



'What Carers Want?'
Carers NSW Survey 2008 Report

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This report was prepared by

Carers NSW
Level 18, 24 Campbell Street
Sydney NSW 2000
(PO Box 20156 World Square NSW 2008)
T: 02 9280 4744
F: 02 9280 4755
E: contact@carersnsw.asn.au
W : www.carersnsw.asn.au

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1. Executive Summary

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependency, chronic condition, terminal illness or who is frail. There are an estimated 750,000 carers living in NSW (ABS, 2004). Of these, 149,700 are primary carers.

Carers usually provide ongoing assistance to the care recipient related to core activities of self-care, mobility and communication.

Caring may include the direct provision of life sustaining activity, and may also include the added value of consideration, comfort and emotional support that gives quality to the life of the care-recipient. The role of a carer is often demanding, stressful and complex, yet it can also be highly rewarding and valuable to both the carer and the care recipient. Carers provide a vital economic contribution to the community by replacing the high costs of formal care through the provision of informal care at home and in the community. It has been estimated that carers' efforts nationally save the government \$30.5 billion annually (Access Economics, 2005).

Carers NSW conducted a survey in October 2008 to collect demographic data about Carers NSW members, non member carers, care recipients and information about the caring role and the then relevance of the Carers NSW 2008/2009 Budget Submission. The survey was distributed via mail to approximately 3,000 members of Carers NSW, as well as other organisations. The survey was also available on the Carers NSW website. The final sample size was 654 respondents, with good representation from metropolitan Sydney and regional and rural NSW. The amount of written comment and depth of considered responses to questions in the survey was reflective of carers lived experience. It was clear that despite being extremely time-challenged, often in poor physical health, and often very stressed, carers in NSW found it very important to have their voices heard on issues of concern to them. Carers are experts in their own needs and it is their own voices that best illustrate their situations and experiences.

The key recurrent issues identified by survey respondents were the need for more respite services, accessible and adequate services in general, better financial assistance, more information and support for carers and greater awareness of carers in the community by health professionals and governments. These issues were also echoed in the *Who Cares...? report of the Better Support for Carers Inquiry* released in May 2009.

Carers NSW thanks Associate Professor Michael Fine, Department of Sociology, Macquarie University, for his valuable advice and input into the survey design and Ms Carin Bertmar, intern student, Macquarie University, for her diligence and patience with data entry and statistical analysis of a large number of the survey responses.

Carers NSW also acknowledges and thanks the many carers who participated in this survey. This report would not have been possible without their time, and generosity in sharing their caring experience.

2. Introduction

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

Carers NSW' vision is that caring is accepted as a shared community responsibility, and that all carers in NSW are recognised, valued and supported by the community and by governments.

Carers NSW, in its role as the peak organisation representing informal carers across NSW, aims to ensure that carers are recognised as an integral part of the community, and aged and community care sectors.

Carers are pivotal to both the community care and public health systems. Some carers provide care for short, intensive periods of time following discharge from hospital. Others provide care intermittently for someone between hospital visits. Others have provided full-time care for many years to people requiring ongoing medical treatment and community support. Some have cared full-time for people with severe and/or multiple disabilities for the lifetime of the care recipient.

With nearly one in eight people in NSW taking on a caring responsibility, Carers NSW strongly believes support for carers is a beneficial and cost effective investment for Australian and NSW Governments. Carers are a valuable resource for governments and are essential for the effective operation of aged and community care and health systems in NSW.

3. Survey Methodology

3.1 Design

Carers NSW Survey 2008 was designed to collect demographic information about carers in NSW. The purpose of the survey determined the type and number of questions posed. The recommendations from the previous Carers NSW carers survey (*Carers NSW Survey 2004*) were also incorporated into this survey design. These were to clearly distinguish between the carer and care recipient, identify the number of care recipients and identify the number of years carers have spent caring.

These resulted in a clearer picture of Carers NSW carer membership and other carers, and the services they require.

3.2 Distribution

A copy of the Carers NSW Survey 2008 may be found in Appendix A of this report. The survey was distributed via mail in October 2008. A reply paid envelope was included to facilitate response.

The survey was also available on the Carers NSW website for download or online submission.

The survey was not distributed to carers younger than 18 years, since an approval from an ethics committee was not sought.

In addition, 50 surveys were distributed at a Carers NSW "Carers Awareness Training" workshop held for employees and management of NSW RailCorp during October 2008.

All participants were requested to complete and return the survey before 24 October 2008. The deadline was extended as a large number of surveys were received during November 2008. All surveys received by mail or through the website by 30 November 2008 were included for analysis.

3.3 Data recording and analysis

A total of 663 completed surveys were received, giving an overall response rate of 22%. Five-hundred-and-seventy-eight questionnaires were returned by mail, one by facsimile and 84 carers responded to the survey online. Nine returned questionnaires were excluded from the final sample because eight people were no longer carers, and one carer did not want to answer the questionnaire, giving the final sample size of 654 carers (n=654).

Quantitative data was analysed using the Statistical Package for Social Sciences (SPSS) for analysis. There was also a dense amount of qualitative data in response to the open questions. Qualitative data was extracted by identifying key themes and issues, recording both the overall number of comments and selecting quotes to provide indication of typical responses. Suggestions for strategies, solutions and changes of personal circumstances of carers relevant to the status of their membership were also recorded.

