	24
I often can't attend, or miss appointments because of my lack of transport.	82	15	3	0	6	26	11	3	40	28	24	8
I can't get to train, tram or bus stop due to limited mobility.	84	13	3	0	57	18	13	12	46	11	12	31
I have a lack of confidence in using public transport.	71	18	8	3	43	17	19	21	41	12	13	34
I have to limit my social activities because transport is too expensive.	76	17	6	1	54	24	13	9	46	19	16	19
The reliability of public transport is poor.	69	11	13	7	52	15	20	13	53	11	21	15
The reliability of taxis is poor.	74	12	10	4	56	20	17	6	40	23	26	11
Taxi drivers don't understand my needs.	86	9	3	1	65	20	12	4	41	28	22	9
I feel socially isolated due to my lack of transport.	80	15	4	1	57	25	12	6	36	24	24	16
I find taxis too expensive even after taxi vouchers.	84	6	5	5	64	10	11	15	39	18	21	22
I find that public transport takes too long.	69	9	14	8	55	10	19	16	56	9	14	21

TRANSPORT SUMMARY

The transport statements were generally most relevant to the participants in the severe symptom group. The participants in the severe symptom group often agreed with the following statements: Wheelchair access on public transport is poor, it is difficult to get to the train, tram, bus stop due to a lack of mobility, I lack confidence in public transport, and I feel that taxis are too expensive.

4.3.1.2.13 SERVICES

Table 43. The percentage level of satisfaction with the current availability and quality of various services by symptom group

Key: NR = Not Required; NS = Not satisfied; SS = Slightly Satisfied; VS = Very Satisfied; DN = Don't Know

Bold percentages include only the participants who required each service

	MILD					MODERATE					SEVERE				
	NR	NS	SS	VS	DK	NR	NS	SS	VS	DK	NR	NS	SS	VS	DK
Case Worker	71	4	5	10	10	55	11	9	14	11	44	15	11	20	11
		21	**26**	**53**			**32**	**26**	**42**			**33**	**24**	**43**	
Counsellor	64	7	6	12	11	53	12	10	12	12	58	12	8	11	11

		28	**24**	**50**			**35**	**30**	**35**			**39**	**26**	**35**	
Dietician	70	8	4	6	12	59	14	8	7	12	57	13	10	11	9
		44	**22**	**33**			**48**	**28**	**24**			**38**	**29**	**32**	
General Practitioner	14	5	19	59	3	6	6	20	66	2	7	5	20	66	2
		6	**23**	**71**			**6**	**22**	**72**			**5**	**22**	**73**	
Physical activity/exercise	41	9	16	24	8	18	18	26	30	9	20	20	23	28	9
		18	**33**	**49**			**22**	**36**	**42**			**29**	**32**	**39**	
Incontinence Nurse	74	4	4	8	10	52	9	12	17	10	35	10	14	32	9
		25	**25**	**50**			**24**	**32**	**44**			**18**	**25**	**57**	
Advice about MS treatments	16	11	27	41	5	11	15	32	36	6	12	22	29	31	7
		14	**34**	**52**			**18**	**39**	**43**			**27**	**35**	**38**	
Massage Therapist	57	8	7	17	11	42	17	10	17	13	38	21	12	16	13
		25	**22**	**53**			**39**	**23**	**39**			**43**	**24**	**33**	
Neurologist	10	6	16	64	4	6	8	22	61	3	10	12	22	53	3
		7	**19**	**74**			**9**	**24**	**67**			**14**	**25**	**61**	
Occupational Therapist	75	3	3	7	11	55	9	10	14	12	31	8	20	33	8
		25	**25**	**60**			**27**	**30**	**43**			**13**	**33**	**54**	
Physiotherapist	63	4	6	16	11	35	13	16	27	9	26	12	18	36	8
		15	**23**	**62**			**23**	**29**	**48**			**18**	**27**	**55**	
Psychologist	69	5	5	10	11	62	9	7	10	12	69	8	6	5	12
		25	**25**	**50**			**35**	**27**	**38**			**42**	**32**	**26**	
Psychiatrist	79	3	2	5	11	73	6	4	5	12	74	8	4	3	11
		30	**20**	**50**			**40**	**27**	**33**			**53**	**27**	**20**	
Specialised Nurse	64	3	5	21	7	61	6	7	16	10	64	7	6	12	11
		10	**17**	**72**			**21**	**24**	**55**			**28**	**24**	**48**	
Speech Pathologist	84	2	1	3	10	76	5	3	4	11	74	5	6	8	7
		33	**17**	**50**			**42**	**25**	**33**			**26**	**32**	**42**	
Accurate information about MS services	15	9	27	44	5	7	17	32	40	4	10	20	30	35	5
		11	**34**	**55**			**19**	**36**	**45**			**24**	**35**	**41**	
Information about MS Australia	14	5	23	52	5	8	11	28	49	4	9	13	30	43	5
		6	**29**	**65**			**12**	**32**	**56**			**15**	**35**	**50**	
Peer Support	45	7	13	25	10	35	13	18	25	9	32	13	17	30	8
		15	**29**	**56**			**23**	**32**	**45**			**22**	**28**	**50**	

SERVICES SUMMARY

A large number of participants in all three symptom groups required a general practitioner, neurologist, advice about MS services and advice about MS Australia and participants were generally very satisfied with these services. A larger percentage of the participants in the severe group generally required each of the services more so than those in the moderate and mild groups. Of the participants who required each service, those in the severe group were least satisfied with services from counsellors, psychologists, psychiatrists, massage therapists, and dieticians. In the moderate group participants were least satisfied with dieticians, psychiatrists, psychologists, counsellors and speech pathologists. Of the participants in the mild group who required a particular service, in general they were more satisfied with the availability and access to the respective services compared to the moderate and serve group participants. Two thirds of participants requiring dietician services reported that they were either not satisfied or only slightly satisfied with the access and availability of this service.

4.3.1.3 NEWLY DIAGNOSED

The following section includes responses only from participants who had recently received a formal diagnosis of MS (i.e. diagnosed in the last year).

4.3.1.3.1 DEMOGRAPHICS

N: 167 participants

Mean age: 46 years of age.

Age range: 22-75 years of age.

Gender: 23% males, 77% females.

Average age for each gender: Males – 47 years of age; Females- 46 years of age.

Table 44. The number of newly diagnosed participants in each state.

	ACT	NSW	QLD	SA/NT	TAS	VIC	WA
n	7	41	26	10	6	46	28

4.3.1.3.2 SERVICES

Table 45. The services/resources required by all participants when first diagnosed.

SERVICES	%
Case Worker	18
Counsellor	**34**
Dietician	13
General Practitioner	**51**
Physical activity/exercise	29
Incontinence Nurse	11
Advice about MS treatments	**73**
Massage Therapist	18
Neurologist	**77**
Occupational therapist	15
Physiotherapist	24
Psychologist	15

Psychiatrist	4
Specialised Nurse	16
Speech Pathologist	4
Accurate information about MS services	**69**
Information about MS Australia	**59**
Peer support	**33**

SERVICES SUMMARY

The participants most commonly reported needing a neurologist, followed by education and information including accurate information about MS services, information about MS Australia and advice about treatment options. The next most highlighted service/resource needs, were psycho-social. These included counselling services and peer support. Given these findings, subsequent analyses of education, information, psychological, and peer support were conducted in order to gain a better understanding of each of these needs.

4.3.1.3.3 EDUCATION NEEDS

Table 46. The following includes the newly diagnosed participants (i.e. diagnosed less than a year ago) levels of satisfaction with various forms of education

Bold percentages include only the participants who required each service

EDUCATION	Not required	Not satisfied	Slightly satisfied	Very satisfied
Location of education sessions	17	23	33	27
		28	**40**	**32**
Education sessions about MS for people with MS	16	15	25	43
		18	**30**	**52**
Education sessions about MS for carer/spouse/partner	32	15	23	30
		22	**34**	**44**
Education about MS aimed at teenagers with MS	83	7	4	6
		41	**24**	**35**
Education about MS for teenagers living with someone with MS	75	9	8	7
		38	**33**	**29**
Education about MS for young children with MS	80	10	4	6
		50	**20**	**30**
Education about MS for young children living with someone with MS	71	14	7	8
		48	**24**	**28**
Education sessions about various treatment	18	25	34	23
		30	**41**	**28**
Community awareness	12	28	41	18
		32	**47**	**21**
Education sessions about symptom management (e.g. nutrition, fatigue)	14	21	37	28
		24	**43**	**33**
Education sessions around financial management	38	25	26	11
		40	**43**	**17**

Online education sessions	32	20	30	17
		30	**45**	**15**

EDUCATION NEEDS SUMMARY

Overall, the newly diagnosed participants were most satisfied with the availability of education sessions about MS and education sessions for carer/spouse/partner.

4.3.1.3.4 INFORMATION

Table 47. The percentage levels of satisfaction with various forms of information

Bold percentages include only participants who required the information

TYPE OF INFORMATION	Not required	Not satisfied	Slightly satisfied	Very satisfied
Up-to-date information about current MS research	6	11	28	55
		12	**30**	**58**
What services the State-based MS organisations provide	6	14	32	48
		15	**34**	**51**
What services you are eligible for from government or local council services	15	51	21	13
		60	**25**	**15**
Information regarding what financial assistance you are eligible for	18	53	19	10
		65	**23**	**12**
Understanding welfare and benefit entitlements	27	47	18	8
		64	**25**	**11**
Centrelink benefits information	28	49	14	9
		67	**20**	**13**
Information about superannuation	35	42	13	11
		65	**20**	**17**

INFORMATION SUMMARY

A large portion of the newly diagnosed participants required up-to-date information about current MS research and information of which over half were very satisfied with such information. A large number of newly diagnosed participants required information about eligibility for services from the government or local councils, understanding welfare and benefit entitlements, Centrelink benefits and information about superannuation, yet few participants were very satisfied with the availability of such information.

4.3.1.3.5 PSYCHOLOGICAL

Table 48. The percentage of newly diagnosed participants who have experienced Depression and/or Anxiety in relation to their MS

	Yes	No
Depression (e.g. feeling sad, helpless, worthless)	78	22
Anxiety (e.g. anxiety about the future)	79	21

PSYCHOLOGICAL SUPPORT

Table 49. Percentage feelings towards the availability of various forms of psychological support for newly diagnosed participants

Bold percentages include only the participants that required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Psychological Support				
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	28	18	23	31
		25	**32**	**43**
Psychological assistance when you were first diagnosed	25	31	18	26
		41	**24**	**35**
Family counselling	51	31	7	12
		62	**14**	**24**
Relationship counselling	50	29	9	11
		59	**19**	**22**
Counselling for child/children	68	18	5	9
		56	**16**	**28**
Psychological support to assist with mental illness	64	17	7	12
		47	**20**	**33**

PSYCHOLOGICAL NEEDS SUMMARY

Over three quarters of the newly diagnosed participants reported feelings of depression and anxiety in relation to their MS. Over half of the participants required counselling for themselves and psychological support when they were first diagnosed and to assist with a mental illness, reported that the service was unavailable or only sometimes available. Family counselling, relationship counselling, and counselling were most commonly perceived by those who required it as being unavailable.

4.3.1.3.6 PEER SUPPORT

Table 50. The percentage of newly diagnosed participants who agree and disagree with the need for peer support.

Bold percentages include only the participants that required the service.

	Not required	Agree	Disagree
Need more variety to meet your particular needs (e.g. younger peer support)	46	37	17
		69	**31**
The meetings are too far away	30	45	25
		64	**44**
Need more variety with times (e.g. after work hours, weekends etc.)	33	50	17
		75	**25**
Need more variety in mode of communication (e.g. phone, email, Skype etc.)	36	39	26
		60	**40**

PEER SUPPORT SUMMARY

For those who required it, there was an expressed need for a greater variety of peer support in terms of meeting participants' needs, location, and type of communication used for these peer support meetings.

4.3.1.3.7 NEWLY DIAGNOSED SUMMARY

Newly diagnosed participants required information about eligibility for services and also psychological support. The level of satisfaction with many of these services was low for many of the newly diagnosed participants.

4.3.1.4 REGIONS

In order to determine if there are differences in the needs of participants in terms of location, an analysis was conducted of the needs of people with MS according to where they live. That is according to whether they live in metropolitan, regional, rural and remote locations. The number of participants in each group is summarized below.

4.3.1.4.1 DEMOGRAPHICS:

Metropolitan: N = 1514 (58%); 21% male, 79% female
Regional: N = 714 (27%); 21% male, 79% female
Rural: N = 365 (14%); 24% male, 76% female
Remote: N = 18 (1%); 11% male, 89% female

4.3.1.4.2 EDUCATION

Table 51. Percentage level satisfaction with education sessions by region

KEY- NR = Not required; NS = Not satisfied; SS = slightly satisfied; VS = Very satisfied

	METRO				REGIONAL				RURAL				REMOTE			
Education	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**
Location of education sessions	33	13	25	29	32	25	27	17	36	25	23	16	33	39	17	11
Education sessions about MS for people with MS	33	8	23	37	28	19	27	26	32	19	25	24	41	24	24	11
Education sessions about MS for carer/spouse/partner	50	8	19	23	42	22	20	16	45	19	20	16	62	25	6	6
Education about MS aimed at teenagers with MS	85	4	5	6	81	7	6	5	84	7	5	3	94	6	0	0
Education about MS for teenagers living with someone with MS	80	7	7	6	74	13	7	6	79	12	5	4	82	18	0	0
Education sessions about MS for young children with MS	86	4	5	5	83	8	4	5	86	8	4	3	88	12	0	0
Education sessions about MS for young children living with someone with MS	78	9	7	6	74	12	7	6	78	12	6	4	79	13	3	5
Education sessions about various treatments	30	18	29	23	25	28	31	16	29	31	24	16	44	33	17	6
Community awareness of MS	23	25	35	17	20	31	36	13	22	34	32	12	41	41	18	0
Education sessions about symptom management (e.g. nutrition, exercise, fatigue, and continence)	26	15	30	29	23	25	31	21	25	28	27	20	35	24	18	23

Education sessions around financial management	48	20	21	11	47	27	19	7	49	29	16	6	65	29	6	0
Education session online	45	19	22	14	44	20	23	13	45	25	19	11	65	18	12	6

EDUCATION SUMMARY

The participants in rural and remote areas were generally less satisfied with the availability and access to education sessions compared to the metropolitan and regional groups. For example, 43% of the participants in the mild group were very satisfied with the location of education sessions compared to 24% and 25% in regional and rural areas respectively. Only 16% were very satisfied with the location of education sessions in remote areas. Despite a small number of participants requiring education aimed at teenagers with MS and teenagers living with someone with MS in the remote areas, all of those participants were not satisfied with these education sessions. Education sessions around financial management was often not satisfactory for participants from all four regions, but the quality of this education was particularly concerning in remote areas, where no participants who required the education sessions were very satisfied with the access and availability.

4.3.1.4.3 INFORMATION

Table 52. percentage level of satisfaction with different kinds of information by region

KEY- NR = Not required; NS = Not satisfied; SS = slightly satisfied; VS = Very satisfied

	METRO				REGIONAL				RURAL				REMOTE			
INFORMATION (printed and online)	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**	**NR**	**NS**	**SS**	**VS**
Up-to-date information about current MS research	10	11	31	48	8	11	35	46	11	13	32	43	29	6	29	35
What services the MS Society provides	13	13	31	43	9	18	35	38	14	17	33	36	28	17	39	17
What services you are eligible for (government, local councils services etc.)	23	36	27	13	14	42	27	16	19	40	26	15	41	41	18	0
Information regarding what financial assistance you are eligible for	27	40	22	11	21	46	23	11	22	43	24	11	45	44	11	0
Understanding welfare and benefit entitlements	30	37	22	11	21	44	23	12	27	37	24	12	53	41	6	0
Centrelink benefits information	33	34	22	11	23	41	22	14	29	33	24	14	59	35	6	0
Information about superannuation	41	30	19	11	40	33	16	11	47	27	16	10	65	35	0	0

INFORMATION SUMMARY

The various forms of information were generally required less often by people residing in remote areas. However, of the people in those areas who did require information, many were not satisfied or only slightly satisfied with its access and availability. Participants in the metropolitan areas were generally either slightly satisfied or very satisfied with information regarding the services state based MS societies provided, whereas participants in remote areas were less satisfied with the availability and access to this information. A larger proportion of participants living in metropolitan areas were satisfied with the availability and access to various information sources.

