MS
AUSTRALIA

Seeking the Cure.
Providing the Care.

SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

A Submission from the Multiple Sclerosis Society of Queensland

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1. Introduction

1.1 Multiple Sclerosis is a chronic, progressive condition, a neurological disease whose cause and cure and not yet known. Approximately 70% of people with MS are diagnosed between aged 20 and 50. It is recently noticeable that increasing numbers of adolescents and children are being diagnosed. This is an international phenomenon.

Multiple Sclerosis is two to three times as common to women as it is to men. It occurs more frequently among Caucasian ethnicities. It is rare among Asian ethnicities and almost unknown among Aboriginal Australians, Maori and African indigenous groups. MS is also more common in temperate areas; less common closer to the equator. Neurologists estimate that there are approximately 3,000people with MS in Queensland. Of these, 2139 are registered clients of the MS Society.

Multiple Sclerosis is an autoimmune disease in which the body's immune system attacks normal tissue. These attacks damage the myelin insulator of the central nervous system. Deterioration of myelin scar tissue or sclerotic plaques interferes with the conduction of nerve impulses within the central nervous system. This in turn causes the symptoms that people experience over the course of the illness.

A wide range of MS symptoms occurs across the various experiences of the disease. These include blurred or double vision; high fatigue; problems with walking; weakness; imbalance; sensory problems, numbness, tingling and pain; bladder and bowel control; sexual functioning; emotional and cognitive changes. Individual experiences of these symptoms occur across a broad spectrum.

Four basis disease courses have been defined:

- **Relapsing - Remitting MS** is known by clearly defined attacks, which last from days to weeks, then subside to a full or partial recovery with no noticeable disease progression between attacks.
- **Primary - Progressive MS** is known by a gradual progression of disability from the onset with no obvious plateaus or only occasional plateaus with minor, temporary improvements.
- **Secondary - Progressive** MS begins with a relapsing-remitting course. It later evolves into a more consistently progressive course with or without relapses.
- **Progressive - Relapsing MS** shows a steady progression in disability from the onset. It has clear, acute relapses that might have some recovery following the acute episode.

1.2 The Multiple Sclerosis Society of Queensland (MSQ) is an active participant in the federal body, MS Australia. As such, MSQ has already contributed to the national submissions already made to this inquiry - and endorses those submissions.

1.3 This submission takes the opportunity to inform the inquiry on the specific challenges encountered by the Society in providing services and supports to approximately 2,300 clients and their families in Queensland. Knowledge of service deficits and types of unmet need arising from current practice will be identified. This will be related to the adequacy and inadequacy of the third CSTDA as well as to related state and commonwealth services and funding supports.

1.4 Reference will be made to the Society's learning from its service engagement with clients as the basis of recommendations made on the desired priorities for the fourth CSTDA.

2. Addressing MS in Queensland: Gap Filling, Growth Challenges and the Statewide Stretch

2.1 Since 1957, MSQ has been heavily occupied with filling gaps in the provision of high need services. Understandably, this service provision was dominated by physical symptom management and specialized, high support accommodation for those with advanced symptoms.

2.2 The attached summary of services (appendix i) outlines the evolutionary journey of the Society in its attempt to adopt a holistic approach - taking a quality of life perspective. Appendix ii is a current statement of the Model of Service of the Society. Only recently has it become possible to form service delivery partnerships and shared care demonstration projects with the public health system. Finite resources have dictated historically that the Society would be so heavily committed to direct service delivery in the physical symptom and accommodation areas. Only recently has it been possible to implement a statewide case management and service co-ordination capacity as well as increased priority for psycho-social supports which address the family relationships and employment realities of clients.

2.3 Over the past five years, new client registrations have increased at an average of 5% per annum. The growth has been distributed across all regions of the state. The regional centre with highest consistent growth during this period is Cairns. Yet, the Society's strategic objective to establish a locally based regional service co-ordinator in North Queensland remains unrealized.

2.4 Through active initiation of contact with all clients throughout Queensland, the Society continues to develop strong inter-agency links with local service providers in all regions. Major commitments are made in referrals, brokering and direct funding to ensure that client needs are met. Major expenditure is committed to the following high need areas: in-home care subsidies; gap funding for equipment; home air-conditioning; home modification subsidy; child education support; holiday subsidy; transport subsidy.