Some comments by respondents have been included in boxes in appropriate sections of this report.

3.4 Sample

The sample is not representative of all carers in NSW in strict statistical terms since random sampling was not undertaken. It is important to keep in mind that selection bias may exist because the carers who responded to the survey may be more inclined to answer these types of questions due to their socioeconomic or cultural backgrounds; or because they were members of Carers NSW and knew the organisation.

However, the number and range of responses received and the consistency between the data collected and the findings of other carer research support the legitimacy of the issues raised throughout the report.

Importantly, the response rate from metropolitan Sydney (51.3%) and regional and rural NSW (44.5%) carers provide some insight into caring across the state.

4. Results of the Survey

4.1 Respondent profile

Section 1 (Questions 1 to 9) of the survey gathered profile information about the survey respondents such as their age, gender, cultural background, whether they are in the paid workforce or not, and their living situation. The results are shown in Table 1 below.

Table 1: Respondent profile

Gender	<ul style="list-style-type: none"> ▪ 79.5% female ▪ 20.2% male ▪ 0.3% did not answer
Age of respondent¹	<ul style="list-style-type: none"> ▪ 0.3% 20 to 24 years ▪ 2.3% 25 to 34 years ▪ 11.2% 35 to 44 years ▪ 20.9% 45 to 54 years ▪ 28.3% 55 to 64 years ▪ 19.2% 65 to 74 years ▪ 17% 75+ years ▪ 0.8% did not answer
Living situation	<ul style="list-style-type: none"> ▪ 58.3% were home owners without a mortgage ▪ 23.1% were home owners with a mortgage ▪ 6.3% were living in private rental ▪ 5% were living in Department of Housing accommodation ▪ 0.3% were living in Aboriginal Housing ▪ 4.4% were living with extended family

¹ Originally recorded in age brackets characterised by five-year increases (eg. 20-25; 25-30; 30-35 etc.). To clearly depict and analyse the data on numbers of older carers (55 years of age and above), the data in this report is represented in ten-year age brackets.

	<ul style="list-style-type: none"> ▪ 2.1% were living in retirement village ▪ 0.2% were living in shared housing ▪ 0.3% did not answer
Carers' residence	<ul style="list-style-type: none"> ▪ 51.3% metropolitan Sydney ▪ 44.5% regional and rural NSW ▪ 1.3% interstate ▪ 3.2% did not answer
Main source of income	<ul style="list-style-type: none"> ▪ 21.7% received an income from employment ▪ 37.1% received government payments and allowances ▪ 29.5% received superannuation, a pension or were self-funded retirees ▪ 1.3% were supporting themselves by their own means ▪ 10.4% received an income from other person (husband or wife or a family member)
CALD	<ul style="list-style-type: none"> ▪ 12.4% of carers surveyed were from culturally and linguistically diverse backgrounds
Languages spoken at home	<ul style="list-style-type: none"> ▪ 8% spoke a language other than English at home: Cantonese, Italian, Greek, Spanish, Mandarin, Punjabi, Filipino, Arabic, Dutch, Turkish, Urdu and Khmer
ATSI	<ul style="list-style-type: none"> ▪ 1.8% of carers surveyed identified themselves as Aboriginal

At a glance:

- The minority categories of carers were males (20.2%); those under the age of 45 (13.8%); those who work full-time (12.7%) or support themselves by their own means (1.3%); carers from culturally and linguistically (CALD) backgrounds (12.4%) and Aboriginal carers (1.8%). Although the numbers were small, and in many cases cannot be used to create broader generalisations, some of their responses will be discussed in the survey report.
- The majority of respondents (79.5%) were women. In comparison with the 2003 ABS Survey of Disability Ageing and Carers (SDAC)² findings (in which 54% of all carers in NSW were women) there is a skew towards female carers in the Carers NSW survey sample. However, if the number of primary carers in the Carers NSW survey sample (66%) is compared with the numbers of *primary* carers in NSW (72% of primary carers are women) then the difference between the two samples is less pronounced.
- One half the respondents (58%) were owners of their homes without a mortgage and about one quarter (23%) were home owners with mortgages. Only 6% of carers surveyed lived in private rental accommodation and a further 5% lived in social housing. These results differ from the 2003 SDAC data for NSW which showed that the corresponding numbers of carers/homeowners without (33.4%) and with a mortgage (33%) were smaller than in the Carers NSW survey sample. In addition, the number of carers who lived in private rental is larger in the 2003 SDAC (14%) than in the Carers NSW survey sample. These (somewhat contradictory) findings may be partially explained by the prevalence of older carers in the Carers NSW survey sample (55 years of age and older) who are more likely to be home owners or with a mortgage (ABS, 2008a).
- Eighty-four (12.4%) of the survey respondents were from CALD backgrounds. Almost a half (39) were responses collected from carer-employees of NSW RailCorp. The low number of carers from CALD backgrounds could be partially explained by lack of translated surveys in several community languages. It is possible that many members of Carers NSW from CALD backgrounds did not return surveys as questions were provided in English only. This raises a concern that the needs of CALD carers may not be heard and represented through a mainstream data collection such as this.