4.3.1.4.4 PSYCHOLOGICAL

Table 53. The percentage of responses regarding the availability psychological services by region

Key: NR = Not Required; U = Unavailable; S = Sometimes Available; E = Easily Available

	METRO				REGIONAL				RURAL				REMOTE			
Psychological services	**NR**	**U**	**S**	**E**	**NR**	**U**	**S**	**E**	**NR**	**U**	**S**	**E**	**NR**	**U**	**S**	**E**
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	41	14	19	25	37	19	23	21	36	20	22	22	39	44	6	11
Psychological assistance when you were first diagnosed	38	28	13	21	35	35	14	16	35	32	15	16	39	44	11	6
Family counselling	58	23	8	11	51	31	8	10	53	26	11	9	44	50	6	0
Relationship counselling	60	22	8	10	55	27	9	9	56	27	9	8	59	35	6	0
Counselling for child/children	75	15	4	6	66	22	6	6	69	19	6	5	50	44	6	0
Psychological support to assist with mental illness	70	13	9	9	64	19	10	8	65	18	11	7	61	11	17	11

PSYCHOLOGICAL SUMMARY

The participants living in metropolitan areas felt that various psychological services were more available compared to those living in the regional and rural areas. Participants in the remote areas often reported that psychological services were unavailable. Seventy-two percent of the participants living in remote areas who required counselling felt that it was unavailable, compared to 31% in rural areas, 30% in regional areas and 24% in metropolitan areas. Participants in all regions who required family counselling, relationship counselling and counselling for children mostly felt that such services were either unavailable, or only sometimes available, with no participants in the remote areas reporting that such services were available.

4.3.1.4.5 PEER SUPPORT

Table 54. The percentage of participants who agree and disagree with the following statements about peer support

Key: NR = Not required; RQ = Required (A = Agree; D= Disagree)

	METRO			REGIONAL			RURAL			REMOTE		
	NR	RQ		NR	RQ			RQ			RQ	
		A	D		A	D		A	D		A	D
Need more variety to meet your particular needs (e.g. younger peer support)	**60**	68	32	**57**	70	30	**60**	63	37	**57**	67	33
Meetings are too far away	**45**	55	46	**36**	64	36	**30**	70	30	**33**	79	21
Need more variety with times (e.g. after work hours, weekends etc.)	**49**	68	38	**49**	66	34	**45**	65	35	**50**	72	28
Need more variety in mode of communication (e.g. phone, email, Skype etc.)	**47**	60	40	**41**	63	37	**44**	64	36	**39**	46	54

PEER SUPPORT SUMMARY

A large portion of the participants living in remote areas felt that peer support meetings were too far away (79%), compared to 70% in rural areas, 64% in regional areas and 55% in metropolitan areas.

4.3.1.4.6 TRANSPORT

Table 55. The percentage agreement with statements about transport per region

KEY: NA = Not applicable; N = Not at all; S = sometimes; Q = quite often

	METRO				REGIONAL				RURAL				REMOTE			
	NA	**N**	**S**	**Q**	**NA**	**N**	**S**	**Q**	**NA**	**N**	**S**	**Q**	**NA**	**N**	**S**	**Q**
Wheelchair access on public transport is poor.	83	4	6	6	82	4	6	8	83	3	6	8	94	0	0	6
I often can't attend, or miss appointments because of my lack of transport.	67	22	9	2	67	22	9	2	71	17	8	3	77	6	6	11
I can't get to train, tram or bus stop due to limited mobility.	66	16	8	10	70	13	9	8	74	12	5	8	94	6	0	0
I have a lack of confidence in using public transport.	54	18	12	15	58	14	15	13	63	14	11	12	71	12	6	12
I have to limit my social activities because transport is too expensive.	62	22	9	7	64	19	11	6	69	14	10	6	83	6	0	11
The reliability of public transport is poor.	58	14	19	9	61	12	17	10	68	6	11	15	76	6	6	12
The reliability of taxis is poor.	61	16	17	6	63	18	14	4	71	12	9	8	76	12	0	12
Taxi drivers don’t understand my needs.	71	16	10	4	70	18	9	3	78	12	7	3	82	12	0	6
I feel socially isolated due to my lack of transport.	64	22	10	4	66	19	10	5	68	14	9	8	78	6	6	11
I find taxis too expensive even after taxi vouchers.	69	10	10	11	70	10	9	11	77	5	7	12	82	12	0	6
11. I find that public transport takes too long.	58	11	18	13	65	8	16	12	72	6	10	12	77	12	6	6

TRANSPORT SUMMARY

There were no major differences between the regions in terms of satisfaction with transport, with most participants for whom transport was important indicating that the transport provided failed to meet their needs.

4.3.1.4.7 SERVICES

Table 56. The percentage level of satisfaction with the current availability and quality of various services by region

Key: NR = Not Required; NS = Not satisfied; SS = Slightly Satisfied; VS = Very Satisfied; DN = Don't Know

	METRO					REGIONAL					RURAL					REMOTE				
	NR %	**NS %**	**SS %**	**VS %**	**DK %**	**NR %**	**NS %**	**SS %**	**VS %**	**DK %**	**NS %**	**NS %**	**SS %**	**VS %**	**DK %**	**NR %**	**NS %**	**SS %**	**VS %**	**DK %**
Case Worker	64	7	6	12	11	57	10	9	14	10	59	11	8	12	10	59	18	12	6	6
		30	**24**	**50**			**30**	**27**	**53**			**35**	**26**	**39**			**50**	**33**	**17**	**0**
Counsellor	60	8	7	14	11	59	11	9	10	11	57	13	7	12	11	59	18	6	12	6
		28	**24**	**48**			**37**	**30**	**33**			**40**	**21**	**39**			**50**	**17**	**33**	0
Dietician	67	10	6	6	12	61	12	7	9	11	62	12	8	9	10	62	19	0	0	19
		46	**27**	**27**			**43**	**25**	**32**			**41**	**28**	**31**			**100**	**0**	**0**	**0**
General Practitioner	12	5	18	62	3	7	5	22	64	2	7	6	22	63	2	19	19	6	44	12
		6	**21**	**73**			**5**	**24**	**71**			**6**	**24**	**70**			**28**	**9**	**63**	**0**
Physical activity/exercise	31	12	20	28	9	25	16	23	29	7	30	18	18	25	9	53	27	7	0	13
		20	**33**	**47**			**23**	**34**	**43**			**30**	**30**	**40**			**79**	**21**	**0**	**0**
Incontinence Nurse	62	6	8	14	11	59	7	8	17	9	55	9	11	17	8	69	13	0	6	12
		21	**29**	**50**			**21**	**25**	**54**			**24**	**30**	**56**			**68**	**0**	**32**	0
Advice about MS treatments	14	12	28	40	6	13	14	31	37	4	12	18	32	31	6	24	18	23	29	6
		15	**35**	**50**			**18**	**38**	**45**			**22**	**40**	**38**			**26**	**33**	**41**	**0**
Massage Therapist	50	11	9	17	13	47	17	7	17	11	49	15	11	13	11	50	12	19	0	19
		30	**24**	**46**			**41**	**18**	**41**			**38**	**28**	**34**			**39**	**61**		
Neurologist	9	6	17	65	4	7	11	21	58	3	10	11	24	52	3	5	19	23	51	2
		7	**19**	**74**			**12**	**23**	**64**			**12**	**28**	**60**			**20**	**25**	**55**	
Occupational Therapist	63	5	8	14	11	56	9	10	13	11	63	8	9	10	10	73	0	0	7	20
		19	**30**	**52**			**28**	**31**	**40**			**30**	**33**	**30**			**0**	**0**	**100**	
Physiotherapist	49	7	11	23	10	44	11	13	23	9	46	13	11	22	8	73	0	7	7	13
		17	**27**	**56**			**23**	**28**	**49**			**27**	**24**	**49**			**0**	**50**	**50**	
Psychologist	68	6	6	11	10	64	8	7	7	13	68	10	3	8	11	75	6	0	6	
		26	**26**	**48**			**36**	**32**	**32**			**48**	**14**	**38**			**50**	**0**	**50**	
Psychiatrist	77	4	3	5	11	75	6	3	4	12	77	8	3	3	10	80	0	0	7	13
		33	**25**	**42**			**46**	**23**	**31**			**56**	**22**	**22**			**0**	**0**	**100**	
Specialised Nurse	63	4	6	18	8	60	6	7	17	10	65	7	6	15	7	73	0	13	0	10
		14	**21**	**64**			**20**	**23**	**57**			**25**	**21**	**54**			**0**	**100**	**0**	
Speech Pathologist	81	4	3	3	10	76	3	4	6	10	82	3	2	5	8	81	0	0	0	19

		40	**30**	**30**			**23**	**31**	**46**			**30**	**20**	**50**			**0**	**0**	**0**	
Accurate information about MS services	13	12	28	42	5	11	15	30	40	4	7	16	32	41	4	28	11	28	33	0
		15	**34**	**51**			**18**	**35**	**47**			**18**	**36**	**46**			**15**	**39**	**46**	
Information about MS Australia	12	8	24	51	5	10	8	28	50	4	9	10	28	49	4	35	6	24	35	0
		9	**29**	**62**			**9**	**33**	**58**			**12**	**32**	**56**			**9**	**37**	**54**	
Peer Support	13	12	28	42	5	11	15	30	40	4	7	16	32	41	4	30	11	28	33	0
							18	**35**	**47**			**18**	**36**	**46**			**15**	**39**	**46**	

4.3.1.4.8 REGIONAL SUMMARY

Overall the further the participants lived from the city, the less satisfied they were with the availability of informational resources, education sessions, psychological services, the location of peer support groups, access to transport and services.

4.3.1.5 AGE

4.3.1.5.1 DEMOGRAPHICS

The participants were split into three groups based on their age. The three groups include:

Young: 18 to 39 years of age (n = 420; 73% female, 27% male)

Middle aged: 40 to 64 years of age (n = 1765 81% female, 19% male)

Older aged: 65 years of age and older (n =380; 75% female, 75% male)

4.3.1.5.2 SERVICES

Table 57. The percentage of employment status of participants by age group

EMPLOYMENT	YOUNG	MIDDLE	OLDER
Self-employed	8	9	7
Employed, full time (>35 hours)	25	19	12
Employed, part time, casual or seasonal	20	21	17
Unemployed, seeking full time employment	1	1	0
Unemployed, seeking part time employment	3	2	2
Unemployed, not seeking employment	11	11	10
Retired	15	23	41
Home and/or family management	11	9	6
Student	2	1	1
Volunteer	4	3	5

Table 58. The percentage level of satisfaction with the quality and access to different services by age group

Key: NR = Not Required; NS = Not Satisfied; SS= Sometimes Satisfied; VS = Very Satisfied; DN= Don't know

	Young					Middle					Older				
	NR	NS	SS	VS	DK	NR	NS	SS	VS	DK	NS	US	SS	VS	DK
Case Worker	58	8	8	14	11	62	8	7	12	11	62	9	6	13	10
Counsellor	58	10	7	13	12	59	10	8	12	12	64	9	6	12	9
Dietician	57	14	6	10	13	64	11	7	6	12	67	9	4	19	10
General Practitioner	11	7	17	63	2	10	5	20	62	3	8	6	22	62	1
Physical activity/exercise	27	14	23	28	9	29	14	21	27	8	34	16	14	29	7
Incontinence Nurse	64	7	8	12	9	60	6	8	15	11	59	6	12	16	7
Advice about MS treatments	11	15	32	36	6	13	13	28	40	5	19	15	28	33	5
Massage Therapist	46	14	9	17	14	48	14	10	16	12	53	14	6	15	11
Neurologist	7	7	21	60	5	8	8	19	62	3	11	9	17	61	2
Occupational Therapist	59	6	10	15	10	60	6	9	14	12	68	8	6	10	9
Physiotherapist	48	7	12	22	11	47	9	12	23	9	49	9	9	22	10
Psychologist	63	6	6	12	13	66	7	6	9	11	73	7	4	7	9
Psychiatrist	74	5	2	5	13	76	5	3	4	11	79	4	3	4	10
Specialised Nurse	59	6	7	20	9	62	4	7	18	9	70	6	3	12	8
Speech Pathologist	81	4	2	3	10	79	3	3	5	10	82	3	3	2	10
Accurate information about MS services	10	14	28	43	5	11	12	30	42	5	14	17	26	38	5
Information about MS Australia	10	7	24	54	5	11	8	26	50	5	11	11	26	47	4
Peer Support	39	10	17	26	8	40	11	15	10	8	40	10	16	25	10

SERVICES SUMMARY

Overall, the participants in the older age group tended to require each service slightly less than the other two age groups, followed by the middle age group and finally the young age group. The top four services required for all adult groups included general practitioner (92%), Neurologist (89%), Information about MS services (89%), Advice about MS treatment (81%). Generally all of these were sometimes satisfied or very satisfied.

4.3.1.5.3 EDUCATION AND INFORMATION NEEDS

Table 59. The percentage level of satisfaction with the availability of education and information by age group

	Young				Middle				Older			
	NR	NS	SS	VS	NR	NS	SS	VS	NR	NS	SS	VS
EDUCATION												
Location of education sessions	27	20	29	24	33	18	25	24	37	18	22	22
Education sessions about MS for people with MS	27	13	26	34	31	12	24	32	35	14	22	29
Education sessions about MS for carer/spouse/partner	43	14	23	20	48	13	19	21	78	7	10	5
Education about MS aimed at teenagers with MS	81	7	7	5	84	5	5	6	86	7	4	3

Education about MS for teenagers living with someone with MS	75	11	7	7	78	9	7	6	81	9	5	5
Education about MS for young children with MS	82	8	5	5	86	5	4	5	87	6	3	3
Education about MS for young children living with someone with MS	72	12	8	7	77	10	7	6	80	10	5	5
Education sessions about various treatment	24	25	32	19	29	22	29	20	30	23	26	21
Community awareness	17	32	36	16	23	26	36	15	25	30	30	14
Education sessions about symptom management (e.g. nutrition, fatigue)	20	18	38	24	26	20	29	25	50	22	21	7
Education sessions around financial management	43	25	23	9	48	24	19	9	55	21	15	9
Online education sessions	37	22	26	15	45	20	21	14	13	14	30	43
INFORMATION												
Up-to-date information about current MS research	7	12	33	48	9	10	34	47	14	14	29	43
What services the State-based MS organisations provide	10	16	31	43	12	14	33	41	15	19	30	36
What services you are eligible for from government or local council services	19	43	27	11	19	38	28	15	25	35	27	13
Information regarding what financial assistance you are eligible for	25	46	21	8	24	42	23	11	29	39	22	10
Understanding welfare and benefit entitlements	29	42	21	8	26	39	23	12	30	36	22	12
Centrelink benefits information	31	39	21	9	29	36	23	12	31	34	22	14
Information about superannuation	40	33	19	8	39	31	18	11	52	24	14	10

EDUCATION AND INFORMATION NEEDS SUMMARY

Approximately three quarters of the participants in the young and middle age groups required education sessions about symptom management, whereas only half of the participants in the older group required such sessions. Just over half of the participants in the young and middle age groups required education sessions for spouse or partners yet only one fifth of participants in the older group required such service. All three groups highlighted a need for more information regarding eligibility for financial assistance, understanding welfare and benefits, Centrelink benefits and information about superannuation.

4.3.1.5.4 EMPLOYMENT

Table 60. The percentage satisfaction with the availability of information and resources regarding various aspects of employment by age group

	Young				Middle				Older			
Topic	NR	US	SS	OS	NR	US	SS	OS	NR	US	SS	OS
Your right as an employee	25	23	27	24	25	18	28	29	27	16	29	27
Employer education	30	34	20	16	31	27	25	17	38	27	24	11
Flexibility in the workplace	27	17	28	27	28	17	28	27	34	14	32	20
Specialised employment services	43	23	21	13	43	25	20	12	44	22	20	14

Education about symptom management	33	32	12	13	34	26	26	14	30	27	24	19
Advice about workplace adaptations/equipment	30	23	40	7	39	25	23	13	39	21	24	16
Access to transport to get to employment	50	24	17	9	49	24	15	13	47	19	21	13
Information about superannuation	38	26	23	13	32	27	24	16	34	25	26	15

EMPLOYMENT SUMMARY

The participants in the young age group worked on average 15 hours of paid work per week and 4 hours of unpaid work per week. The participants in the middle age group worked on average 14 hours per week paid employment, and 4 hours of unpaid work per week, and finally the participants in the older age group worked on average 10 hours per week of paid employment and 3 hours per week of unpaid employment. The participants in the young group were most likely to be employed full time or part time, in the middle group retired or part time and close to half of the participants in the older group were retired. There were no major differences between the three age groups in the participants' level of satisfaction with the availability of information and resources regarding various aspects of employment (refer to earlier section for information on the overall needs of people with MS in respect to employment).