2.5 The MSQ services budget for 2005-06 is $5.2 million, 56 per cent of which is received from governments. The trend is for self generated revenue to compensate for under-indexing of government revenue as well as to support growth in service costs and service development.

2.6 Current critical challenges facing clients in Queensland are:

- Inadequacy of in-home care funding available.
- Lack of flexible funding packages to support independent living for younger clients.
- Continuing cost-gaps in obtaining necessary equipment from MASS.
- Barriers to retaining existing employment - as a result of the Welfare to Work legislation.
- Access to public allied health and community mental health services.

3. Addressing the Four Priority Areas for this Review

3.1 The current CSTDA has five priorities:

- Strengthen access to generic services for people with disabilities.
- Strengthen across government linkages
- Strengthen individuals, families and carers
- Improve long-term strategies to respond to and manage demand for specialist disability services.
- Improve accountability, performance reporting and quality.

The Society's experience of the effectiveness or otherwise of these priorities will guide and inform this attempt to offer a future-oriented contribution to the stated priority areas for this review. MSQ has invested recently in a new client services data base. This has enabled the Society to explore actively a world class register of met and unmet needs with the AIHW and relevant university researchers.

3.2 To assist the perspective of this inquiry, some essential goals are delineated here.

The MS Society is……

- Supporting Australian research to accelerate the potential for prevention, symptom relief and a cure.
- Partnering with health and disability services to improve care for all Australians with MS.
- Working with pharmaceutical companies to ensure client access to improved treatments for slowing disease progression and symptom reduction.
- Working with state and federal governments to improve social policy for chronic neurological conditions and to reduce discrimination against Australians with MS.

The Commonwealth Government can……

- Integrate health, social security and employment policies to reduce the burden of MS.
- Fund better accommodation options and packages based on functionality for younger people with disabilities.
- Match financial support for specified collaborative research that contributes to the worldwide effort to cure MS.

4. The Intent and effect of the three CSTDAs to date

4.1 It is not intended here to address all three CSTDA agreements. This submission is supportive of material from MS Australia which has covered this adequately. It is more current and beneficial for this submission to consider the impact and value of the current agreement in the following critical areas:

4.2 Access to generic services for people with MS continues to be problematic in Queensland. Information and education done by the Society and others promoting healthy living will be thwarted while public health services lack capacity in much of Queensland to provide symptom management services as part of allied health services. Only in the past year have there been significant beginnings in the upgrading of community health services in Queensland.

4.3 The COAG agreement of 2006 to fund jointly the provision of accommodation suited to the needs of younger people with disabilities is an outstanding exception to the general lack of inter-governmental linkage. This is a matter of deep concern as state and federal governments show little inclination to put community need before partisan political rivalry.

4.4 The strengthening of individuals, families and carers has been assisted by the various carer resources available. Limits to support however are too restrictive for many clients and their families. The major shortfall of adequate individual funding packages to support independent living in Queensland brings many crises in the lives of clients and their families. Even merging funding for defined periods is very limited in its capacity to achieve the intended objective.

4.5 The improvement of long-term strategies to respond to and manage demand for specialist disability services has been a frustrating matter - largely because of limited funding commitments by both state and federal governments; reluctance of policy makers to address the full scope of unmet need; limited consultation with NGO agencies at the highest levels of government. The latter comment in the experience of MSQ applies more to the Commonwealth government than to the State.

5. The appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support.

5.1 The Queensland experience of joint funding arrangements is addressed here only from the unmet needs perspective. It is a matter of great concern that such a high proportion of people with MS in Queensland are unable to obtain a continuing funding package sufficient to enable their independent living. For want of such supports in the home, such people too often see institutional accommodation as their only alternative. The predictable strains of care burden on their family relationships are too evident and too frequently experienced. In April 2006 there were 81 people with MS aged under 65 residing in aged care facilities. 27 of these were under 50. Currently, there are in Queensland 34 people with MS aged under 50, known to our service co-ordinators, who experience an enormous struggle in order to maintain their independent living in the community. Very few of these have relevant funding packages to assist with in-home supports. They get by on inadequate and ad-hoc “cocktail” funding (pooling of small funding inputs by 2 or 3 agencies).