² The 2003 Survey of Disability, Ageing and Carers (SDAC) is the Australian Bureau of Statistics preferred source for carer estimates, although it also publishes other surveys that include carer statistics. The ABS is conducting the 2009 SDAC and data will be published in 2010.

4.2 Diverse roles of carers

Section 2 (Questions 10 to 15) of the survey was devised to gather specific information about the caring role, such as the number of people cared for, the existence of secondary carers, the length of the caring role and the existence of social and emotional support. Multiple responses were allowed in these questions to capture the diversity of caring relationships.

The results demonstrated that the majority of carers surveyed provide care for one care recipient (77%), although 101 carers (or 15%) indicated that they provide care for two care recipients. There were 18 carers (or 2.8%) who provided care for more than two people at the same time; and this was the case for inter-generational carers, who care for their elderly parents or relatives as well as children with a disability.

The categories breakdown (see Chart 1 below):

- 37% of carers provide care for their spouse or partner
- 23% provide care for an adult child
- 19% provide care for a child under the age of 18.

These findings correspond with the 2003 SDAC statistics that indicate the partner is the main recipient of care (40%), followed by a child (29%).

Graph 1: Categories of Care Recipients

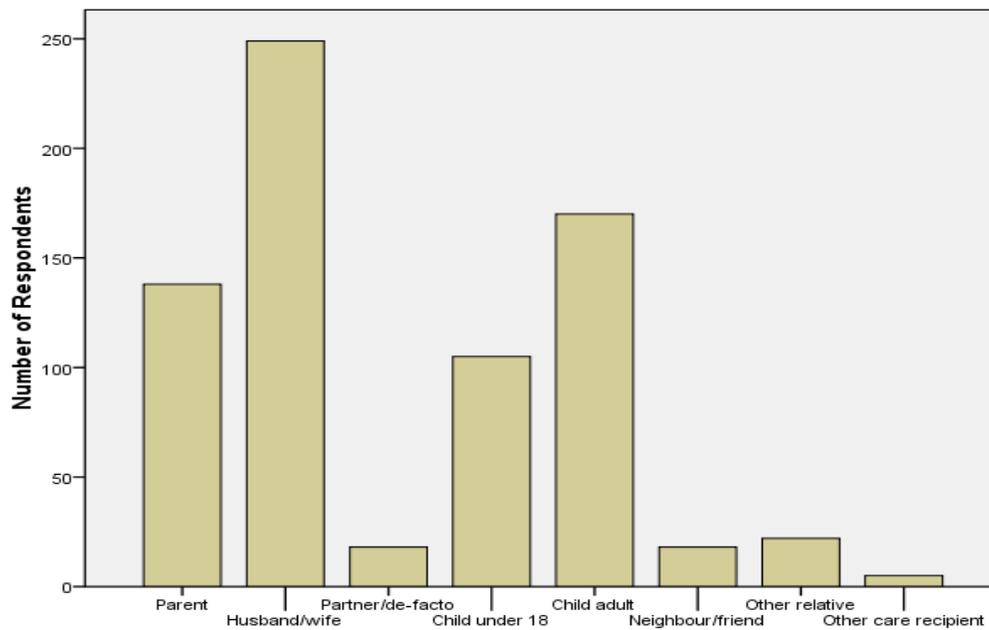
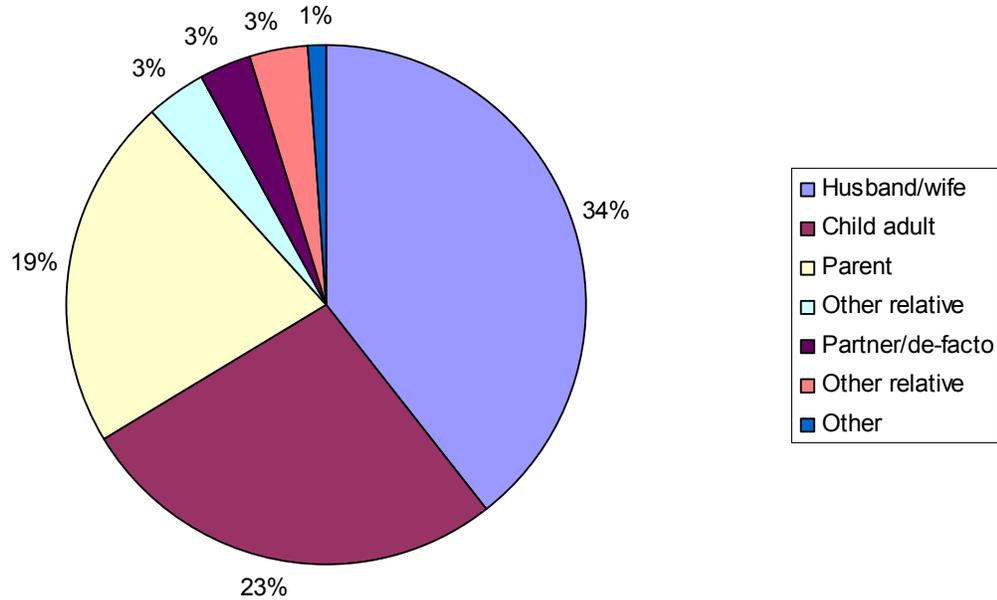


Chart 1: Categories of Care Recipients (percentage breakdown)



The majority of carers surveyed (64%) indicated that they are the only ones providing care. Only 16% of carers indicated their partners or spouses helped with the tasks of caring.