4.3.1.5.5 PSYCHOLOGICAL SERVICES

Table 61. The percentage level of satisfaction with access to psychological services by age group

Key: NR = Not Required; UN = Unavailable; O = Only Sometimes available; EA = Easily available

	Young				Middle				Older			
	NR	UN	OS	EA	NR	UN	OS	EA	NR	UN	OS	EA
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	39	16	20	25	38	17	21	24	44	18	18	20
Psychological assistance when you were first diagnosed	34	36	14	19	37	31	14	18	39	31	11	19
Family counselling	50	25	8	17	55	27	9	10	60	24	8	8
Relationship counselling	57	25	10	8	58	25	7	10	63	22	8	7
Counselling for child/children	72	15	7	6	71	19	5	5	74	18	4	4
Psychological support to assist with mental illness	68	13	9	10	67	16	9	8	73	13	7	8

4.3.1.5.6 PEER SUPPORT

Table 61. Percentage responses to variations in peer support by age group

Key: NR = Not Required; RQ = Required (A = Agree; B = Disagree)

	Young			Middle			Older	
	NR	RQ		NR	RQ		RQ	
		A	D		A	D	A	D

Need more variety to meet your particular needs (e.g. younger peer support)	**55**	30	15	**61**	26	13	**58**	29	13
		67	**33**		**67**	**33**		**69**	**31**
Meetings are too far away	**44**	35	21	**40**	36	23	**40**	36	24
		63	37		61	39		60	40
Need more variety with times (e.g. after work hours, weekends etc.)	**55**	33	13	**48**	35	17	**53**	30	17
		72	28		67	33		64	36
Need more variety in mode of communication (e.g. phone, email, Skype etc.)	**47**	32	21	**44**	33	23	**45**	34	21
		60	40		59	41		62	38

PSYCHOLOGICAL AND PEER SUPPORT SUMMARY

There were no major differences in the level of requirement of psychological services between the age groups, nor were there any major differences between the participants' perceptions of the availability of each service. Similarly, there were no major differences between the age groups on their need for peer support.

4.3.1.5.7 AGE GROUP SUMMARY

There was a higher need for services among older participants with MS, but a greater need for information and education among the young and middle age groups. Not surprisingly, the younger age groups were more likely to be employed than older participants. Psychological and peer support was required by all groups.

4.3.2 STATE NEEDS

4.3.2.1 AUSTRALIAN CAPITAL TERRITORY (ACT) (N = 88)

4.3.2.1.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	14	9	27	50
		10	**31**	**58**
Employer education	16	26	30	28
		31	**36**	**33**
Flexibility in the workplace	16	16	18	50
		19	**21**	**60**
Specialised employment services	43	14	31	12
		22	**53**	**25**
education about symptom management	36	14	34	16
		10	51	39
Advice about workplace adaptations/equipment	29	7	36	27
		31	**42**	**27**
Access to transport to get to employment	48	16	23	14
		19	**44**	**39**
Information about superannuation	27	14	32	27

EMPLOYMENT SUMMARY

Over half of the participants felt that their rights as an employee and employer education were often available compared to only 36% and 23% of the national sample respectively. Specialised employment services were more often seen as unavailable (22%) or only sometimes available (53%) similar to the national findings, highlighting a need for such service.

4.3.2.1.2 PSYCHOSOCIAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who require the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	31	10	27	32
		14	**39**	**47**

ACT

Psychological assistance when you were first diagnosed	30	26	12	32
		37	**17**	**46**
Family counselling	62	15	12	11
		39	**32**	**29**
Relationship counselling	63	14	12	11
		38	**32**	**30**
Counselling for child/children	74	11	7	8
		42	**27**	**31**
Psychological support to assist with mental illness	73	9	9	10
		32	**32**	**36**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who require the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	55	27	18
		60	**40**
Meetings are too far away	43	19	37
		34	**66**
More variety with times (e.g. after work hours, weekends etc.)	43	31	25
		55	**45**
More variety in mode of communication (e.g. phone, email, Skype etc.)	46	27	28
		49	**51**

PSYCHOSOCIAL NEEDS SUMMARY

A higher percentage of participants in the ACT felt that psychological services were easily available compared to the national sample. Unlike the national sample, a larger portion of the participants disagreed with the statement “peer support is too far away” suggesting that the ACT is currently meeting the needs of people with MS in relation to psychosocial needs.

4.3.2.1.3 EDUCATION AND INFORMATION

The percentage level of satisfaction with various forms of education available to them.

Type	Not required	Not satisfied	Slightly satisfied	Very satisfied
Location of education sessions	20	11 **14**	20 **25**	49 **60**
Education sessions about MS for people with MS	19	6 **7**	22 **27**	53 **66**
Education sessions about MS for carer/spouse/partner	40	5 **8**	24 **40**	31 **52**

ACT

Education about MS aimed at teenagers with MS	88	0 **0**	6 **50**	6 **50**
Education about MS for teenagers living with someone with MS	79	5 **24**	8 **38**	8 **38**
Education about MS for young children with MS	90	3 **30**	3 **30**	4 **40**
Education about MS for young children living with someone with MS	77	10 **43**	7 **30**	6 **26**
Education sessions about various treatment	20	14 **18**	42 **52**	24 **30**
Community awareness	18	21 **26**	41 **50**	20 **24**
Education sessions about symptom management (e.g. nutrition, fatigue)	18	21 **26**	41 **50**	20 **24**
Education sessions around financial management	18	14 **17**	30 **37**	38 **46**
Online education sessions	44	16 **29**	24 **44**	16 **29**

The percentage level of satisfaction with various forms of information.

Type	**Not required**	**Not satisfied**	**Slightly satisfied**	**Very satisfied**
Up-to-date information about current MS research	6	6 **6**	38 **40**	50 **53**
What services the State-based MS organisations provide	8	12 **13**	36 **39**	43 **47**
What services you are eligible for from government or local council services	26	36 **49**	31 **42**	7 **9**
Information regarding what financial assistance you are eligible for	29	42 **59**	26 **37**	4 **5**
Understanding welfare and benefit entitlements	33	38 **49**	25 **32**	4 **12**
Centrelink benefits information	39	30 **49**	24 **39**	7 **12**

EDUCATION AND INFORMATION NEEDS SUMMARY

Three quarters of the participants in the ACT were very satisfied with the location of education sessions compared to only 36% nationally. Just over half of the participants were very satisfied with education sessions about MS for people with MS, education sessions about MS for carer/spouse/partner and education aimed at teenagers with MS. Similar to the national sample, participants in ACT highlighted a need for additional education sessions around symptom management, education for young children and teenagers living with someone with MS, and just over half were not satisfied or only slightly satisfied with education around financial management. As per the national sample, a large number of the participants in ACT were either not satisfied or only slightly satisfied with information about eligibility for financial assistance, services, and understanding welfare and benefit entitlements and Centrelink benefits.

ACT

4.3.2.1.4 TRANSPORT

The percentage agreement with various transport statements.
Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
1. Wheelchair access on public transport is poor.	81	2	6	11
		11	**31**	**58**
2. I often can't attend, or miss appointments because of my lack of transport.	58	28	7	7
		66	**17**	**17**
3. I can't get to train, tram or bus stop due to limited mobility.	62	24	7	7
		64	**18**	**18**
4. I have a lack of confidence in using public transport.	55	26	8	11
		58	**18**	**24**
5. I have to limit my social activities because transport is too expensive.	55	28	8	8
		64	**18**	**18**
6. The reliability of public transport is poor.	57	14	14	15
		33	**14**	**15**
7. The reliability of taxis is poor.	57	20	12	11
		61	**36**	**33**
8. Taxi drivers don’t understand my needs.	65	20	7	8
		57	**20**	**23**
9. I feel socially isolated due to my lack of transport.	58	27	11	5
		63	**26**	**11**
10. I find taxis too expensive even after taxi vouchers.	63	11	12	14
		30	**32**	**38**
11. I find that public transport takes too long.	58	12	12	18
		29	**29**	**42**

TRANSPORT NEEDS SUMMARY

Overall, transport needs were generally well met. In fact, 89% of the participants (for whom it was applicable) felt that wheelchair access on public transport was generally satisfactory but felt public transport takes too long (71%), was sometimes or often poor, similar to the national findings. Of note, a larger portion of participants in the ACT felt that taxis were too expensive in comparison to the national group.

4.3.2.1.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

Statements	Disagree	Agree a little	Strongly agree	Don’t Know
It would be nice to go into respite with children/spouse/partner	30	20	50	0

ACT

Respite accommodation is not age appropriate	10	20	30	40
Respite accommodation is too expensive	10	10	30	50
Respite accommodation is too far away	10	20	10	60
The permitted length of stay is too short	10	10	10	70
The waiting lists for respite are too long	20	0	10	70
There is not enough respite available	10	0	40	50
There is not enough variety of respite	10	10	10	70
I am able to get to respite accommodation	10	20	20	50
I am able to get in home day respite	20	30	0	50
I am able to get out of home day respite	10	10	80	100
I am able to get in home overnight respite	10	10	0	80

RESPITE SUMMARY

There was not a high expressed need for respite by participants in the ACT, consistent with the national sample.

4.3.2.1.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't Know
Case Worker	60	4	6	21	10
		13	**19**	**68**	
Counsellor	82	9	7	20	12
		25	**19**	**56**	
Dietician	54	10	10	11	16
		32	**32**	**36**	
General Practitioner	6	4	21	65	4
		4	**23**	**72**	
Physical activity/exercise	26	6	22	33	12
		10	**36**	**54**	
Incontinence Nurse	61	6	6	15	12
		22	**22**	**56**	
Advice about MS treatments	10	9	40	38	3
		10	**46**	**44**	
Massage Therapist	42	10	11	27	11
		31	**23**	**56**	
Neurologist	5	7	21	62	5
		8	**22**	**66**	
Occupational Therapist	67	9	6	5	13
		45	**30**	**25**	

ACT

Physiotherapist	52	8	13	18	8
		21	**33**	**46**	
Psychologist	69	6	6	5	13
		35	**35**	**30**	
Psychiatrist	81	1	3	1	14
		20	**60**	**20**	
Specialised Nurse	55	7	4	24	10
		21	**11**	**68**	
Speech Pathologist	78	5	2	3	12
		50	**20**	**30**	
Accurate information about MS services	7	10	34	44	5
		11	**39**	**50**	
Information about MS Australia	6	5	24	61	4
		5	**27**	**68**	
Peer Support	39	5	18	34	4
		8	**32**	**60**	

SERVICE NEEDS SUMMARY

Only 30% of the participants were very satisfied with the quality of and access to a psychologist, and speech pathologist, and 36% for dietician and 20% for access to a psychiatrist. Also 45% of the participants who required access to a speech pathologist and 45% of the people that required an occupational therapist felt that these services were unavailable.

4.3.2.2 NEW SOUTH WALES (NSW) (N = 816)

4.3.2.2.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	27	23	26	24
		32	**36**	**33**
Employer education	32	32	21	15
		47	**31**	**22**
Flexibility in the workplace	31	17	27	25
		25	**39**	**36**
Specialised employment services	42	28	20	10
		48	**34**	**17**
Education about symptom management	33	31	25	11
		46	**37**	**16**
Advice about workplace adaptations/equipment	38	27	21	14
		44	**34**	**22**
Access to transport to get to employment	50	26	12	12
		52	**24**	**24**
Information about superannuation	34	27	22	17
		41	**33**	**26**

EMPLOYMENT SUMMARY

The employment needs for participants in NSW were similar to the national sample. There is a need for specialised employment services, with close to half of the participants requiring this service stating that it was unavailable and 34% stating it was only sometimes available. Participants indicated that advice about workplace adaptations/equipment, education about symptom management and information about superannuation were often seen as being unavailable. Notably, although only applicable to half of the participants, of those participants who required it, 52% felt that access to transport to get to employment was unavailable.

NSW

4.3.2.2.2 PSYCHOSOCIAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	41	19	19	21
		32	**32**	**36**
Psychological assistance when you were first diagnosed	39	31	13	17
		51	**21**	**29**
Family counselling	56	24	9	11
		55	**21**	**24**
Relationship counselling	60	24	8	9
		59	**19**	**22**
Counselling for child/children	70	18	5	7
		60	**17**	**23**
Psychological support to assist with mental illness	67	16	9	8
		49	**27**	**24**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	53	33	14
		71	**29**
Meetings are too far away	38	36	26
		58	**42**
More variety with times (e.g. after work hours, weekends etc.)	46	34	20
		63	**37**
More variety in mode of communication (e.g. phone, email, Skype etc.)	40	37	23
		62	**38**

PSYCHOSOCIAL NEEDS SUMMARY

The psychological needs of the participants in NSW were similar to the national findings. Many of the psychological services were seen as unavailable or only sometimes available by the participants who required such services highlighting an important area of need that warrants further investigation. Peer support was generally required by approximately fifty to sixty percent of the participants. Seventy one percent of the participants who required peer support felt that there was a need for more variety of peer support groups to meet their needs. In addition, more variety with peer support times and mode of peer support were needed, as per the national findings of peer support needs.

4.3.2.2.3 EDUCATION AND INFORMATION

EDUCATION

The percentage level of satisfaction with various forms of education available to them.

*** Bold percentages only include the participants who required each form of education.**

Type	Not required %	Not satisfied %	Slightly satisfied %	Very satisfied %
Location of education sessions	36	20	26	18
		32	**40**	**28**
Education sessions about MS for people with MS	33	15	25	27
		22	**38**	**40**
Education sessions about MS for carer/spouse/partner	48	16	18	18
		31	**35**	**35**
Education about MS aimed at teenagers with MS	84	6	5	5
		38	**31**	**31**
Education about MS for teenagers living with someone with MS	76	12	7	5
		50	**29**	**21**
Education about MS for young children with MS	84	8	4	4
		50	**25**	**25**
Education about MS for young children living with someone with MS	76	12	7	5
		50	**30**	20
Education sessions about various treatment	29	24	27	19
		34	**38**	**27**
Community awareness	24	28	32	16
		37	**42**	**21**
Education sessions about symptom management (e.g. nutrition, fatigue)	27	22	30	21
		30	**41**	**29**
Education sessions around financial management	50	26	17	7
		52	**34**	**14**
Online education sessions	45	20	22	13
		36	**40**	**24**

NSW

INFORMATION

The percentage level of satisfaction with various forms of information.

*** Bold percentages only include the participants who required each form of information.**

Type	Not required %	Not satisfied %	Slightly satisfied %	Very satisfied %
Up-to-date information about current Ms research	9	10	35	46
		11	**38**	**51**
What services the State-based MS organisations provide	14	16	32	38
		19	**37**	**44**
What services you are eligible for from government or local council services	22	39	27	12
		50	**35**	**15**
Information regarding what financial assistance you are eligible for	28	40	22	10
		56	**31**	**13**
Understanding welfare and benefit entitlements	31	38	21	10
		55	**68**	**32**
Centrelink benefits information	33	36	20	11
		47	**26**	**14**
Information about superannuation	42	30	17	10
		52	29	**17**

EDUCATION AND INFORMATION SUMMARY

The areas of information and education needs for the NSW participants were similar to the national findings. While only applicable to a small number of participants, of those participants that required education aimed at teenagers and young children living with MS or living with someone with MS felt that it was unavailable or only sometimes available. Finally, education sessions around financial management, and symptom management were areas of unmet need. Consistent with the national findings, participants in NSW highlighted a desire for more information about eligibility around financial assistance and services, understanding welfare and benefit entitlements, Centrelink benefits information and information about superannuation.

NSW

4.3.2.2.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	82	5	6	7
		27	**34**	**39**
I often can't attend, or miss appointments because of my lack of transport.	68	22	8	2
		69	**24**	**7**
I can't get to train, tram or bus stop due to limited mobility.	37	16	8	7
		52	**25**	**23**
I have a lack of confidence in using public transport.	57	17	13	13
		40	**30**	**30**
I have to limit my social activities because transport is too expensive.	64	20	9	6
		57	**25**	**18**
The reliability of public transport is poor.	62	12	16	10
		33	**41**	**26**
The reliability of taxis is poor.	65	17	14	4
		49	**36**	**15**
Taxi drivers don’t understand my needs.	74	16	8	2
		58	**33**	**9**
I feel socially isolated due to my lack of transport.	65	19	11	5
		54	**32**	**14**
I find taxis too expensive even after taxi vouchers.	73	9	8	10
		33	**30**	**37**
I find that public transport takes too long.	62	10	16	12
		27	**42**	**31**

TRANSPORT SUMMARY

There were no major differences the transport needs of the nation and the transport needs specific to participants residing in NSW.

4.3.2.2.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

	Disagree	Agree a little	Strongly agree	Don’t Know
It would be nice to go into respite with children/spouse/partner	33	29	27	11
Respite accommodation is not age appropriate	24	17	36	23
Respite accommodation is too expensive	14	34	25	27
Respite accommodation is too far away	29	19	31	21
The permitted length of stay is too short	31	18	11	40

The waiting lists for respite are too long	14	18	27	41
There is not enough respite available	10	18	39	33
There is not enough variety of respite	11	20	41	28
I am able to get to respite accommodation	16	26	24	34
I am able to get in home day respite	10	14	17	59
I am able to get out of home day respite	18	10	8	64
I am able to get in home overnight respite	18	13	12	58

RESPITE SUMMARY

The respite needs were generally congruent with those of the national respite needs.