5.2 The Society has at the advanced planning stage a new facility in a congenial suburban location which will provide independent living in purpose designed units for 8 residents as long term tenants. A nearby respite facility will also be available for 2 persons. All land and construction costs are the responsibility of the Society. Recurrent staffing costs have been committed by Disability Services Queensland. While the Society could not itself expand or replicate this facility, it is developed as a demonstration project in the hope that others will borrow from it and improve upon it. It is clear however that such types of supported independent living accommodation are required in all regional centres, for people with MS and other neurological conditions. The main answer appears to lie in a more closely co-operative level of joint funding (Commonwealth-State) to continue on after the COAG agreement of 2006 has been implemented.

6. An examination of the ageing/disability interface with respect to health aged care and other services, including the problems of jurisdictional overlap and inefficiency

6.1 Very frequently it appears to MSQ staff that a dangerous "fault line" runs through the ageing/disability interface. There are two main reasons for this. Firstly, there is the predicament of younger people with disability who need high care and for whom the aged care resources are an inappropriate (and over-extended) last resort. Secondly, there is the common experience of people aged over 65 for whom the main supports available do not address their level of disability.

6.2 A practice-based opinion of several MSQ service co-ordinators is that funding for adults with a disability should not be age based but rather functionally based, ie: two persons with the same functional support needs should get the same level of disability funding support even if one is aged 35 and the other is aged 75.

HACC and ACAT assessments are functionally based but Adult Lifestyle Support Package assessments are largely socio-emotionally based. HACC and ACAT assessments are completed by professional assessors in approximately 1 hour.

The DSQ application process is more complicated and time consuming. HACC approval and placement on a waiting list normally takes about one week whereas the DSQ process typically takes well over 12 months in a very hierarchical process. Who supports the applicant in the meantime?

Unsuccessful applicants with DSQ must re-apply after each time they have been refused. Two many find that this application process is overtaken by their progressive condition and lose the option of independent living.

MSQ is heavily pressed to continue with gap-filling contributions to ensure the viability of independent living for people who are at high risk of failing in this quest. To achieve this and to meet increasing levels of client demand, it is necessary to constantly supplement grant funds with self-generated fundraising proceeds.

6.3 A greater level of consistency and co-operation between Commonwealth and State governments could expand (rather than duplicate) the ACAT model of assessment to allow specific access to younger people with a disability. The aged care funding model (CACPS, 6-10 hours, EACH, 15-21 hours) could also be the basis of a guaranteed funding support entitlement for people with a disability - dependent on their functionality. The CSTDA could advance a new co-operative model in its fourth cycle. Attached to this would need to be the capacity to re-assess and increase an individual's package - for people with chronic progressive conditions.

7. An examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas

7.1 In this priority area, the MSQ has little to add to the substantial material already presented in the MSA submission - which is strongly supported. Specifically, the model of care instanced in the "National Service Framework for Long Term Conditions" from the UK Department of Health is seen as a valuable guide to Australian government consideration.

8. Recommendations

8.1 The intentional development of the fourth CSTDA from a structured/transactional agreement to a detailed and dynamic partnership which manages both strategic policy and funding arrangements.

8.2 Total re-consideration of old funding formulas - towards rebuilding Commonwealth-State partnerships around nationally agreed disability services outcomes.

8.3 The inclusion of the following outcome objectives in the fourth CSTDA:

- Complex care services
- Accommodation support (functionality based)
- Chronic illness management
- Equipment services (national equity in access and affordability)
- Carer support
- Employment and vocational services
- Transport

8.4 Active investigation of the feasibility of a national social insurance model - with particular reference to the circumstances of people with chronic progressive forms of disability.

8.5 Ensure that the Department of Employment and Workplace Relations and the Department of Health and Ageing are signatories to the fourth CSTDA.

Appendix (i)

AUSTRALIA

Seeking the Cure.
Providing the Care.

The MS Society of Queensland provides a range of ***individualised services*** to people with MS throughout the state who are registered clients. **Regional Service Co-ordinators (RSCs)** support clients living throughout seven regions across the state and are the central point of contact for all MS Society services.