The reported average length of the caring role is long. The survey results reveal that 38% of carers have cared longer than 10 years (15% of carers reported between 10 and 15 years in the caring role, and 23% reported more than 20 years spent caring). There is also a large percentage of people (22%) in 'less lengthy' roles (6-10 years), as Graph 2 below illustrates.

Twenty-eight per cent of respondents indicated that their average length of caring per day is between 16 and 20 hours, with another 23% of carers who indicated that caring takes up to 5 hours per day. This grouping of results could probably be explained by the fact that quite a large number of carers surveyed (48%) reported "out of home activity" such as paid work (part-time and full-time), education and volunteering. The different caring requirements necessary for different types of disabilities or conditions of the care recipients may also have contributed to this grouping of results. Further statistical analysis is required to confirm this explanation.

Graph 2: The length of caring role (in years)

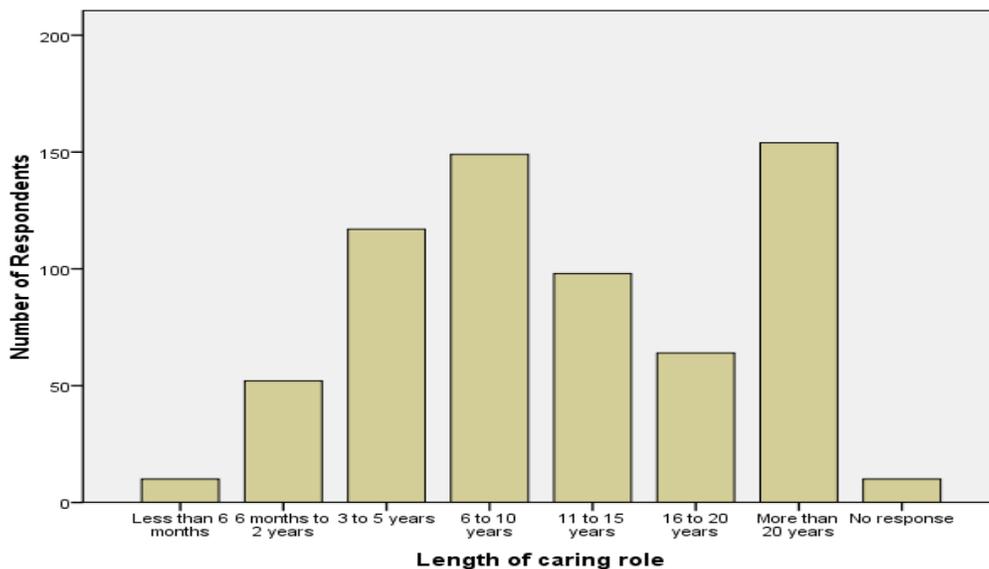
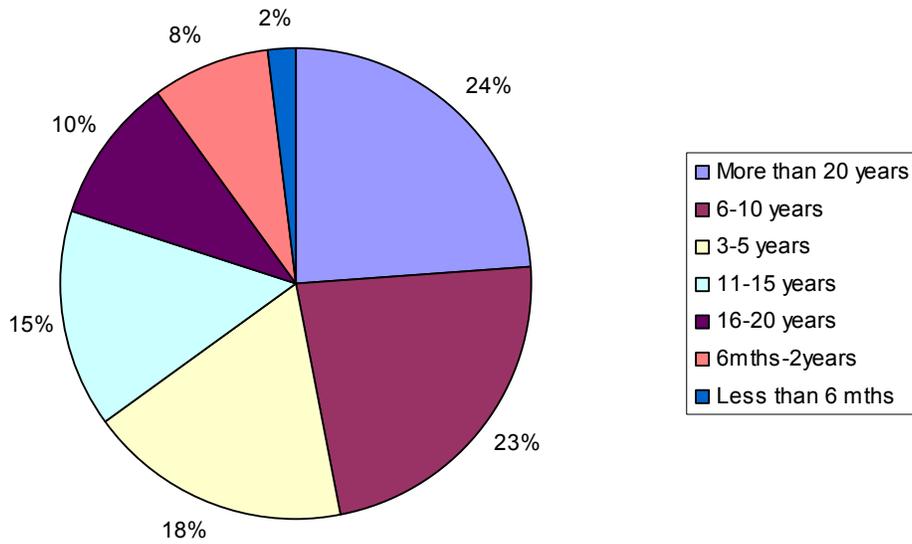


Chart 2: The length of caring role (percentage breakdown)



About half (51%) the respondents indicated their reliance on family and friends for social and emotional support, in comparison with support groups (18%), counsellors (6%) and employers (2%). Also notable was that 156 of carers surveyed (or 15%) indicated that they did not receive any support in their caring. It would be worth examining further these reasons and whether this survey provided incentive to seek help from services for this last group of the survey respondents.