4.3.2.2.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Note: Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don’t Know
Case Worker	63	8	8	10	11
		30	**29**	**41**	
Counsellor	62	9	8	9	12
		36	**31**	**33**	
Dietician	63	11	7	6	13
		45	**29**	**26**	
General Practitioner	10	6	19	63	2
		7	**22**	**71**	
Physical activity/exercise	30	16	19	26	9
		26	**31**	**43**	
Incontinence Nurse	62	7	9	13	9
		24	**30**	**46**	
Advice about MS treatments	15	13	29	37	5
		17	**36**	**46**	
Massage Therapist	50	15	7	14	14
		41	**20**	**39**	
Neurologist	9	6	18	63	3
		7	**21**	**72**	
Occupational Therapist	64	7	5	11	13
		28	**24**	**48**	
Physiotherapist	50	10	9	20	11
		25	**23**	**52**	
Psychologist	66	7	5	9	13
		34	**24**	**42**	
Psychiatrist	74	5	4	4	13

NSW

		42	**29**	**29**	
Specialised Nurse	65	5	6	14	11
		19	**24**	**57**	
Speech Pathologist	80	3	4	3	10
		31	**38**	**31**	
Accurate information about MS services	14	13	28	40	5
		16	**34**	**50**	
Information about MS Australia	11	8	25	52	4
		9	**29**	**61**	
Peer Support	44	11	15	20	10
		26	**32**	**42**	

SERVICE SUMMARY

The services most commonly reported as being unsatisfactory included dietician (45%), massage therapist (41%) and psychiatrist (42%), although in general these services were required by a low number of participants.

4.3.2.3 QUEENSLAND (QLD) (N = 348)

4.3.2.3.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	20	20	35	24
		25	**44**	**30**
Employer education	21	28	31	20
		36	**39**	**25**
Flexibility in the workplace	20	17	35	28
		21	**44**	**35**
Specialised employment services	36	26	24	14
		41	**38**	**21**
Education about symptom management	28	28	29	14
		39	**40**	**19**
Advice about workplace adaptations/equipment	33	21	33	13
		31	**49**	**20**
Access to transport to get to employment	39	29	18	14
		48	**29**	**23**
Information about superannuation	23	33	30	14
		43	**39**	**18**

EMPLOYMENT SUMMARY

The employment needs for participants in QLD were similar to the national summary. There is a need for specialised employment services, with close to half of the participants requiring this service stating that it was unavailable and 34% stating it was only sometimes available. Participants indicated that advice about workplace adaptations/equipment, education about symptom management and information about superannuation were often seen as being unavailable.

QLD

4.3.2.3.2 PSYCHOSOCIAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	35	21	22	22
		32	**34**	**34**
Psychological assistance when you were first diagnosed	29	37	15	19
		51	**22**	**27**
Family counselling	49	33	8	10
		66	**14**	**20**
Relationship counselling	51	32	7	10
		65	**14**	**21**
Counselling for child/children	70	22	5	3
		71	**17**	**12**
Psychological support to assist with mental illness	62	20	10	8
		51	**27**	**22**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Note: Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	53	33	14
		71	**29**
Meetings are too far away	38	36	26
		58	**42**
More variety with times (e.g. after work hours, weekends etc.)	46	34	20
		63	**37**
More variety in mode of communication (e.g. phone, email, Skype etc.)	40	37	23
		62	**38**

PSYCHOSOCIAL SUMMARY

The psychological needs of the participants in QLD were similar to the national findings. Many of the psychological services were seen as unavailable or only sometimes available by the participants that required such services highlighting an important area of need that warrants further investigation. The peer support findings were congruent with those of the national sample, with over half of the participants needing such services agreeing that there was a need for more variety to meet their particular needs, more variety with times, and more variety in mode of communication

4.3.2.3.3 EDUCATION AND INFORMATION

EDUCATION

The percentage level of satisfaction with various forms of education available to them.

*** Bold percentages only include the participants who required each form of education.**

Type	Not required %	Not satisfied %	Slightly satisfied %	Very satisfied %
Location of education sessions	30	18	28	24
		26	**40**	**34**
Education sessions about MS for people with MS	27	17	29	27
		23	**40**	**37**
Education sessions about MS for carer/spouse/partner	41	20	22	16
		34	**37**	**27**
Education about MS aimed at teenagers with MS	85	5	5	5
		33	**33**	33
Education about MS for teenagers living with someone with MS	77	12	6	5
		36	**18**	15
Education about MS for young children with MS	85	6	4	5
		40	**27**	**33**
Education about MS for young children living with someone with MS	76	10	8	6
		42	**33**	**25**
Education sessions about various treatment	24	29	30	17
		38	**39**	**22**
Community awareness	18	32	39	11
		39	**48**	**13**
Education sessions about symptom management (e.g. nutrition, fatigue)	20	23	35	22
		29	**44**	27
Education sessions around financial management	47	29	16	8
		55	**30**	**15**
Online education sessions	41	27	20	12
		46	**34**	**20**

QLD

INFORMATION

The percentage level of satisfaction with various forms of information

*** Bold percentages only include the participants who required each form of information.**

Type	Not required %	Not satisfied %	Slightly satisfied %	Very satisfied %
Up-to-date information about current Ms research	8	11	35	46
What services the State-based MS organisations provide	12	15	32	40
What services you are eligible for from government or local council services	17	41	28	14
Information regarding what financial assistance you are eligible for	20	45	26	9
Understanding welfare and benefit entitlements	23	42	25	10
Centrelink benefits information	22	40	25	13
Information about superannuation	39	34	16	11

EDUCATION AND INFORMATION SUMMARY

The areas of information and education needs were similar for the QLD participants and the national findings. While only applicable to a small number of participants, of those participants who required education aimed at teenagers and young children living with MS or living with someone with MS felt that it was unavailable or only sometimes available. Finally, education sessions around financial management, symptom management were areas of unmet need. As per the national findings, participants in QLD highlighted a desire for more information about eligibility around financial assistance and services, understanding welfare and benefit entitlements, Centrelink benefits information and information about superannuation.

4.3.2.3.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	76	4	9	11
		15	**37**	**47**
I often can't attend, or miss appointments because of my lack of transport.	63	22	11	4
		60	**28**	**11**
I can't get to train, tram or bus stop due to limited mobility.	63	14	10	12
		38	**28**	**34**
I have a lack of confidence in using public transport.	51	17	13	19
		35	**26**	**39**

QLD

I have to limit my social activities because transport is too expensive.	59	18	14	9
		43	**36**	**21**
The reliability of public transport is poor.	57	11	16	15
		27	**38**	**35**
The reliability of taxis is poor.	58	16	16	9
		39	**38**	**23**
Taxi drivers don’t understand my needs.	65	16	13	6
		46	**38**	**16**
I feel socially isolated due to my lack of transport.	63	20	10	7
		53	**28**	**19**
I find taxis too expensive even after taxi vouchers.	66	9	12	13
		24	**37**	**39**
I find that public transport takes too long.	61	9	15	14
		23	**40**	**37**

TRANSPORT SUMMARY

There were no major differences the transport needs of the nation and the transport needs specific to participants residing in QLD.

4.3.2.3.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

	Disagree	Agree a little	Strongly agree	Don’t Know
It would be nice to go into respite with children/spouse/partner	26	29	26	18
Respite accommodation is not age appropriate	12	22	33	33
Respite accommodation is too expensive	10	36	26	28
Respite accommodation is too far away	18	26	23	33
The permitted length of stay is too short	21	18	13	47
The waiting lists for respite are too long	8	18	33	41
There is not enough respite available	8	15	44	33
There is not enough variety of respite	5	15	44	36
I am able to get to respite accommodation	18	20	25	37
I am able to get in home day respite	13	18	23	46
I am able to get out of home day respite	13	11	22	54
I am able to get in home overnight respite	28	10	7	55

QLD

RESPITE SUMMARY

The respite needs were generally congruent with those of the national respite needs. While only a very small portion of participants needed respite, of those participants 44% agreed that there was is not enough respite available and not enough variety of respite available.

4.3.2.3.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't know
Case Worker	53	11	10	15	11
		31	**28**	**41**	
Counsellor	55	13	8	12	12
		41	**23**	**36**	
Dietician	61	11	6	11	11
		41	**22**	**37**	
General Practitioner	8	5	22	63	2
		6	**25**	**69**	
Physical activity/exercise	24	17	24	29	7
		24	**34**	**42**	
Incontinence Nurse	57	8	10	16	10
		24	**29**	**47**	
Advice about MS treatments	12	16	28	38	6
		19	**34**	**47**	
Massage Therapist	45	18	11	13	13
		43	**26**	**30**	
Neurologist	11	14	20	52	3
		16	**24**	**60**	
Occupational Therapist	57	8	14	13	9
		23	**40**	**37**	
Physiotherapist	40	13	15	24	8
		25	**29**	**46**	
Psychologist	59	11	9	12	10
		34	**28**	**37**	
Psychiatrist	72	7	3	8	10
		39	**16**	**45**	
Specialised Nurse	62	7	5	16	10
		26	**19**	**56**	

QLD

Speech Pathologist	75	5	4	7	10
		31	**25**	**43**	
Accurate information about MS services	11	16	30	40	3
		10	**35**	**35**	
Information about MS Australia	12	9	29	46	4
		10	**35**	**55**	
Peer Support	30	14	19	29	8
		23	**31**	**46**	

SERVICES SUMMARY

The service needs most commonly reported as being unsatisfactory included counsellor services (41%), dietician (41%), massage therapist (43%), psychologist (34%), and psychiatrist (39%).

4.3.2.4 SOUTH AUSTRALIA & NORTHERN TERRITORY (SA&NT) (N = 237)

4.3.2.4.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	28	17	26	29
		24	**36**	**40**
Employer education	35	24	27	15
		37	**42**	**23**
Flexibility in the workplace	33	14	28	25
		21	**42**	**37**
Specialised employment services	43	17	22	18
		30	**38**	**32**
Education about symptom management	36	29	19	16
		45	**30**	**25**
Advice about workplace adaptations/equipment	41	22	21	16
		37	**36**	**27**
Access to transport to get to employment	46	25	17	13
		46	**31**	**24**
Information about superannuation	40	27	20	13
		45	**33**	**22**

EMPLOYMENT SUMMARY

A slightly larger percentage of SA participants felt that employment services were often available compared to the national sample, yet there was still a number of participants who required this service but felt it was unavailable or sometimes available. Participants indicated that advice about workplace adaptations/equipment, education about symptom management and information about superannuation were often seen as being unavailable.

SA & NT

4.3.2.4.2 PSYCHOSOCIAL SERVICES

PSYCHOLOGICAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	42	17	19	22
		28	**34**	**38**
Psychological assistance when you were first diagnosed	44	28	14	15
		50	**24**	**26**
Family counselling	64	22	7	7
		62	**18**	**20**
Relationship counselling	66	21	7	6
		61	**21**	**18**
Counselling for child/children	75	17	3	5
		63	**12**	**20**
Psychological support to assist with mental illness	74	10	7	9
		38	**27**	**35**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	66	20	14
		60	**40**
Meetings are too far away	43	34	23
		60	**40**
More variety with times (e.g. after work hours, weekends etc.)	54	29	17
		64	**36**
More variety in mode of communication (e.g. phone, email, Skype etc.)	47	30	23
		56	**44**

PSYCHOSOCIAL SUMMARY

The psychological needs of the participants in SA/NT were similar to the national findings. Many of the psychological services were seen as unavailable or only sometimes available by the participants that required such services highlighting an important area of need that warrants further investigation. The peer support findings were congruent with those of the national sample, with over half of the participants needing such services agreeing that there was a need for more variety to meet their particular needs, more variety with times, and more variety in mode of communication.

4.3.2.4.3 EDUCATION

The percentage level of satisfaction with various forms of education available to them.

Type	Not required%	Not satisfied%	Slightly satisfied%	Very satisfied%
Location of education sessions	37	19	22	22
		26	**35**	**35**
Education sessions about MS for people with MS	38	12	24	26
		19	**39**	**42**
Education sessions about MS for carer/spouse/partner	52	15	19	14
		31	**40**	**29**
Education about MS aimed at teenagers with MS	87	4	4	5
		31	**31**	**38**
Education about MS for teenagers living with someone with MS	82	7	5	6
		39	**28**	**33**
Education about MS for young children with MS	90	3	3	4
		30	**30**	**40**
Education about MS for young children living with someone with MS	80	9	5	6
		45	**25**	**30**
Education sessions about various treatment	37	22	26	15
		35	**41**	**24**
Community awareness	22	34	33	11
		39	38	**13**
Education sessions about symptom management (e.g. nutrition, fatigue)	31	20	27	22
		29	**39**	**32**
Education sessions around financial management	54	22	16	8
		48	**35**	**17**
Online education sessions	51	23	15	11
		47	**31**	**22**

INFORMATION

The percentage level of satisfaction with various forms of information

Type	Not required%	Not satisfied%	Slightly satisfied%	Very satisfied %
Up-to-date information about current Ms research	11	13	33	43
		15	37	**48**
What services the State-based MS organisations provide	12	13	35	40
		15	**40**	**45**
What services you are eligible for from government or local council services	22	39	27	12

		50	**35**	**15**
Information regarding what financial assistance you are eligible for	25	40	22	12
		53	**29**	**16**
Understanding welfare and benefit entitlements	30	35	23	12
		50	**33**	**17**
Centrelink benefits information	34	27	25	14
		41	**38**	**21**
Information about superannuation	50	27	11	12
		54	**22**	**24**

EDUCATION AND INFORMATION SUMMARY

The areas of information and education needs were similar for the SA/NT participants and the national findings. While only applicable to a small number of participants, of those participants that required education aimed at teenagers and young children living with MS or living with someone with MS felt that it was unavailable or only sometimes available. Finally, education sessions around financial management and symptom management were areas of unmet need. As per the national findings, participants in SA/NT highlighted a desire for more information about eligibility for financial assistance and services, understanding welfare and benefit entitlements, Centrelink benefits information and information about superannuation.

4.3.2.4.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	85	4	4	7
		26	**26**	**48**
I often can't attend, or miss appointments because of my lack of transport.	68	20	11	1
		64	**35**	**1**
I can't get to train, tram or bus stop due to limited mobility.	73	11	5	11
		41	**18**	**41**
I have a lack of confidence in using public transport.	63	15	9	13
		40	**25**	**35**
I have to limit my social activities because transport is too expensive.	69	20	6	6
		64	**18**	**18**

SA & NT

The reliability of public transport is poor.	65	9	15	10
		27	**44**	**29**
The reliability of taxis is poor.	67	15	12	6
		46	**36**	**18**
Taxi drivers don't understand my needs.	75	15	8	2
		62	**30**	**9**
I feel socially isolated due to my lack of transport.	68	16	9	7
		51	**28**	**21**
I find taxis too expensive even after taxi vouchers.	73	10	7	10
		37	**26**	**37**
I find that public transport takes too long.	68	7	13	11
		22	**43**	**35**

TRANSPORT SUMMARY

There were no major differences in the transport needs of participants from SA & NT compared to the national sample.

4.3.2.4.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

	Disagree	Agree a little	Strongly agree	Don't Know
It would be nice to go into respite with children/spouse/partner	35	4	39	22
Respite accommodation is not age appropriate	12	8	42	38
Respite accommodation is too expensive	13	13	17	57
Respite accommodation is too far away	29	21	13	37
The permitted length of stay is too short	38	8	8	46
The waiting lists for respite are too long	29	13	21	38
There is not enough respite available	17	13	37	33
There is not enough variety of respite	12	21	25	42
I am able to get to respite accommodation	21	13	29	37
I am able to get in home day respite	17	22	4	57
I am able to get out of home day respite	16	16	14	54
I am able to get in home overnight respite	25	13	8	54

RESPITE SUMMARY

The respite needs of participants in SA/NT were generally congruent with those of the national respite needs. While only a very small portion of participants needed respite, of those participants, 42% of participants in SA/NT felt that strongly agreed that respite it not are appropriate and 37% agreeing that there is not enough respite. There was is not enough respite available and not enough variety of respite available.