The RSC, based on identified client need, co-ordinates support through a range of MS Society service options or through external services such as medical and allied health professionals, and aged care and community health organisations. RSCs for all Queensland regions can be contacted via the toll free Information Line on **1800 177 591.**

MS SOCIETY SERVICES

Information

The Information Resource Centre has a comprehensive collection of MS information in Queensland and can provide specialised information to clients, families, and health and service providers about most aspects of MS, such as treatment, symptom management, and research. To facilitate access to information for both clients and health and service providers, the 1800 Information Line is operated Monday to Friday during office hours.

Allied Health

Physiotherapy, Occupational Therapy, Vocational Counselling and Support, and Clinical Psychology services are available to clients and their families to address identified problems and needs related to MS such as:

Ø *Fatigue management*

Fatigue and heat fatigue are major factors affecting people with MS. Information and support to assist clients to manage fatigue can be provided. A limited number of interest-free loans are available to assist clients to purchase items such as air-conditioners in the absence of other financial support options.

Ø *Clinical psychology support for psychological and cognitive changes*

MS can cause difficulties for clients in cognitive areas such as memory and problem solving, and may also impact on the mental health and relationships of people with MS and their families as they come to terms with the effects of MS on their life. Psychological and counselling support can be provided to clients and their families to assist them to cope with these changes and maintain psychological health and well being.

Ø *Maintaining physical abilities and independent living*

With support from physiotherapy and occupational therapy, clients can access specialist assessment and information, exercise programs, and appropriate equipment and home modifications to assist them in the maintenance of their physical abilities. In cases of extreme need and the absence of other options, limited financial support can be provided.

Ø *Bladder and bowel problem management*

Bladder and bowel problems are a difficulty many people with MS face, and through information, support and referral to local health professionals, clients can be assisted to manage this often difficult to discuss issue.

Ø *Employment Support*

The symptoms associated with MS may raise issues for people with MS pertaining to the maintenance of their employment. Clients can be assisted with employment issues such as disclosing a diagnosis, workplace modifications, & jobs in jeopardy.

Ø *Immunotherapy*

Immunotherapy is available in the Brisbane metropolitan area through the MS Clinic at the Royal Brisbane Hospital, and in the regional areas of Queensland through trained registered nurses.

Peer Support

People with MS can be invaluable sources of support for others with MS. The Society can link clients to **MS support groups** which meet on a regular basis throughout the state, or if individual peer support is preferred, clients can access telephone support through trained **Peer Support Volunteers.**

Residential Respite and In-home Support

The Society can provide residential respite to clients and families for both planned and emergency stays. Limited in-home support can also be provided where existing community based options are insufficient.
29.05.03

Appendix (ii)

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MULTIPLE SCLEROSIS SOCIETY OF QUEENSLAND
MODEL OF SERVICE

The Society works for a **cure** for MS and in the interim, the **provision of care** for people with MS. Its community sector identity enables strategic development on several fronts.

The **central values** guiding our work are:

1. **Worth and Dignity**
   Recognise individual worth of each person; respect difference and diversity; assist independence, self-esteem and quality of life; practise empathy and compassion.

2. **Inclusion**
   Encourage participation in the community; foster a sense of belonging with MSQ; commit to equitable access to services; engage to achieve effective partnerships; build unity of purpose through teamwork; connect to achieve a two way street with PwMS.

3. **Ethical Behaviour**
   Ensure integrity, honesty and transparency; promote professionalism, ownership and accountability; foster mutual responsibility; deliver all services in line with best practice standards.

4. **Continuous Improvement**
   Develop as an innovative learning organisation in pursuit of excellence; deliver high quality customer service standards; build, share and apply specialised knowledge; maintain constant awareness of partners, competitors, market place.

5. **Visionary Leadership**
   Find a cure for MS; Lead in scientific discovery; Practise flexibility and creativity; advocate with and for PwMS; develop and maintain strategic collaborations.

The Major Strategic Objectives are:

1. **Engagement through "Episodes of Care" tailored for each client**
   This requires ongoing screening and prioritising for client needs; management and brokerage of appropriate services and resources; effective engagement processes to deliver tailored solutions through episodes of care.

2. **Collaboration with Service Providers to Build Specialised Capability**

   The specialised knowledge foundations of services to people with MS can be described as:

   - Growing high levels of **MS specific knowledge** and relevant **professional expertise**
   - Advanced **clinical reasoning** to **meet** and **predict** the multi-faceted mix of needs of people with MS across the life course.
   - A consistently **holistic perspective** towards clients and their life circumstances.
   - **Applied research** to improve practice outcomes.