Overall, the caring role of respondents was long in years of caring, and also demanding as reflected in hours per day dedicated to the care recipient. A large number (51%) of all respondents cared more than 10 hours per day. Thirty two (or 5%) of survey respondents indicated that their role was a 24-hour duty. Only one quarter of respondents (23%) had a less lengthy caring role of 1 to 5 hours per day, as seen in Graph 3 below.

Graph 3: The length of the caring role (in hours)

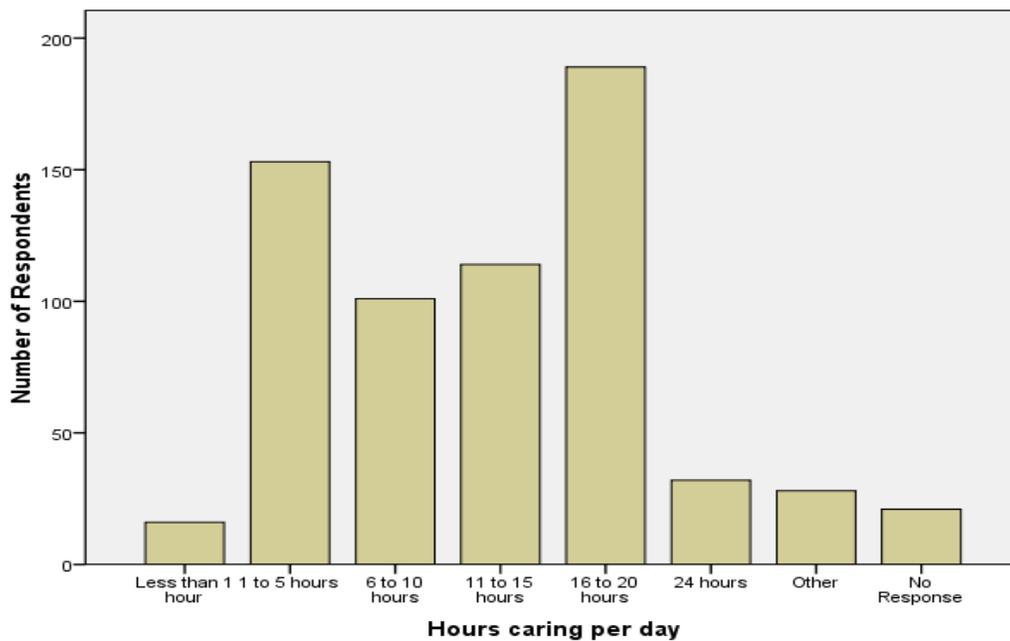
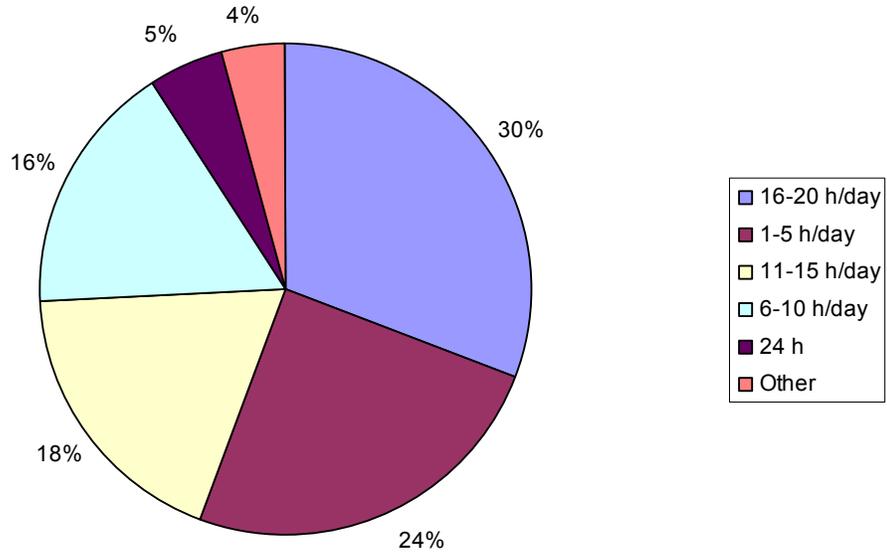


Chart 3: The length of caring role (percentage breakdown)