4.3.2.4.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't Know
Case Worker	67	8	6	9	10
		34	**28**	**38**	
Counsellor	69	9	6	8	10
		39	**25**	**36**	
Dietician	71	11	2	5	11
		60	**10**	**30**	
General Practitioner	10	4	21	62	3
		4	**24**	**72**	
Physical activity/exercise	33	14	16	29	8
		24	**27**	**49**	
Incontinence Nurse	63	7	7	14	9
		26	**24**	**50**	
Advice about MS treatments	15	16	27	37	5
		20	**33**	**46**	
Massage Therapist	56	11	6	14	12
		36	**20**	**44**	
Neurologist	8	11	21	59	1
		12	**23**	**65**	
Occupational Therapist	70	5	4	10	11
		28	**23**	**49**	
Physiotherapist	52	6	10	23	9
		15	**26**	**59**	
Psychologist	77	4	3	7	9
		29	**23**	**48**	
Psychiatrist	82	3	2	3	10
		44	**25**	**31**	
Specialised Nurse	63	4	4	21	8
		13	**14**	**73**	
Speech Pathologist	83	4	1	3	9
		47	**12**	**41**	
Accurate information about MS services	13	12	26	44	4
		16	**31**	**53**	
Information about MS Australia	14	12	26	44	4
		10	**28**	**62**	
Peer Support	45	11	13	21	10
		23	**30**	**47**	

SERVICES SUMMARY

The participants were least satisfied with dietician (60%), psychiatrist (44%), speech pathologist (47%) and counsellor (39%). While only a small number of participants required such services, it is apparent that such participants are commonly unsatisfied with access to the services.

4.3.2.5 TASMANIA (TAS) (n = 136)

4.3.2.5.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	35	18	20	27
		28	**31**	**42**
Employer education	43	35	5	17
		61	**9**	**30**
Flexibility in the workplace	34	18	24	24
		28	**36**	**36**
Specialised employment services	47	18	24	11
		34	**45**	**21**
education about symptom management	37	25	18	20
		40	**29**	**31**
Advice about workplace adaptations/equipment	43	25	10	22
		44	**18**	**38**
Access to transport to get to employment	55	23	7	15
		51	**16**	**33**
Information about superannuation	40	25	17	18
		42	**28**	**30**

EMPLOYMENT SUMMARY

Employer education was perceived by 61% of participants in TAS as unavailable compared to 41% of the national sample. Similar to the national sample, 51% of participants reported that access to transport to get to employment was unavailable, 44% felt that advice about workplace adaptations/equipment was unavailable and 40% of participants felt education about symptom management was unavailable. Information about superannuation was also seen as an unmet need which was congruent with the findings of the national sample.

TAS

4.3.2.5.2 PSYCHOSOCIAL SERVICES

PSYCHOLOGICAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	42	12	23	23
		20	**40**	**40**
Psychological assistance when you were first diagnosed	42	27	10	21
		47	**17**	**36**
Family counselling	50	26	7	17
		52	**14**	**34**
Relationship counselling	58	23	5	14
		55	**12**	**33**
Counselling for child/children	71	17	4	8
		58	**14**	**28**
Psychological support to assist with mental illness	69	14	6	10
		47	**20**	**33**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	62	24	15
		62	**38**
Meetings are too far away	41	23	35
		40	**60**
More variety with times (e.g. after work hours, weekends etc.)	45	23	27
		46	**64**
More variety in mode of communication (e.g. phone, email, Skype etc.)	45	27	28

PSYCHOSOCIAL SUMMARY

The psychological needs of the participants in TAS were similar to the national findings. Many of the psychological services were seen as unavailable or only sometimes available by the participants that required such services highlighting an important area of need that warrants further investigation. Unlike the national sample, of the participants who required peer support, over half disagreed the meetings were too far way and also disagreed that there was a need for more variety with times and mode of communication. However similar

TAS

to the national findings, over half of the participants expressed a need for more variety of peer support groups to meet their needs (e.g. younger, peer support).

4.3.2.5.3 EDUCATION AND INFORMATION

The percentage level of satisfaction with various forms of education available to them.

*** Bold percentages only include the participants who required each form of education.**

Type	Not required%	Not satisfied%	Slightly satisfied%	Very satisfied%
Location of education sessions	33	6	24	37
		9	**36**	**55**
Education sessions about MS for people with MS	33	7	18	42
		10	**27**	**63**
Education sessions about MS for carer/spouse/partner	49	6	17	28
		12	**33**	**55**
Education about MS aimed at teenagers with MS	83	5	6	6
		30	**35**	**35**
Education about MS for teenagers living with someone with MS	81	6	7	6
		32	**36**	**32**
Education about MS for young children with MS	86	3	6	5
		21	**43**	**36**
Education about MS for young children living with someone with MS	77	9	10	4
		39	**43**	**18**
Education sessions about various treatment	32	17	33	18
		25	**49**	**26**
Community awareness	22	29	35	14
		37	**45**	**18**
Education sessions about symptom management (e.g. nutrition, fatigue)	22	15	33	30
		19	**42**	**39**
Education sessions around financial management	48	21	25	6
		40	**48**	**12**
Online education sessions	61	16	14	9
		41	**36**	**23**

TAS

INFORMATION

The percentage level of satisfaction with various forms of information

*** Bold percentages only include the participants who required each form of information.**

Type	Not required%	Not satisfied%	Slightly satisfied%	Very satisfied%
Up-to-date information about current Ms research	12	14	28	46
		16	**32**	**52**
What services the State-based MS organisations provide	12	14	28	46
		16	**32**	**52**
What services you are eligible for from government or local council services	17	31	32	20
		37	**39**	**24**
Information regarding what financial assistance you are eligible for	23	39	24	14
		51	**31**	**18**
Understanding welfare and benefit entitlements	22	32	29	17
		41	**37**	**22**
Centrelink benefits information	24	29	30	18
		38	**39**	**24**
Information about superannuation	42	23	20	15
		40	**34**	**26**

EDUCATION AND INFORMATION SUMMARY

The location of education sessions, education sessions about MS for people with MS and education for carer/spouse, or partner were generally met for the TAS participants, with more participants very satisfied with such services compared to the national sample. However, similar to the national findings, there was a need for more education aimed at children and teenagers living with MS or living with someone with MS. Finally, education sessions around financial management, symptom management were areas of unmet need. As per the national findings, participants in TAS highlighted a desire for more information about eligibility for financial assistance and services, understanding welfare and benefit entitlements, Centrelink benefits information and information about superannuation.

TAS

4.3.2.5.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	87	2	6	4
		17	**50**	**33**
I often can't attend, or miss appointments because of my lack of transport.	69	23	6	2
		74	**19**	**6**
I can't get to train, tram or bus stop due to limited mobility.	74	11	6	9
		42	**23**	**35**
I have a lack of confidence in using public transport.	65	14	12	9
		40	**34**	**26**
I have to limit my social activities because transport is too expensive.	69	14	10	7
		45	**32**	**23**
The reliability of public transport is poor.	64	10	15	11
		28	**42**	**31**
The reliability of taxis is poor.	64	18	13	5
		50	**36**	**14**
Taxi drivers don’t understand my needs.	72	18	7	3
		64	**25**	**11**
I feel socially isolated due to my lack of transport.	65	22	9	4
		63	**26**	**11**
I find taxis too expensive even after taxi vouchers.	68	9	13	10
		28	**41**	**29**
I find that public transport takes too long.	67	10	13	10
		30	**40**	**30**

TRANSPORT SUMMARY

There were no major differences in the needs of the sample from Tasmania compared to the national sample

TAS

4.3.2.5.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

	Disagree	Agree a little	Strongly agree	Don't Know
It would be nice to go into respite with children/spouse/partner	25	25	42	8
Respite accommodation is not age appropriate	8	31	46	15
Respite accommodation is too expensive	0	39	46	15
Respite accommodation is too far away	23	15	23	39
The permitted length of stay is too short	22	0	39	39
The waiting lists for respite are too long	8	17	42	33
There is not enough respite available	8	8	50	33
There is not enough variety of respite	0	8	58	34
I am able to get to respite accommodation	27	18	27	27
I am able to get in home day respite	8	25	0	67
I am able to get out of home day respite	8	25	0	67
I am able to get in home overnight respite	17	8	17	58

RESPITE SUMMARY

Despite a small number of participants requiring respite, of the participants who did, over fifty percent felt that there is not enough variety of availability of respite, and just under half agreed that respite accommodation is not age appropriate, it is too expensive and the felt that they waiting lists were too long.

4.3.3.5.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't Know
Case Worker	48	6	11	32	4
		11	**23**	**66**	
Counsellor	58	9	8	19	6
		24	**22**	**53**	
Dietician	67	11	10	5	8
		42	**39**	**19**	
General Practitioner	4	8	17	65	5
		9	**19**	**72**	
Physical activity/exercise	31	14	22	23	11
		23	**38**	**39**	
Incontinence Nurse	52	2	12	29	5

		5	**27**	**68**	
Advice about MS treatments	18	9	33	35	6
		11	**43**	**46**	
Massage Therapist	54	7	11	20	8
		19	**29**	**52**	
Neurologist	7	17	16	54	6
		20	**19**	**62**	
Occupational Therapist	66	6	10	9	9
		27	**38**	**35**	
Physiotherapist	51	8	12	19	10
		20	**32**	**48**	
Psychologist	75	4	2	8	11
		28	**17**	**55**	
Psychiatrist	82	1	3	5	9
		9	**36**	**55**	
Specialised Nurse	65	2	3	22	7
		8	**12**	**80**	
Speech Pathologist	78	3	2	7	8
		25	**25**	**50**	
Accurate information about MS services	12	11	24	50	3
		12	**19**	**59**	
Information about MS Australia	14	9	20	54	3
		11	**25**	**65**	
Peer Support	39	9	19	27	6
		17	**34**	**49**	

SERVICE SUMMARY

More participants in the TAS group were very satisfied with psychologist, psychiatrist, massage therapist, specialised nurse compared to the national sample. Of the participants who required it, the services that participants were least satisfied with included dietician (42%) and occupational therapist (27%).

4.3.3.6 VICTORIA (VIC) (N = 716)

4.3.3.6.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

Bold percentages include only the participants who required each type of employment resource.
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	23	19	29	29
		24	**38**	**38**
Employer education	31	25	27	17
		36	**39**	**25**
Flexibility in the workplace	27	18	30	25
		25	**41**	**34**
Specialised employment services	41	25	20	14
		42	**34**	**24**
education about symptom management	32	23	29	16
		34	**43**	**23**
Advice about workplace adaptations/equipment	37	19	27	17
		30	**43**	**27**
Access to transport to get to employment	45	21	23	11
		38	**42**	**20**
Information about superannuation	31	26	28	15
		38	**40**	**22**

EMPLOYMENT SUMMARY

The employment need results from VIC participants were generally congruent with the responses from the national sample. The areas which participants felt were most unavailable included specialised employment services, information about superannuation, employer education and education about symptom management.

4.3.3.6.2 PSYCHOSOCIAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	36	17	24	23

VIC

		26		**26**
Psychological assistance when you were first diagnosed	33	35	15	17
		52	**22**	**26**
Family counselling	52	29	9	9
		62	**19**	**19**
Relationship counselling	54	28	8	9
		62	**18**	**19**
Counselling for child/children	70	19	5	6
		63	**17**	**19**
Psychological support to assist with mental illness	63	16	11	9
		44	**30**	**26**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	55	32	13
		71	**29**
Meetings are too far away	36	38	25
		60	**40**
More variety with times (e.g. after work hours, weekends etc.)	44	39	17
		69	**31**
More variety in mode of communication (e.g. phone, email, Skype etc.)	42	36	22
		62	**38**

PSYCHOSOCIAL SUMMARY

The responses from Victoria participants were generally congruent with those of the national responses regarding psychological services. Over 50% of the participants requiring these services felt that psychological services to assist when first diagnosed, family counselling, relationship counselling, and counselling for children were either unavailable or only sometimes available. The peer support findings were consistent with the national findings the national findings, in that participants appear to want more variety of peer support meetings to meet their needs, and a larger variety of locations, times and modes of communication for peer support groups.

VIC

4.3.3.6.3 EDUCATION AND INFORMATION

The percentage level of satisfaction with various forms of education available to them.

*** Bold percentages only include the participants who required each form of information.**

Type	Not required%	Not satisfied%	Slightly satisfied%	Very satisfied%
Location of education sessions	29	22	25	24
		31	**35**	**34**
Education sessions about MS for people with MS	29	13	24	35
		18	**34**	**49**
Education sessions about MS for carer/spouse/partner	46	12	21	21
		22	**39**	**39**
Education about MS aimed at teenagers with MS	81	7	7	5
		37	**37**	**26**
Education about MS for teenagers living with someone with MS	78	9	7	6
		41	**32**	**27**
Education about MS for young children with MS	82	7	6	5
		39	**34**	**27**
Education about MS for young children living with someone with MS	74	10	8	8
		38	**31**	**31**
Education sessions about various treatment	27	21	30	22
		27	**41**	**30**
Community awareness	23	18	29	29
		24	**38**	**38**
Education sessions about symptom management (e.g. nutrition, fatigue)	23	18	30	29
		23	**39**	**38**
Education sessions around financial management	41	23	24	12
		39	**41**	**20**
Online education sessions	42	19	24	15
		33	**41**	**26**

INFORMATION

The percentage level of satisfaction with various forms of information.

*** Bold percentages only include the participants who required each form of education.**

Type	Not required %	Not satisfied %	Slightly satisfied %	Very satisfied %
Up-to-date information about current Ms research	9	13	32	46
		14	**35**	**51**
What services the State-based MS organisations provide	11	16	34	39
		18	**38**	**44**
What services you are eligible for from government or local council services	16	40	28	16

VIC

		48	**33**	**19**
Information regarding what financial assistance you are eligible for	20	45	21	14
		57	**26**	**17**
Understanding welfare and benefit entitlements	21	42	23	14
		53	**29**	**18**
Centrelink benefits information	25	40	21	14
		53	**28**	**19**
Information about superannuation	36	34	19	11
		53	**30**	**17**

EDUCATION AND INFORMATION SUMMARY

Similar to the national findings, there was a need for more education aimed at children and teenagers living with MS or living with someone with MS. There were slightly less participants dissatisfied with community awareness in VIC (24%) compared to the national finding (36%). Finally, education sessions around financial management, symptom management were areas of unmet need. As per the national findings, participants in TAS highlighted a desire for more information about eligibility for financial assistance and services, understanding welfare and benefit entitlements, Centrelink benefits information and information about superannuation.

4.3.3.6.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	83	4	7	6
		23	**41**	**36**
I often can't attend, or miss appointments because of my lack of transport.	67	21	9	2
		64	**27**	**6**
I can't get to train, tram or bus stop due to limited mobility.	65	15	10	10
		43	**29**	**28**
I have a lack of confidence in using public transport.	50	17	16	17
		34	**32**	**34**
I have to limit my social activities because transport is too expensive.	60	22	11	7
		55	**28**	**17**
The reliability of public transport is poor.	55	14	22	10
		31	**49**	**22**
The reliability of taxis is poor.	60	17	18	6

VIC

		42	**45**	**15**
Taxi drivers don’t understand my needs.	69	18	10	3
		58	**32**	**10**
I feel socially isolated due to my lack of transport.	64	22	9	5
		61	**25**	**14**
I find taxis too expensive even after taxi vouchers.	68	10	9	13
		31	**28**	**41**
I find that public transport takes too long.	57	10	20	13
		23	**47**	**30**

TRANSPORT SUMMARY

The participants often (41%) or sometimes (28%) felt that taxis were too expensive even after taxi vouchers. A small number of participants found it relevant, but of those participants 41% and 36% felt that wheelchair access on public transport is poor sometimes and often, respectively. Public transport was found to take too long for some participants and other participants lacked confidence in public transport.

4.3.3.6.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

	Disagree	Agree a little	Strongly agree	Don’t Know
It would be nice to go into respite with children/spouse/partner	20	27	35	18
Respite accommodation is not age appropriate	13	17	28	42
Respite accommodation is too expensive	10	20	23	47
Respite accommodation is too far away	18	18	22	42
The permitted length of stay is too short	12	17	11	61
The waiting lists for respite are too long	5.2	8	27	60
There is not enough respite available	3	7	41	49
There is not enough variety of respite	4	14	29	53
I am able to get to respite accommodation	9	23	28	40
I am able to get in home day respite	15	21	3	61
I am able to get out of home day respite	14	16	3	68
I am able to get in home overnight respite	18	12	3	68

RESPITE SUMMARY

Of the small number of participants who required respite it was found that a large portion agreed that there is not enough respite available and the waiting lists for respite are too long, and it would be nice to go to respite with a spouse/partner/child. This is generally congruent with the national findings on respite.

4.3.3.6.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't Know
Case Worker	61	10	6	12	11
		34	**24**	**42**	
Counsellor	58	10	8	11	13
		36	**28**	**36**	
Dietician	65	11	7	6	11
		45	**30**	**25**	
General Practitioner	11	5	19	62	2
		6	**22**	**72**	
Physical activity/exercise	26	15	23	29	7
		22	**34**	**49**	
Incontinence Nurse	61	6	9	14	10
		23	**30**	**47**	
Advice about MS treatments	13	15	28	39	5
		18	**35**	**47**	
Massage Therapist	48	14	9	17	12
		35	**22**	**43**	
Neurologist	8	6	19	64	3
		25	**21**	**72**	
Occupational Therapist	57	6	10	18	9
		17	**29**	**54**	
Physiotherapist	46	7	11	26	9
		64	**26**	**58**	
Psychologist	63	7	7	11	11
		28	**28**	**44**	
Psychiatrist	76	6	3	4	10
		44	**24**	**32**	
Specialised Nurse	62	6	7	17	8
		18	**25**	**57**	
Speech Pathologist	80	4	3	4	9
		35	**26**	**39**	
Accurate information about MS services	10	14	32	39	5
		17	**37**	**45**	
Information about MS Australia	10	8	27	50	5
		10	**31**	**58**	
Peer Support	39	9	15	27	10
		18	**29**	**53**	

SERVICES SUMMARY

Of the participants who required it, the services that participants were least satisfied with included dietician (45%), psychiatrist (44%), counsellor (36%) and speech pathologist (35%).