CURRENT SERVICES OFFERED BY MS AUSTRALIA IN QUEENSLAND

Accommodation Support Services

The Society's understanding of this range of client needs has evolved over recent decades. **Granston Lodge** provides high support accommodation for 28 residents who have advanced levels of disability. In addition, Granston Lodge provides high demand **planned respite** services with a five-bed capacity and an added crisis response capacity.

Four **transition flats** are owned and maintained by the Society to assist persons who are able to live independently while on the public housing waiting list.

A new **enhanced respite** facility is currently being designed as a pilot project for people with low support needs.

In all accommodation issues relevant to people with MS, the Society is committed to a process of deinstitutionalisation. In practical terms this demands that we do everything possible to assist clients to live independently in the community. The new **Life Options** project (currently in planning) expresses this commitment.

McKinnon House at the Gold Coast has been rebuilt in recent years. It is in high demand as a most attractive **family holiday location.** It offers the best of facilities and surroundings at concessional rates. An **alternative rural holiday and recreation facility** is now operating in partnership with Boystown Beaudesert.

Financial support services are provided on a means tested basis. These are in the form of interest-free loans to clients for the installation of essential equipment such as air-conditioners, as well as for home modifications and purchase of wheelchairs, scooters and other mobility aids. Some clients in extreme hardship are given small grants for planned respite and similar urgent needs.

A very high proportion of clients have the Disability Support Pension as their sole or main income. A small proportion are self-funded retirees. Income support is therefore a major issue for many and the Society provides special purpose grants to such people on application. These are for clients who have no other resources to pay for necessary equipment or services. Small transport grants paid to clients on a means tested basis make a vital difference to their mobility options.

The Society is a safety net in such cases because the public sector provision is insufficient and the private sector is mostly unable to assist.

Specialist Assessments and Advice

These services are facilitated and, in some cases, funded by the Society. They include Neuro-psychology, neurology, speech pathology, employment aptitude, and medical specialist areas such as urology. The services are more readily available in the south-east of the state and this disparity is being addressed.

Therapies especially **physiotherapy,** are provided to clients of the Society. Physiotherapy is provided mainly at the Dutton Park MS Centre and at Chermside, Sandgate and the Gold Coast on a part-time clinic basis. A small hydrotherapy service operates part-time at Townsville. Typically, 300 clients receive physio service each week from MSQ. Queensland Health has agreed in principle to establish demonstration projects for exercise therapy services at four high demand regional locations, in partnership with the Society.

Occupational Therapy services are provided both by a single practitioner and by referrals to occupational therapists throughout the state. There is frequent need for such services to be provided in the homes or workplaces of clients.

Immunotherapy clinics are conducted by the clinical nursing staff of the MS Clinic at the Royal Brisbane Hospital and on a part time weekly basis at the Gold Coast. The MS Clinic also operates a toll free immunotherapy phone support service.

Employment Counselling is made available to clients and their employers. Referrals are made to external specialists with training in rehabilitation counselling (employment focus). The focus is “Job in Jeopardy”. The advocacy aspect with clients and their employers is high priority.

Clinical Psychological services are provided by an experienced professional on a half time consultant basis with flexible time availability to meet the urgent requirements of clients. Many clients consult the psychologist by phone from various parts of the state. He also visits the Gold Coast regularly for in-person consultations. Provision of some assessment and testing services is also a part of this service. Approximately 40 persons per month make contact with the psychologist regarding personal and relationship issues.

A **Kids of People with MS** project is now in its early stage of development.

Regional Service Co-ordination (RSC) is the nerve centre of our ongoing contact between professional staff and clients. Our seven regions cover the entire state. Of the more than 2200 clients currently registered, approximately 500 are in active contact with their respective service co-ordinators at any given time. Of these, approximately 400 are located in the greater Brisbane and Southern coastal area. Such client density and concentration of demand require that we employ full time co-ordinators in metropolitan Brisbane. Locally based co-ordinators now operate at Gold Coast – Logan and Toowoomba.

Essentially, the RSC links, co-ordinates refers, brokers and advocates with and for the client. The ongoing point of reference in this relationship is the Individual Program Plan which the RSC maintains with full participation from the client. RSCs are heavily involved in ensuring clients access to needed health and community services.