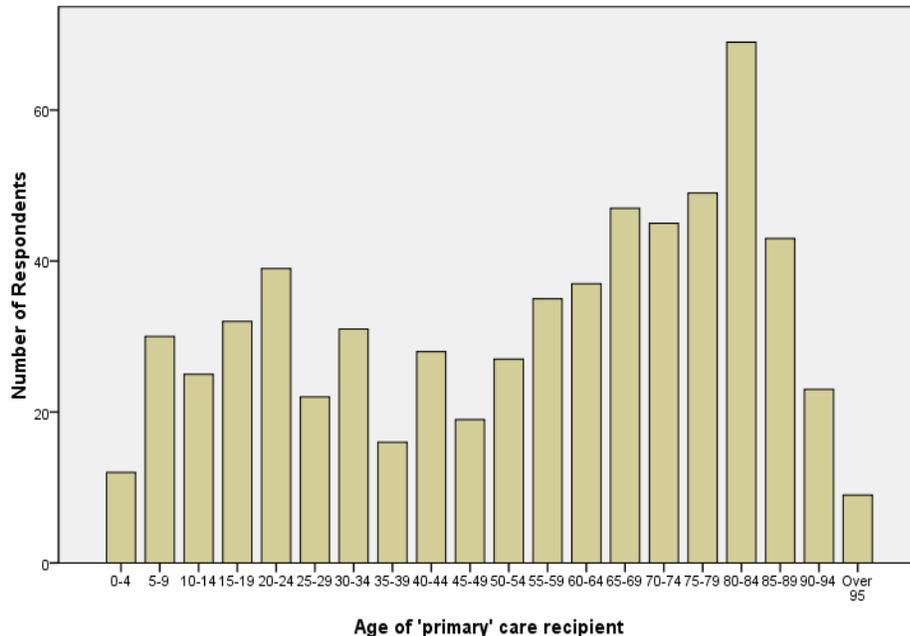
4.3 The profile of care recipients

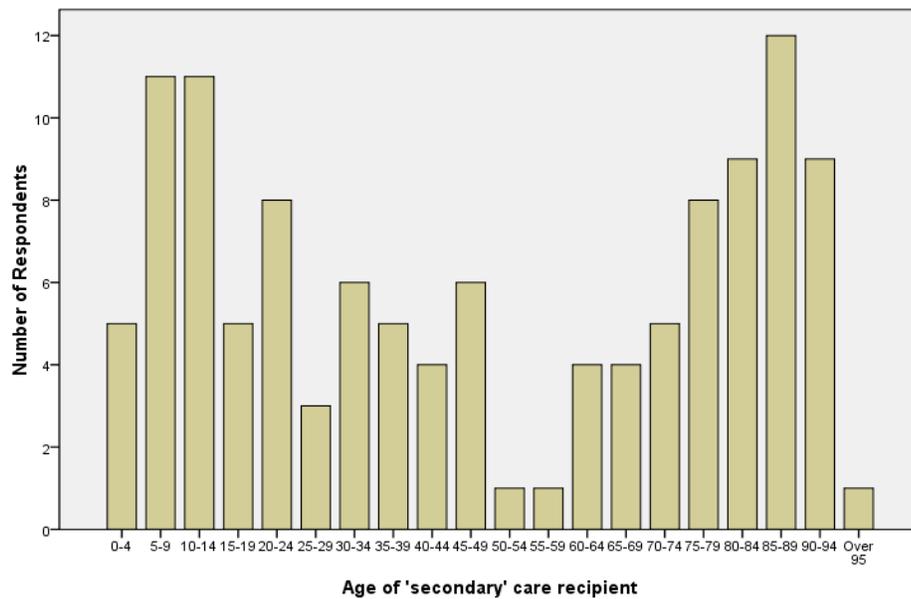
Section 3 (Questions 16 to 33) of the survey was designed to collect specific information about the care recipients such as their age, gender, their illness or condition, cultural background and type and level of their income.

To acknowledge multiple caring roles, Section 3 was separated into two columns to collect data about care recipients separately, providing space to indicate if there were more than two care recipients.

The 'primary' care recipient (or care recipient 1, as it appears in the graphs) was more likely to be male than female (56% of the 'primary' care recipients were males) in comparison with the larger percentage of females as 'secondary' care recipients (55%). However, a relatively small number of 'secondary' care recipients (118 overall or 18%) and their age brackets suggests that the two categories of care recipients are quite different. The 'primary' care recipients tend to be elderly parents or elderly partners, while the category of 'secondary' care recipient is equally divided between children or younger dependants and elderly parents/partners (as shown in Graphs 4 and 5 below).

Graphs 4 and 5: Differences between 'primary' and 'secondary' care recipient





The differences between 'primary' and 'secondary' care recipients are also reflected in the type of condition or illness they had. The 'primary' care recipients were reported to have illnesses and conditions characteristic of older age such as frailty and dementia, plus neurological disability, cancer and chronic illness. The 'secondary' care recipient category revealed an almost equal number of occurrences of mental illness, physical and intellectual disability, but also ADHD, Down and Asperger's Syndromes.

Both categories ('primary' and 'secondary' care recipients) relied almost equally on government benefits and allowances as their main source of income (69% of the 'primary' care recipients and 66% of 'secondary' care recipients).

4.4 Carer workforce participation and level of income

Question 9 asked respondents to indicate their level of paid workforce participation by choosing the most applicable option for their current situation.

The majority (42%) indicated that they were not currently in paid employment. Only 12.7% of respondents indicated that they have a full-time job, in comparison with 17.8% of carers who are employed on a part-time basis. A small number of participants also indicated that they were presently studying while out of the paid workforce or combining study with part-time work. The survey findings are similar to ABS data which showed that 45% of all carers in NSW are not in paid work due to their caring responsibilities (ABS, 2004).