4.3.3.7 WESTERN AUSTRALIA (WA) (N = 292)

4.3.3.7.1 EMPLOYMENT

The percentage of responses regarding the availability of information and resources pertaining to employment.

***Bold percentages include only the participants who required each type of employment resource.**
***** Note: table includes only participants employed or seeking employment at the time of the questionnaire.

Topic	Not required	Unavailable	Sometimes available	Often available
Your right as an employee	29	16	31	24
		22	**44**	**34**
Employer education	37	28	25	10
		44	**40**	**16**
Flexibility in the workplace	37	16	29	18
		25	**46**	**29**
Specialised employment services	50	27	14	9
		54	**28**	**18**
education about symptom management	50	23	18	9
		46	**36**	**18**
Advice about workplace adaptations/equipment	38	31	19	12
		50	**31**	**19**
Access to transport to get to employment	59	21	13	7
		51	**32**	**17**
Information about superannuation	37	29	24	10
		46	**38**	**16**

EMPLOYMENT SUMMARY

Fifty four percent of the participants in WA who needed it, felt that specialised employment services were unmet. Over half the participants also felt that access to transport and advice about workplace adaptations and equipment was unavailable. Similar to the national findings, participants in WA also felt that employer education and information about superannuation were generally unmet.

WA

4.3.3.7.2 PSYCHOSOCIAL SERVICES

The percentage level of satisfaction with access to psychological services.

Bold percentages include only the participants who required the service.

	Not required	Unavailable	Only sometimes available	Easily available
Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	44	9	14	32
		17	**25**	**58**
Psychological assistance when you were first diagnosed	42	23	11	34
		39	**20**	**41**
Family counselling	64	16	10	11
		62	**27**	**41**
Relationship counselling	66	15	10	9
		46	**28**	**26**
Counselling for child/children	81	10	7	3
		49	**34**	**17**
Psychological support to assist with mental illness	78	9	7	6
		43	**30**	**28**

PEER SUPPORT

The percentage of participant agreement and disagreement to various peer support statements.

Bold percentages include only the participants who required the service.

	Not required	Agree	Disagree
More variety to meet your particular needs (e.g. younger peer support)	64	23	13
		62	**38**
Meetings are too far away	42	36	22
		62	**38**
More variety with times (e.g. after work hours, weekends etc.)	42	36	22
		71	**29**
More variety in mode of communication (e.g. phone, email, Skype etc.)	46	29	25
		53	**47**

PSYCHOSOCIAL SUMMARY

A high percentage of participants in WA expressed a high level of satisfaction with the availability of a wide range of counselling services for themselves and when they were first diagnosed. These figures are higher than the national sample in which counselling for the self was perceived to be easily available by only 38% of the people who required it and 29%

psychological assistance when first diagnosed. The other areas of need were similar to the national findings and included a greater need for family counselling, counselling for children and relationship counselling. There appeared to be a need for more variety of times with peer support meetings (71%), locations and variety to meet various needs among people requiring peer support. These findings were similar to the national findings.

4.3.3.7.3 EDUCATION AND INFORMATION

The percentage level of satisfaction with various forms of education available to them.

*** Bold percentages only include the participants who required each form of education.**

Type	Not required	Not satisfied	Slightly satisfied	Very satisfied
Location of education sessions	37	14	22	28
		22	**34**	**44**
Education sessions about MS for people with MS	36	8	19	37
		12	**30**	**58**
Education sessions about MS for carer/spouse/partner	53	8	14	25
		17	**30**	**53**
Education about MS aimed at teenagers with MS	88	3	5	4
		25	**42**	**33**
Education about MS for teenagers living with someone with MS	80	7	8	5
		35	**40**	**25**
Education about MS for young children with MS	88	4	3	4
		36	**28**	**36**
Education about MS for young children living with someone with MS	82	7	5	6
		39	**28**	**33**
Education sessions about various treatment	33	18	25	24
		27	**37**	**36**
Community awareness	27	20	33	20
		27	**46**	**27**
Education sessions about symptom management (e.g. nutrition, fatigue)	30	16	25	30
		23	**36**	**43**
Education sessions around financial management	56	18	16	10
		41	**36**	**23**
Online education sessions	47	12	23	19
		23	**43**	**36**

WA

INFORMATION

The percentage level of satisfaction with various forms of information.

*** Bold percentages only include the participants who required each form of information.**

Type	Not required	Not satisfied	Slightly satisfied	Very satisfied
Up-to-date information about current MS research	12	10	25	53
		11	**28**	**61**
What services the State-based MS organisations provide	15	7	25	53
		8	**29**	**63**
What services you are eligible for from government or local council services	27	34	23	17
		47	**32**	**23**
Information regarding what financial assistance you are eligible for	32	37	21	10
		54	**31**	**15**
Understanding welfare and benefit entitlements	35	35	20	10
		54	**31**	**15**
Centrelink benefits information	37	33	22	8
		52	**35**	**13**
Information about superannuation	37	33	21	9
		52	**33**	**15**

EDUCATION AND INFORMATION SUMMARY

The participants were generally satisfied with the location of education sessions, education sessions about MS for people with MS and education sessions about MS for carer/spouse/partner. Similar to the national findings, participants requiring education sessions about symptom management and financial management were mostly not satisfied or only slightly satisfied. However, participants in WA generally reported a greater level of satisfaction with education sessions about symptom management (43%) compared to the national sample (21%). Similar to the national findings, participants in WA were not satisfied with information regarding understanding welfare and benefits, Centrelink benefits, superannuation, and eligibility for services and financial assistance.

WA

4.3.3.7.4 TRANSPORT

The percentage agreement with various transport statements.

Bold percentages include only participants for whom the statement was applicable.

	NA	Not at all	Sometimes	Often
Wheelchair access on public transport is poor.	87	4	3	6
		33	**23**	**44**
I often can't attend, or miss appointments because of my lack of transport.	77	14	8	1
		61	**32**	**7**
I can't get to train, tram or bus stop due to limited mobility.	77	11	5	7
		49	**22**	**29**
I have a lack of confidence in using public transport.	67	13	9	11
		39	**29**	**32**
I have to limit my social activities because transport is too expensive.	73	15	8	4
		55	**29**	**16**
The reliability of public transport is poor.	72	11	12	5
		38	**44**	**18**
The reliability of taxis is poor.	71	10	14	5
		32	**49**	**19**
Taxi drivers don’t understand my needs.	82	10	6	2
		54	**36**	**10**
I feel socially isolated due to my lack of transport.	74	15	8	3
		55	**31**	**14**
I find taxis too expensive even after taxi vouchers.	76	8	9	7
		32	**37**	**31**
I find that public transport takes too long.	70	6	11	13
		19	**37**	**44**

TRANSPORT SUMMARY

The cost of taxis was relevant to a small number of participants, however of those participants over 50% felt that taxis were too expensive even after taxi vouchers. Similar to the national findings, a number of WA participants (44%) felt that wheelchair access on public transport is poor.

WA

4.3.3.7.5 RESPITE

The percentage of agreement with various respite statements, for participants who require respite.

Statements	Disagree	Agree a little	Strongly agree	Don't Know
It would be nice to go into respite with children/spouse/partner	19	19	33	29
Respite accommodation is not age appropriate	35	15	15	35
Respite accommodation is too expensive	19	14	14	52
Respite accommodation is too far away	29	19	14	38
The permitted length of stay is too short	29	14	0	57
The waiting lists for respite are too long	9	15	19	57
There is not enough respite available	5	14	29	52
There is not enough variety of respite	10	14	24	52
I am able to get to respite accommodation	18	36	18	27
I am able to get in home day respite	20	0	65	3
I am able to get out of home day respite	22	5	14	59
I am able to get in home overnight respite	35	0	0	65

RESPITE SUMMARY

Many of the participants stated that they did not know about the availability and access to various types of respite suggesting that there may be a lack of understanding of respite, or that respite is generally more of a need of a carer.

4.3.3.7.6 SERVICES

The percentage level of satisfaction with the quality and access to different services.

Bold percentages include only the participants who required the service.

Services	Not Required	Not Satisfied	Slightly Satisfied	Very Satisfied	Don't Know
Case Worker	66	7	5	7	15
		26	**17**	**57**	
Counsellor	56	5	5	24	10
		14	**16**	**70**	
Dietician	66	7	5	7	15
		37	**26**	**37**	
General Practitioner	13	4	19	61	4
		4	**22**	**73**	
Physical activity/exercise	39	5	18	28	10
		10	**35**	**55**	
Incontinence Nurse	58	5	7	7	13

WA

		17	**24**	**59**	
Advice about MS treatments	11	13	30	40	6
		15	**36**	**49**	
Massage Therapist	46	9	11	24	19
		20	**26**	**54**	
Neurologist	8	4	19	64	5
		5	**21**	**74**	
Occupational Therapist	56	6	8	17	12
		18	**26**	**55**	
Physiotherapist	48	5	12	24	11
		13	**29**	58	
Psychologist	75	4	3	**7**	11
		29	**21**	**50**	
Psychiatrist	77	4	3	4	12
		30	**26**	**41**	
Specialised Nurse	60	3	8	23	6
		7	**20**	**73**	
Speech Pathologist	83	2	<1	4	11
		24	**4**	**72**	
Accurate information about MS services	11	9	28	46	6
		11	**34**	**56**	
Information about MS Australia	12	7	28	48	6
		8	**34**	**58**	
Peer Support	34	7	12	36	11
		14	**22**	**64**	

SERVICE SUMMARY

A larger portion of the participants requiring counselling were very satisfied with the access and quality of the service (70%) compared to the national sample (41%). Unlike the national sample nearly three quarters of the participants requiring a speech pathologist were very satisfied with this service. Participants were least satisfied with access to and quality of a dietician which was an important unmet need among the national sample.

5. OVERALL DISCUSSION

The aim of the project was to determine the needs of the MS population, investigate the types of services currently available to people with MS, and assess the relative usefulness of such services. A large number of people with MS from all states and territories, and from metropolitan, regional, rural and remote areas across Australia were approached to take part in the study through the Australian MS Longitudinal Study. The participants included both females and males and a broad spectrum of age groups. Following the results from study one and other national and international studies investigating the needs of people with MS, the study examined six key areas of needs. They included employment needs, psychosocial needs (psychological and peer support), education and information needs, and environmental needs (equipment, transport, assistance).

5.1 EMPLOYMENT SUMMARY

A number of key employment resources were identified as unavailable or only sometimes available by a large number of the participants. These included specialised employment services, education around symptom management in the workplace, information about superannuation, and to a lesser degree, transport to get to and from work.

There is a need for specialised employment services to assist people with MS seeking employment and/or changing career paths. Vocational support to assist individuals in retaining their employment, or seeking alternate employment, up-skilling or transitioning are important needs that are consistently identified as needs of people with MS (Kersten 2000; McCabe et al., 2008a; Tribe, 2006). Similar results have been found in previous investigations of the needs of people with MS. In a sample of people living with MS in New South Wales, Australia, employment support was found to be unmet need among people with MS (Tribe et al., 2006).

There is a need for education around symptom management in the workplace with a large portion of the participants indicated that it was unavailable or only sometimes available. This is similar to findings of another Australian study which found that people with MS expressed a consistent desire for more access to reliable information sources regarding symptom management (Matti et al. 2010). A smaller number of participants reported a need for transport to employment. In an Australian study of people living with MS investigating reasons by which employment had been lost or was perceived to be at risk of being lost was ineffective management of symptoms in the workplace, while a lack of transport was not seen as a major contributor (Simmons, Tribe, & McDonald, 2010). The preservation of employment is important for people living with MS both financially and for the upkeep of self-regard and social confidence (Johnson et al., 2010; Simmons et al., 2010). As such, it is evident that there needs to be more of a focus on symptom management in the workplace to allow people with MS to remain in the workplace for as long as possible. Finally, a large percentage of the participants reported that information about superannuation was either unavailable or only sometimes available, suggesting that such information needs to be more readily available.

5.2 PSYCHOSOCIAL NEEDS

Approximately three quarters of the participants had experienced depression (feeling sad, helpless, worthless) and just under three quarters of the participants had experienced anxiety (anxiety about the future, racing thoughts, heart palpitations) in relationship to their MS. Irrespective of the disease course people with MS have been shown to be at an elevated risk for severe depression than the general population (Holland et al., 2011; Minder, Orav, & Reich, 1987). Overall there appeared to be a large unmet need for more psychological services for the client and their significant others (e.g. family, children). About two thirds of the participants indicated that they required counselling services, but many of the participants indicated that such service was either not available or only sometimes available. Psychological support/counselling needs have been found to be unmet across nations. In a study in Sweden, Ytterberg et al. (2008) found that participants were least satisfied with the availability of psychosocial support/counselling, while in an Australian study the needs associated with physical disabilities were more often met than the emotional needs of people living with MS (Black et al. 1994). Family counselling was required by just under half of the participants in this report. Of those participants, close to 60% felt that it was not available. Family members are likely to be affected by the presence of parental multiple sclerosis, hence support for the whole family is recommended (Pakenham & Bursnall, 2006). A small number of people required counselling for children. Studies have found that children living with a parent with MS can find it stressful and a source of anxiety (Mutch, 2005). It is evident that there are a number of psychological needs that are not being met and as such this is an area that requires further investigation.

The findings of the present study suggest that there is a need for more variety of peer support to meet different needs. In addition, peer support was often seen as being too far away, and required more variety with times and mode of communication. It is important that peer support is readily available to people who seek it as support from others has been shown to be an important need of people living with MS.

5.3 INFORMATION AND EDUCATION NEEDS

The participants were generally satisfied with the information about current MS research and information regarding the services the state-based MS organisations provide.

However, there appears to be a strong unmet need for information pertaining to financial assistance, understanding welfare and benefits, Centrelink benefits and information about superannuation. These findings are consistent with those of Black et al. (1994) who found that financial support in terms of pension was important. Education for teenagers and young children both with MS or living with someone with MS was deemed to either be not available for a majority of the participants who required it, suggesting a need for additional education sessions aimed at this population. Attending these sessions may also be an important source of support for young children living with a parent with MS because of the isolation and lack of formal support they often report (Pakenham & Bursnall, 2006). Pakenham and Bursnall (2006) suggested interventions for young carers should target social support. Interestingly, in the current study, although the level of unmet need for those who required information for teenagers was high, many of the participants indicated that there was no need for education for their teenage children. This finding is at variance with findings from previous studies. Community awareness was another important unmet need. These findings are consistent with previous studies where increased public awareness about neurological diseases in general and community education have been shown to be important unmet needs (Yetterberg, 2008).

5.4 ENVIRONMENTAL NEEDS

Participants frequently identified heating and cooling as an important unmet need. Just under half of the participants stated that they did not have it because they couldn’t afford it. In general, where participants did not have, but currently needed, equipment, it was often due to an inability to afford such devices. A small number of participants required more assistance with outdoor maintenance, domestic duties and shopping. While it was only applicable to a small number of participants, of those participants, three quarters indicated that wheelchair access on public transport is not available. There were no major differences between the states in equipment needs. Issues surrounding access to public transport, a lack of confidence in public transport and public transport taking too long was a frequently identified problem.

5.5 NEWLY DIAGNOSED

The newly diagnosed participants most commonly reported needing a neurologist, followed by education and information, including accurate information about MS services, information about MS Australia and advice about treatment options. The next most highlighted service/resource needs were psychosocial. These included counselling services and peer support. Given these findings, subsequent analyses of education, information, psychological, and peer support were conducted in order to gain a better understanding of each of these needs. In this analysis, approximately three quarters of newly diagnosed participants had experienced feelings of anxiety and depression in relation to their MS. Other studies have shown that the early days and weeks after diagnosis have been shown to lead them into a state of disbelief and devastation. The feelings were felt by both the person with MS and their family members as the diagnosis involved changes in roles, loss of financial security and loss of dreams and increased stress placed on the family unit (Jassens et al., 2003). Counselling for the client and psychological assistance when first diagnosed were required by approximately three quarters of the participants, yet less than half of those participants felt that it was readily available. Given the known psychological impact of MS on patients, this is an area that requires further investigation.