Research projects are entered into by services staff in a co-ordinated, time-limited manner. These mostly take place with external partners. Recent **projects** have included:

- continence
- nursing practices with MS patients
- carer – local issues
- occupational therapy services with MS patients in rural-remote areas
- genomics
- speech pathology issues
- pain management
- resilience and depression

Partner institutions have included:

- The Queensland University of Technology
- Griffith University
- The University of Queensland
- The James Cook University of North Queensland
- Deakin University
- The University of Melbourne
- Edith Cowan University

These partnerships are mostly pursued at post-graduate level with significant placements done by undergraduates.

Advocacy is ongoing at the Society. It could be a matter as **simple** as getting the mail carried to the door of a person with MS in Cairns. It could be a larger and **longer running challenge** to gain government recognition of the plight of younger people with MS who are presently `accommodated in aged care nursing homes. Regional co-ordinators are the front line advocates for our clients. The RSCs work closely with their colleagues and with the Manager for individual and family services to ensure that our advocacy is relevant, and effective.

Publications and Information provision are a major ongoing priority for the Society's services staff. The **Information Resource Centre Co-ordinator** maintains a library, which is moving steadily from traditional hard copy materials towards maximum on line mode for information requirements. National integration of MS on-line libraries is currently in progress. Current web sites operated by MS Societies from various locations are increasingly linked and co-ordinated both internally to the MS movement internationally and externally to tertiary institutions and research bodies.

A 1 – 800 **information line** concerning the experience of MS with its many implications is operated Monday - Friday during office hours by a roster of professional staff members of the Society and a new group of specially trained info-line volunteers.

Information sessions to **newly diagnosed** clients are given on request by RSCs either individually or at small group meetings. Other single issue small group information sessions are co-ordinated by RSCs in their own regions. **Internet tutorials** by clients and for clients are increasingly popular – all held at the MS Centre, Dutton Park.

There are two further avenues for providing information which also generate much valuable consultation and feedback for services staff. These are regional client gatherings and professional seminars. They visit 12 key locations statewide over a 24 month cycle.

Publications and related resources have been well received in recent years. booklets on **Continence issues, Sexuality and Relationships and Cognition** have been widely circulated among people with MS. Video series addressing **relationship issues and the impact of MS** and **Children of People with MS** have now been produced with corporate sponsor support.

Table 5.23: Primary carers of people aged under 65 years, by carers age group and assistance needed, 2003

	15-64 years		65+ years		Total 15+ years	
	No.('000)	Per cent	No.('000)	Per cent	No.('000)	Per cent
Need for and receipt of assistance						
Receives assistance and:						
Does not need further assistance	64.1	34.3	6.0	39.0	70.0	34.7
Needs further assistance	22.6	12.1	2.1	13.7	24.7	12.2
Does not receive assistance and:						
Needs assistance	15.3	8.2	1.0	6.9	16.4	8.1
Does not need assistance	84.7	45.4	6.2	40.5	90.9	45.0
Total	186.7	100.0	15.3	100.0	202.0	100.0
Availability of fall-back carer						
Available	120.5	64.5	6.8	44.5	127.3	63.0
Not available	50.5	27.1	7.1	46.2	57.6	28.5
Don't know if available	15.7	8.4	1.4	9.3	17.1	8.5
Total	186.7	100.0	15.3	100.0	202.0	100.0
Need for and receipt of respite care						
Received in the last 3 months and:						
Does not need further care	*6.2	*3.3	**0.2	**1.5	*6.5	*3.2
Needs further care	10.4	5.6	**0.5	**3.5	10.9	5.4
None received in the last 3 months and:						
Does not need care	*6.7	*3.6	**0.7	**4.7	*7.4	*3.7
Needs care	*7.0	*3.8	**0.9	**5.6	*7.9	*3.9
Never received respite care and:						
Does not need or want care	139.7	74.8	12.9	84.6	152.6	75.5
Needs care	16.7	8.9	-	-	16.7	8.3
Total	**186.7**	**100.0**	**15.3**	**100.0**	**202.0**	**100.0**

Notes

1. Includes primary carers aged 15 years or more living in households with the main recipient of care.
2. Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
3. Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file