Graph 6: Carers occupation

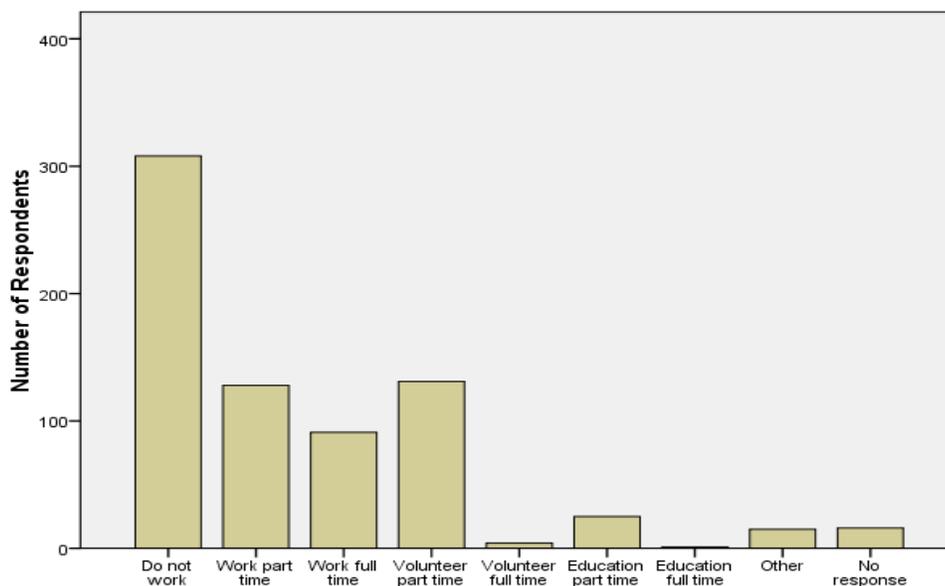
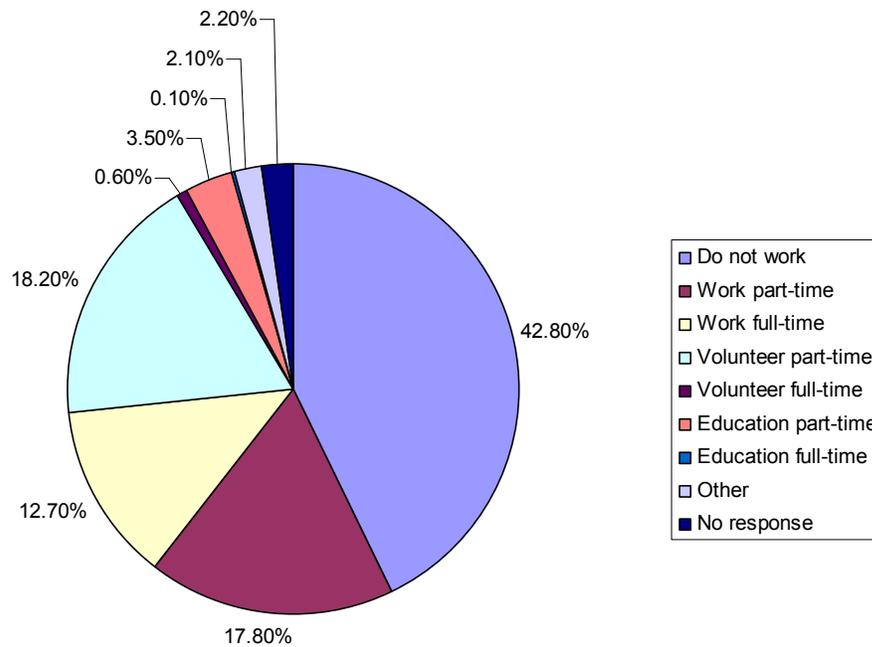


Chart 4: Carers occupation (percentage breakdown)

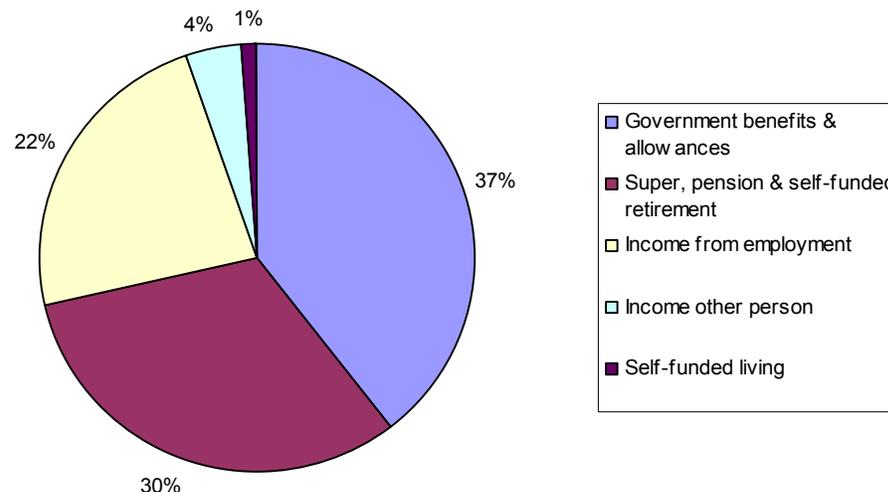


Participants were also asked to indicate their main source of income. Only 21% indicated their income comes from employment, and 37% of carers surveyed relied on government allowances as their main source of income (in the form of Carer Payment and/or Carer Allowance).