A large portion of newly diagnosed patients required up-to-date information about current MS research and information regarding the various services the state-based MS organisations provide. This is consistent with previous studies which have generally found that newly diagnosed patients in the early stages of the disease onset have been identified to have a high need for information (Forbes, 2000). Overall these needs were generally met. Education around symptom management was also required by a number of newly diagnosed participants. Information regarding symptom alleviation and management, and treatment have been identified as important informational needs of people newly diagnosed with MS (Black, 1994; Forbes, 2000). However, less than one third of the participants were very satisfied with the availability of these education sessions.

5.6 REGIONS

Overall, the further the participants lived from the city, the less satisfied they were with the availability of informational resources, education sessions, psychological services, the location of peer support groups, access to transport and services. Other studies have found similar results. In a study of needs identified by people with MS, rural and isolated communities reported the most difficulty with services and they had to move to obtain the support and services they needed (Wollin, Yates, & Kristjanson, 2006).

5.7 STRENGTHS

The present study had a number of strengths. The study was the largest study to examine the needs of Australians with MS. The study provided a good representation of people ranging in symptom severity, age, sex, regions (metropolitan, regional, rural, and remote) and states/territories. The demographic distribution and characteristics of the Australian MS Longitudinal Study cohort of people with MS has been validated against other Australian MS cohorts and the MS society clients have been shown to be highly representative (Palmer, 2011). Unlike many previous studies, the current study looked at a vast range of needs, rather than focusing on one area of need in the absence of other possibly more important areas of needs. The findings provide a strong base for the ongoing surveillance of the needs of Australians with MS, and provide baseline data on which future national service strategies can be built.

5.8 WEAKNESSES

There were a number of weaknesses of the present study. Firstly the study provided only a snap shot of needs of people with MS at one point in time. The needs of people with MS are not homogenous, and rather vary considerably from individual to individual and are not static over time. As such, a more effective measure would have been a longitudinal study of the needs of people with MS. The female participants greatly outnumbered the male participants. However, this imbalance is reflective of the gender ratio of people with MS in the general population and analyses of gender differences did not find any major differences between the two groups.

5.9 SUMMARY

The present study provided a good insight into the needs of Australian people with MS as a whole and also by symptom group, age, region and state/territory. There were a number of key unmet needs. These needs included employment services, symptom management in the workplace, psychological support for children and family counselling, a variety of peer support group types and modes of peer support communication. Information pertaining to eligibility for financial services, Centrelink benefits, understanding welfare and benefits and information about superannuation were strong unmet needs. Education aimed at children and teenagers with MS or living with someone with MS was also an unmet need, although it was required by a smaller number of participants. Community awareness of MS was also seen as an unmet need. For a smaller number of participants, equipment needs were not being met, often due to participants’ inability to afford such equipment.

6. RECOMMENDATIONS

6.1 INFORMATION AND EDUCATION NEEDS

a) There is a need for more information and education around the following areas: understanding welfare and entitlements, Centrelink benefits information, information regarding the financial assistance people are eligible for, and information about superannuation. A one-stop-shop brochure or document outlining all of this information is recommended.

b) There is a need for more education sessions aimed at children and teenagers living with someone with MS. While this need was applicable to a small number of participants, of those participants who required the sessions, a large portion felt that the education was unavailable. It is recommended that more age appropriate information and education sessions need to be developed in order to cater for children and teenagers living with someone with MS.

c) Community awareness of MS was often seen as being unsatisfactory or only slightly satisfactory. It is recommended that strategies are developed to increase awareness and to better educate the community about MS.

6.2 PSYCHOSOCIAL NEEDS

a) There is a need for better access to a range of psychological services. It is recommended that psychosocial services are more easily accessible. This may include increased access hours to psychologists at each of the state MS office locations or discounted prices for people seeking assistance outside of their respective state MS office.

b) While relevant to a small number of participants, family counselling and counselling for children were often found to be an unmet need. It is recommended that such services are more easily accessible to the participants requiring them.

c) There is a need for a broader variety of peer support groups to meet the needs of people with MS (e.g., stage of illness and age appropriate groups). There is also a need for more locations of peer support, a wider variety of peer support meeting times, and an increase in the mode of communication for peer support (e.g., face-to-face, video link, email, etc.). It is recommended that peer support is further investigated by each state to determine the locations, times, and modes of peer support meetings needed by people with MS.

6.3 EMPLOYMENT AND FINANCIAL NEEDS

a) Education around symptom management in the workplace and advice about workplace adaptations/equipment is needed. It is recommended that additional education and information sessions and brochures regarding these matters are made available to both people with MS and employers.

6.4 ENVIRONMENTAL NEEDS (EQUIPMENT AND TRANSPORT)

a) It is recommended that people with MS receive greater financial assistance to allow them access to equipment and/or modifications that they currently need, but cannot afford. This includes the following types of equipment/modifications: Mobility aids, computer related aids, home modifications, heating and cooling, and car modifications.

b) Larger pieces of equipment appear to be too expensive for participants.

The participants most commonly reported requiring assistance at least sometimes with domestic duties and outdoor maintenance, and of those participants, approximately half needed more help with such tasks. This was especially a concern among the more severely disabled clients. It is recommended that such assistance is more readily available at a more affordable price for people requiring such help.

6.5 RESPITE

a) There appears to be a greater need for education and information around respite. This was reflected in the participant responses, where a large number of participants stated that they did not know about the availability of different kinds of respite.

b) A small number of participants required respite. However, of those participants a general trend was a need for a greater availability of respite.

c) Further investigation of the respite needs of carers of people with MS is recommended.

6.6 SERVICE NEEDS

a) Of the participants who required the service, participants were not satisfied with the quality of and access to a Dietician, Massage Therapist, Psychiatrist, and Speech Pathologist. Notably, the service satisfaction differed somewhat from state to state reflecting the priorities placed by the different states on their service provision. The availability of each of these services should be examined at each state.

b) Consistent across the nation and states, a high percentage of participants who required a dietician were unsatisfied with access to this service. It is recommended that access is improved through either discounted sessions to a dietician, or more resources and information around health and diet in general.

6.7 REGIONS

a) The level of satisfaction with the availability and quality of services reduced as the participant lived further from metropolitan regions, such that participants in the remote areas were least satisfied with the services, followed by rural, remote and metro. There is a greater service need for participants residing in rural and remote areas. It is recommended that strategies are developed to address this issue and aim to improve the services available to people living in these areas.

6.8 NEWLY DIAGNOSED

a) The key services identified by participants for newly diagnosed individuals include a neurologist, followed by education and information including accurate information about MS services, information about MS Australia and advice about treatment options. The next most highlighted service/resource needs were psychosocial needs, including counselling services and peer support. Over three-quarters of the newly diagnosed participants reported having feelings of depression and anxiety in relation to their MS. Given the high degree of feelings of depression and anxiety in this subgroup, it is recommended that psychosocial services are made more readily available to those newly diagnosed with MS.

6.9 SEVERITY OF SYMPTOMS

a) The needs of people with MS depended greatly on the degree of symptom severity. The most severely affected individuals appear to have a greater number of unmet environmental needs, including access and affordability of equipment, transportation and assistance with a range of tasks. It is recommended that individuals with severe symptoms have an increased level of financial support to assist them with meeting their unmet needs, or an increase in access to services assisting them with these areas of need.

b) Transportation appears to be more of a concern for individuals experiencing more severe symptoms. It is important that transport needs are addressed, or people with more severe symptoms and mobility issues may become socially isolated. For example, picking the participants up from their houses to attend meetings, appointments or social activities, or access to cheaper taxis may be some options to address these transport needs.

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8. APPENDICES

APPENDIX A

INTERVIEW QUESTIONS FOR CLIENTS/CARERS

Needs

1. It is important to understand the needs people have, to help them manage the changes and challenges of Multiple Sclerosis. Could you please talk about the types of needs you have? For example, support needs, physical needs and financial planning needs.

Unmet needs

2. Are there any needs that you might have now or in the future that you think could be better addressed or managed (e.g., transportation, housing)?

Services

3. Could you please identify the most valuable assistance/services?

4. Please identify any service or assistance that you require now or in the future that is currently not available to you?

5. Why do you think it is not available (e.g. distance, cost, not available).

6. What would prevent you from continuing to live independently at home?

7. Do you have enough access to respite care/short breaks from home?

Information

8. Where do you access your information regarding your disease, prognosis and the services available to you?

9. Do you feel that there is enough access to information?

Psychosocial

10. Do you feel that there is enough social support for you and your family (support groups, meeting others with MS/family, counselling)?

Employment

11. What types of things will/have prevented you from working?

12. Is there enough vocational support?

Environmental

13. Do you have appropriate equipment for you to function with?

14. Do you have transport services to assist you with attending appointments, shopping, getting around, and away from home?

Other

15. Are there any other areas in terms of your needs we have not covered that you would like to discuss?

APPENDIX B

INTERVIEW QUESTIONS FOR STAFF

Needs

1. It is important to understand the needs people have, to help them manage the changes and challenges of Multiple Sclerosis. Could you please talk about the types of needs people with MS have? For example, support needs, physical needs and financial planning needs.

2. How about their family members/carers

Unmet Needs

3. Are there any needs that you believe that people with MS generally have that you think could be better addressed or managed (e.g., transportation, housing)?

Services

4. Could you please identify the most valuable assistance/services for people with MS? How about their family/carers

5. Please identify any service or assistance that people with MS or their carers/family require now or in the future that is currently not available to people with MS?

6. Why do you think it is not available (e.g. distance, cost, not available).

7. In your opinion, what would prevent someone with MS from continuing to live independently at home?

8. Do you think that people with MS have enough access to respite care/short breaks from home?

Information

9. Where, in your opinion do most people with MS and or their family members/carers access information regarding the disease, prognosis and the services available to them?

10. Do you feel that there is enough access to information?

Psychosocial

11. Do you feel that there is enough social support for people with MS and their family (support groups, meeting others with MS/family, counselling)?

Employment

12. What types of things generally prevented people with MS from working?

13. Is there enough vocational support?

Environmental

14. Do you feel that people with MS have enough appropriate equipment to function with? i.e. walker, wheelchair

15. Do you feel that people with MS have enough access to transport services to assist them with attending appointments, shopping, getting around, and away from home?

Other

16. Are there any other areas in terms of needs or services we have not covered that you would like to discuss?

APPENDIX C

CHECKLIST FOR NEEDS					
	HOW IMPORTANT				
ACTIVITIES	**RANK**	**(1-10)**	**MET**	**SOMEWHAT MET (A,B,C,D,E,F,G)**	**NOT MET (A,B,C,D,E,F,G)**
Access to, and attending recreation activities					
Administering medications					
Assistance looking after children when unwell					
Bladder/bowel control					
Childcare					
Communication (i.e. writing letters, checking bills).					
Community understanding/education					
Cooking (preparing meals)					
Coping with feelings or emotions					
Education for family/carer					
Equipment (e.g. mobility aids)					
Fatigue management					
Family counselling					
Financial planning					
Finding/adjusting to employment					
Home modifications					
Homecare					
Housekeeping (i.e. cleaning, laundry, vacuuming etc.)					
Information about available services					
Information about the disease					
Meet others with ms and/or their carers or family members					
Moving around away from home					
Outdoor maintenance tasks (i.e. gardening)					
Personal care (i.e. showering, dressing)					
Property maintenance (i.e.change lightbulb)					
Rehabilitation services					
Respite care					
Shopping for groceries and other essentials					
Support from others with ms/peer groups					
Transport (e.g. to get to appointments, places of leisure)					
Using medical machinery					
***Other**					
***Other**					
***Other**					

KEY						
A	**B**	**C**	**D**	**E**	**F**	G
Service is not available	Service is available but I am not eligible	I don't know how to access the existing service	Service is available but too far	Service is available but is not satisfactory	Service is available but it is too expensive	I don't know if service is available

APPENDIX D

SERVICE/SUPPORT NEEDS				
	HOW IMPORTANT			
	RANK (1-10)	**MET**	**SOMEWHAT MET**	**NOT MET (A,B,C,D,E,F,G)**
MEDICAL SERVICES				
Dietician				
General practitioner				
Neurologist				
Neuropsychologist				
Occupational therapist				
Physiotherapist				
Psychologist				
Specialised nurse				
Speech pathologist				
Other				
EMPLOYMENT SERVICES				
Specialised employment service				
Support while in work				
HOME HELP				
Meals on wheels				
Gardener/handyman service				
Housekeeper				
TRANSPORT				
Adapting a vehicle				
Information on disabled parking				
Local and community transport				
LEISURE AND RECREATION				
Shopping (essential and pleasure)				
Sports and hobbies				
OTHER SERVICES AND SUPPORT				
Childcare/babysitter				
Counselling				
Financial advice				
Information nights				
In-house respite				
Ms society				
Peer support groups				
Rehabilitation				
Residential respite				
Self-help groups				
Support for family/carer				
Telephone helpline				
***Other**				

KEY						
A	**B**	**C**	**D**	**E**	**F**	G
Service is not available	Service is available but I am not eligible	I don't know how to access the existing service	Service is available but too far	Service is available but is not satisfactory	Service is available but it is too expensive	I don't know if service is available

APPENDIX E

Needs Analysis of Australians with MS, 2012

Your Study ID Number is ☐ ☐ ☐ ☐

Australian MS Longitudinal Study (AMSLS)

Survey: Needs Analysis of Australians with MS

Purpose of Survey

This Survey has been compiled by MS Research Australia in collaboration with MS researchers at Deakin University, Melbourne. The survey aims to determine the current needs of Australians with MS in many aspects of life, including needs that are both met and unmet. By completing this survey you will be providing very valuable anonymous information to service agencies, including State-based MS organisations, that seek to provide better support to Australians with MS. The Survey is divided into several sections; please read each part carefully and answer each question as best you can, then return the form in the reply-paid envelope. If necessary, a carer or family member may help you fill in the form.

Your Privacy

Please do not write your name on the questionnaire. The information you give will be identified only by your Study ID number, and people entering the data for analysis will not know who you are. Only anonymous, grouped results will be reported or made public.

Questions about the form?

If you have any questions about how to complete this form, please call
Dr Rex Simmons on 02 6244 4228 during Eastern office hours.

SECTION A – GENERAL INFORMATION

1. **Today's date is: DD/MM/YYYY** ☐☐/☐☐/☐☐☐☐
2. **Please state your date of birth:** DD/MM/YYYY ☐☐/☐☐/☐☐☐☐
3. **Please state your gender.** Tick one:
   1. ☐ Male
   2. ☐ Female
4. **What State/Territory do you live in?** Please tick one:
   1. ☐ Australian Capital Territory
   2. ☐ New South Wales
   3. ☐ Queensland
   4. ☐ South Australia
   5. ☐ Tasmania
   6. ☐ Victoria
   7. ☐ Western Australia
   8. ☐ Northern Territory
5. **What area do you live in?** Please tick one:
   1. ☐ Metropolitan
   2. ☐ Regional town
   3. ☐ Rural area
   4. ☐ Remote area
6. **Are you registered with your local/State-based MS organisation?**
   Please tick one:
   1. ☐ Yes
   2. ☐ No
7. **What type of accommodation do you live in?** Please tick one:
   1. ☐ A self/family owned property
   2. ☐ A private rental property
   3. ☐ Public housing
   4. ☐ Residential Aged care facility
   5. ☐ Supported accommodation
   8. ☐ Other (please specify) ______________________
8. **Who do you live with?** Please tick one:
   1. ☐ Alone
   2. ☐ Spouse/partner/children
   3. ☐ Parent(s)
   4. ☐ Friend/housemate(s)
   8. ☐ Other (please specify) ______________________

9. **If you live in a family home, how many people do you live with?**
Please specify: ________ (if you live alone, enter zero)

10. **How many people, including children are financially dependent on you?**
Please specify: ________ (if none, enter zero)

11. **a) Do you currently have a carer?** Please tick one:
    1. ☐ Yes
    2. ☐ No .... **Go to Question 12**

    b) If you have a carer what relation is your main carer to you?
    Please tick one:

1. ☐ Spouse/partner	4. ☐ Other family member
2. ☐ Child	5. ☐ Friend/house mate
3. ☐ Parent	6. ☐ Paid care

12. **The following questions relate to your symptoms and formally diagnosed.**
    a) **In what year did your MS symptoms commence?**
    Please specify: ☐☐☐☐

    b) **In what year were you formally diagnosed with MS?**
    Please specify: ☐☐☐☐

    c) **Who formally diagnosed you?**
    Please tick one:
    1. ☐ Neurologist
    2. ☐ Ophthalmologist
    3. ☐ Consultant physician
    4. ☐ General Practitioner, Local Doctor
    8. ☐ Other (please specify)______________________

13. **What is your <u>highest</u> education level?**
Please tick one:
    1. ☐ Primary school
    2. ☐ Secondary school
    3. ☐ Occupational certificate or diploma
    4. ☐ University bachelor's degree
    5. ☐ University postgraduate degree
    8. ☐ Other (please specify)______________________

Please turn over…

SECTION B – CURRENT STATE OF MS

14. This section tells us about your MS. Please select from the following list the description which best describes how MS restricts your activity, if in fact it does at all. This question emphasises walking because that is an important part of people's ability to engage in everyday activities. Please note that not everyone's symptoms of MS progress as implied by the scale, and that some or all of the described limitations on activity may never apply to you.

Please tick only one box that BEST represents the description of how MS currently restricts your activity:

1. ☐ I may have some mild symptoms, mostly sensory, due to MS but they do not limit my activity or lifestyle.
2. ☐ I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.
3. ☐ MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need to use a walking stick [cane] or other walking aid, but I might during an MS attack.
4. ☐ I can walk about 8 metres [or 25 feet] without using a walking stick or other walking aid such as a splint, brace or crutch, but I may use a walking aid for greater distances.
5. ☐ To be able to walk 8 metres [or 25 feet], I have to have a walking stick, single crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.
6. ☐ To walk 8 metres [or 25 feet], I must have two walking sticks, two crutches or a walking frame [walker]. I may use a scooter or wheelchair for greater distances.
7. ☐ My main form of mobility is a wheelchair. I may be able to stand and or take one or two steps, but I can't walk 8 metres [or 25 feet], even with crutches or a walking frame.
8. ☐ I am unable to sit in a wheelchair for more than one hour, and I spend most of my time in bed.
9. ☐ None of the above options describes my MS. I don't have any mobility problems, but I do have other kinds of MS symptoms such as eyesight or memory problems that significantly interfere with my activities and lifestyle.

SECTION C – SPECIFIC SYMPTOMS

15. Please circle a number on each line of the scale that best describes your experience of each symptom:

	Symptoms	Not at all	Sometimes	Often
a.	Concentration Problems	1	2	3
b.	Memory Difficulties	1	2	3
c.	Judgement Difficulties	1	2	3
d.	Planning Difficulties	1	2	3
e.	Visual Problems	1	2	3
f.	Ringing in the ears	1	2	3
g.	Sleep Disturbances	1	2	3
h.	Speech Difficulties	1	2	3
i.	Fatigue	1	2	3
j.	Mood Changes	1	2	3
k.	Depression	1	2	3
l.	Heat Intolerance	1	2	3
m.	Balance Problems	1	2	3
n.	Bowel Problems	1	2	3
o.	Bladder Problems	1	2	3
p.	Muscle Weakness	1	2	3
q.	Muscle Spasticity	1	2	3
r.	Numbness	1	2	3
s.	Pain	1	2	3
t.	Sexual Dysfunction	1	2	3
u.	Twitching	1	2	3
v.	Walking Difficulties	1	2	3
w.	Other (please specify)	1	2	3
x.	Other (please specify)	1	2	3

SECTION D – EMPLOYMENT AND INCOME

16. a) **How many hours of PAID work do you do each week?**
_______ paid hours (if no paid work, enter zero)

b) **How many hours of UNPAID work do you do each week?**
______ unpaid hours (if no unpaid work, enter zero)

17. What BEST describes your current employment status?
Please tick one:

1. ☐ Self-employed (e.g. contractor, sole trader, farmer) .....**Go to Q20**
2. ☐ Employed, full time (35 hrs per week or more)
3. ☐ Employed, part time (including casual or seasonal workers)
4. ☐ Unemployed, seeking full-time employment
5. ☐ Unemployed, seeking part time employment
6. ☐ Unemployed, not seeking employment ....**Go to Q20**
7. ☐ Retired ....**Go to Q20**
8. ☐ Home and/or family management.................................**Go to Q20**
9. ☐ Student ....**Go to Q20**
10. ☐ Volunteer

18. If you currently work for an employer or are seeking such work, do you feel that there is enough information and resources regarding the following aspects of employment and MS? Please circle a number on each line from the scale below that best represents how you feel about the availability of useful information about each aspect of employment and MS.

	Aspect of employment and MS	Not required	Unavailable	Sometimes available	Often available
a.	Your rights as an employee	0	1	2	3
b.	Education about MS for employers	0	1	2	3
c.	Flexibility in the workplace to accommodate your MS (e.g. hours, leave)	0	1	2	3
d.	Specialised Employment Services	0	1	2	3
e.	Education about symptom management in the workplace	0	1	2	3
f.	Advice about workplace adaptions and equipment	0	1	2	3
g.	Access to transport to get to employment	0	1	2	3
h.	Information about superannuation or moving out of employment	0	1	2	3

19. If you currently work, have you disclosed your MS to your employer?

Please tick one:

1. ☐ Yes
2. ☐ No
3. ☐ Not applicable (e.g., I'm seeking work)

20. What is your combined household income?

Please tick one:

1. ☐ <$25 000
2. ☐ $25 000 - $49 999
3. ☐ $50 000 - $74 999
4. ☐ $75 000 - $99 999
5. ☐ $100,000 +

21. Do you have enough money to meet your needs?

Please tick one:

1. ☐ Yes
2. ☐ No

22. Has your partner or carer changed his/her work and income level or stopped work due to your MS?

Please tick one:

1. ☐ Yes
2. ☐ No
3. ☐ Not applicable

SECTION E: TRANSPORT

23. What is your main form of transport?
Please tick one:

1. ☐ Private vehicle – self driver
2. ☐ Private vehicle modified for disability – self driver
3. ☐ Private vehicle – driver is carer/family/friend
4. ☐ Public transport (buses, trains, trams)
5. ☐ Taxis
8. ☐ Other (please specify) ______________________

24. What was your main form of transport before the onset of symptoms?
Please tick one:

1. ☐ Private vehicle – self driver
2. ☐ Private vehicle modified for disability – self driver
3. ☐ Private vehicle – driver is carer/family/friend
4. ☐ Public transport (buses, trains, trams)
5. ☐ Taxis
8. ☐ Other (please specify) ______________________

25. The following is a list of statements regarding various forms of transport.
Please circle the number on each line from the scale below that best reflects how much the following statements apply to you.

Forms of transport	Not applicable	Not at all	Sometimes	Quite often
a. Wheelchair access on public transport is poor.	0	1	2	3
b. I often cannot attend, or miss appointments because of my lack of transport.	0	1	2	3
c. I cannot get to train, tram or bus stop due to limited mobility.	0	1	2	3
d. I have a lack of confidence in using public transport.	0	1	2	3
e. I have to limit my social activities because transport is too expensive.	0	1	2	3
f. The reliability of public transport is poor.	0	1	2	3
g. The reliability of taxis is poor.	0	1	2	3
h. Taxi drivers do not understand my needs.	0	1	2	3
i. I feel socially isolated due to my lack of transport.	0	1	2	3
j. I find taxis too expensive even after taxi vouchers.	0	1	2	3
k. I find that public transport takes too long.	0	1	2	3

SECTION F: RESPITE ACCOMMODATION

The following section includes statements about respite accommodation.

26. From time to time, I do need or would like respite accommodation.
Please tick one:

1. ☐ Yes
2. ☐ No .... **Go to Section G, Question 28**
3. ☐ Not applicable............. **Go to Section G, Question 28**

27. If you need or would like respite accommodation, please indicate how strongly you agree or disagree with the following statements.
Please circle the number on each line from the scale below that best reflects how much you agree or disagree.

	Respite accommodation	**Disagree**	**Agree a little**	**Strongly agree**	**Don't Know**
a.	It would be nice to go into respite with children/spouse/partner	1	2	3	4
b.	Respite accommodation is not age appropriate	1	2	3	4
c.	Respite accommodation is too expensive	1	2	3	4
d.	Respite accommodation is too far away	1	2	3	4
e.	The permitted length of stay is too short	1	2	3	4
f.	The waiting lists for respite are too long	1	2	3	4
g.	There is not enough respite available	1	2	3	4
h.	There is not enough variety of respite	1	2	3	4
i.	I am able to get to respite accommodation	1	2	3	4
j.	I am able to get in home day respite	1	2	3	4
k.	I am able to get out of home day respite	1	2	3	4
l.	I am able to get in home overnight respite	1	2	3	4

Please turn over...

SECTION G: EQUIPMENT

28. Because of your MS do you need, but do not currently have any of the following aids, equipment or modifications?
Please tick all that apply:

1. ☐ Mobility aids (e.g. scooter, electric wheelchair, etc.)
2. ☐ Computer-related aids (e.g. for vision, manual difficulties, or other assistive technology)
3. ☐ Continence aids
4. ☐ Home modifications to assist your mobility (e.g. ramps, railings, remote control equipment)
5. ☐ Home modifications to assist your personal care (e.g. toileting, showering)
6. ☐ Car modifications
7. ☐ Other equipment (e.g. lifting aids, special beds, etc.)
8. ☐ Heating or cooling (e.g. an air-conditioning unit)

29. If you ticked any of the above, can you afford to purchase such aids?

1. ☐ Yes 2. ☐ No 3. ☐ Not applicable

30. Again, if you indicated that you require any of the aids listed above, are you satisfied with the available advice on how you might obtain and use such aids?

1. ☐ Yes 2. ☐ No 3. ☐ Not applicable

31. If you answered NO to Question 29, please indicate which aids you cannot afford to purchase.
Please tick all that apply:

1. ☐ Mobility aids (e.g. scooter, electric wheelchair, etc.)
2. ☐ Computer-related aids (e.g. for vision, manual difficulties, or other assistive technology)
3. ☐ Continence aids
4. ☐ Home modifications to assist your mobility (e.g. ramps, railings, remote control equipment)
5. ☐ Home modifications to assist your personal care (e.g. toileting, showering)
6. ☐ Car modifications
7. ☐ Other equipment (e.g. lifting aids, special beds, etc.)
8. ☐ Heating or cooling (e.g. an air-conditioning unit)

SECTION H: EDUCATION SESSIONS AND INFORMATION

32. Please circle a number on each line from the scale that best describes your level of satisfaction with each form of MS education and type of information available to you.

		Not required	Not satisfied	Slightly satisfied	Very satisfied
	EDUCATION SESSIONS				
a.	Location of education sessions	0	1	2	3
b.	Education sessions about MS for people with MS	0	1	2	3
c.	Education sessions about MS for carer/spouse/partner	0	1	2	3
d.	Education about MS aimed at teenagers with MS	0	1	2	3
e.	Education about MS for teenagers living with someone with MS	0	1	2	3
f.	Education sessions about MS for young children with MS	0	1	2	3
g.	Education sessions about MS for young children living with someone with MS	0	1	2	3
h.	Education sessions about various treatments	0	1	2	3
i.	Community awareness of MS	0	1	2	3
j.	Education sessions about symptom management (e.g. nutrition, exercise, fatigue, and continence)	0	1	2	3
k.	Education sessions around financial management	0	1	2	3
l.	Online education sessions	0	1	2	3
	INFORMATION (printed and online)				
a.	Up-to-date information about current MS research	0	1	2	3
b.	What services the State-based MS organisation provide	0	1	2	3
c.	What services you are eligible for from government or local council services	0	1	2	3
d.	Information regarding what financial assistance you are eligible for	0	1	2	3
e.	Understanding welfare and benefit entitlements	0	1	2	3
f.	Centrelink benefits information	0	1	2	3
g.	Information about superannuation	0	1	2	3

Please turn over...

SECTION I – SERVICES/RESOURCES WHEN FIRST DIAGNOSED

33. What services/resources did you most need when you were first diagnosed?

Please tick all that apply:

1. ☐ Case Worker
2. ☐ Counsellor
3. ☐ Dietician
4. ☐ General Practitioner
5. ☐ Physical activity/exercise
6. ☐ Continence Nurse
7. ☐ Advice about MS treatments
8. ☐ Massage Therapist
9. ☐ Neurologist
10. ☐ Occupational therapist
11. ☐ Physiotherapist
12. ☐ Psychologist
13. ☐ Psychiatrist
14. ☐ Specialised Nurse
15. ☐ Speech Pathologist
16. ☐ Accurate information about MS services
17. ☐ Information about MS Australia
18. ☐ Peer support

19. ☐ Other (please specify) ______________________

20. ☐ Other (please specify) ______________________

SECTION J – SERVICES

34. **Please circle a number on each line from the scale below that best describes your level of satisfaction with the current availability and the quality of each of the services listed below.**

	Services	Not required	Not satisfied	Slightly satisfied	Very satisfied	Don't know
a.	Case Worker	0	1	2	3	4
b.	Counsellor	0	1	2	3	4
c.	Dietician	0	1	2	3	4
d.	General Practitioner	0	1	2	3	4
e.	Physical activity/exercise	0	1	2	3	4
f.	Incontinence Nurse	0	1	2	3	4
g.	Advice about MS treatments	0	1	2	3	4
h.	Massage Therapist	0	1	2	3	4
i.	Neurologist	0	1	2	3	4
j.	Occupational therapist	0	1	2	3	4
k.	Physiotherapist	0	1	2	3	4
l.	Psychologist	0	1	2	3	4
m.	Psychiatrist	0	1	2	3	4
n.	Specialised Nurse	0	1	2	3	4
o.	Speech Pathologist	0	1	2	3	4
p.	Accurate information about MS services	0	1	2	3	4
q.	Information about MS Australia	0	1	2	3	4
r.	Peer support	0	1	2	3	4
s.	Other (please specify)	0	1	2	3	4
t.	Other (please specify)	0	1	2	3	4

Please turn over...

SECTION K: PSYCHOLOGICAL SUPPORT and SOCIAL SUPPORT

The following section addresses your current social support and psychological support needs.

35. Have you ever experienced any of the following feelings in relation to your MS? Please tick one answer for each part of the question:

a) **Depression** (e.g. feeling sad, helpless, worthless)

1. ☐ Yes 2. ☐ No

b) **Anxiety** (e.g. anxiety about the future, racing thoughts, heart palpitations)

1. ☐ Yes 2. ☐ No

36. Please circle a number on each line from the scale below that best reflects how you feel about your access to the following psychological services:

	Psychological services	Not required	Unavailable	Only sometimes available	Easily available
a.	Counselling for you (e.g. talking about feelings, relapses, emotions etc.)	0	1	2	3
b.	Psychological assistance when you were first diagnosed	0	1	2	3
c.	Family counselling	0	1	2	3
d.	Relationship counselling	0	1	2	3
e.	Counselling for child/children	0	1	2	3
f.	Psychological support to assist with mental illness	0	1	2	3

37. Please circle a number on each line from the scale below that best reflects any changes you would like in various aspects of peer support provided by the MS Society.

	Aspects of peer support	Not required	Agree	Disagree, its currently okay
a.	More variety to meet your particular needs (e.g. younger peer support)	0	1	2
b.	Meetings are too far away	0	1	2
c.	More variety with times (e.g. after work hours, weekends etc.)	0	1	2
d.	More variety in mode of communication (e.g. phone, email, Skype etc.)	0	1	2

SECTION L: ASSISTANCE

38. Please circle a number on each line on the scale that best describes how often you require assistance with the various tasks listed below.

	Required assistance	Never	Sometimes	Quite often
a.	Administering medications	1	2	3
b.	Assistance with managing finances	1	2	3
c.	Communication- reading or writing tasks	1	2	3
d.	Domestic duties (e.g. cleaning, ironing)	1	2	3
e.	Meal preparation/cooking	1	2	3
f.	Moving around in-home	1	2	3
g.	Outdoor maintenance (e.g. gardening)	1	2	3
h.	Personal care (e.g. showering, bathing)	1	2	3
i.	Shopping	1	2	3
j.	Social activities	1	2	3
k.	Attending/making appointments	1	2	3
l.	Other (please specify)	1	2	3

39 When you need assistance, who is the main person that helps you?
Please tick one:

1. ☐ No one
2. ☐ Partner/spouse
3. ☐ Child/children
4. ☐ Other family/friends
5. ☐ Home care agency
6. ☐ Nursing staff
8. ☐ Other (please specify) ______________________

40. Do you need more help with any of the tasks mentioned in question 38?
Please tick all tasks that you require more assistance with:

1. ☐ Administering medications
2. ☐ Assistance with managing finances
3. ☐ Communication- reading or writing tasks
4. ☐ Domestic duties (e.g. cleaning, ironing)
5. ☐ Meal preparation/cooking
6. ☐ Moving around in-home
7. ☐ Outdoor maintenance (e.g. gardening)
8. ☐ Personal care (e.g. showering, bathing)
9. ☐ Shopping
10. ☐ Social activities
11. ☐ Attending/making appointments
88. ☐ Other (please specify) ______________________

END OF SURVEY

THANK YOU FOR YOUR ASSISTANCE.

Please check again carefully to make sure you haven't missed any pages.

Please return the form promptly in the reply-paid envelope provided, or mail to the address below (no stamp required):

Australian MS Longitudinal Study
Level 2 East, Building 5
Canberra Hospital
Reply Paid 11
WODEN ACT 2606