The 2003 SDAC data had a different picture about carers' sources of income: 42% of all carers in NSW had indicated that salary was their main source of income as opposed to 37% of carers who were reliant on government benefits and allowances. The differences between the Carers NSW Survey 2008 and ABS data may be due to the greater presence of older carers in the Carers NSW sample (64% of respondents as compared to 35% in the 2003 SDAC sample).

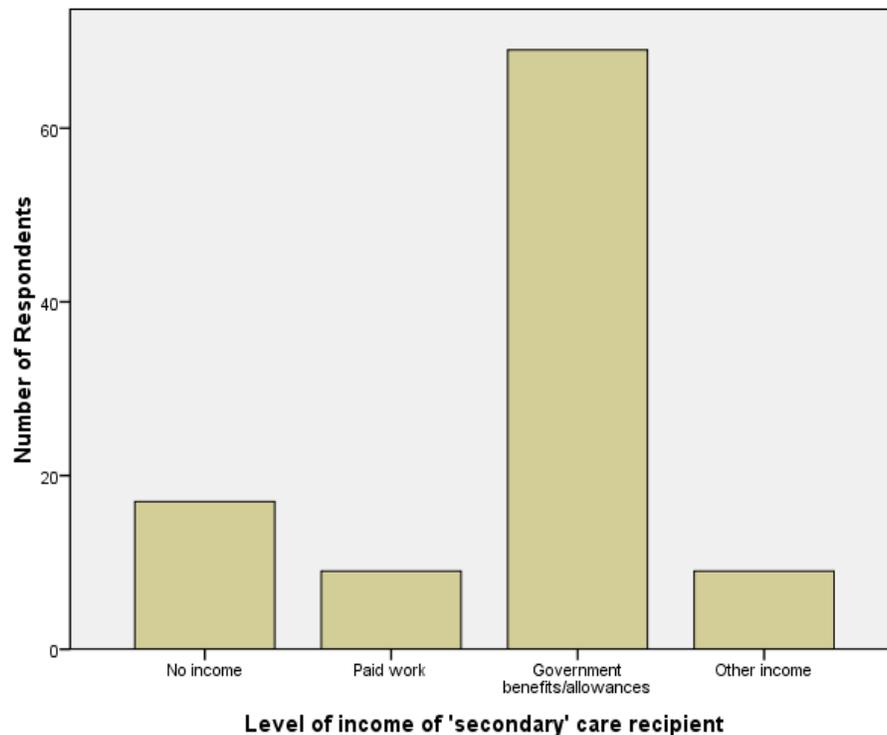
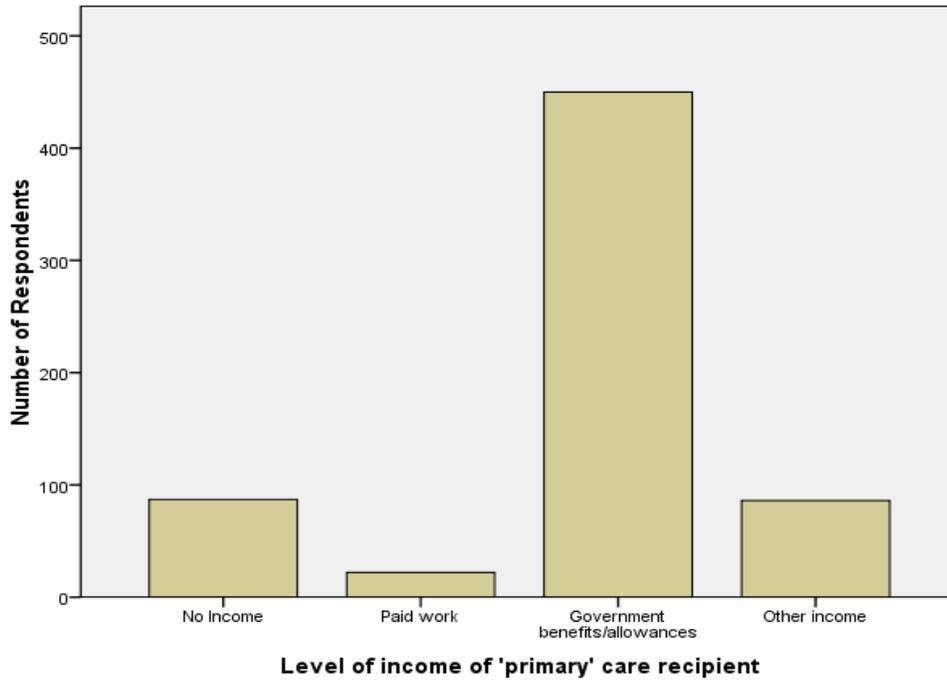
More than a quarter of respondents (or 29%) of the Carers NSW survey reported their income as being the age pension or superannuation (or other form of self-funded retirement). Only 1.3% of respondents to the Carers NSW survey were financially self-reliant and received an income from their business or assets (workers compensation, own business, rent from property and book royalties were some of the things mentioned). A small percentage of respondents (10%) were reliant on other family members' income (husband or wife or other family member).

Chart 5: Carer sources of income (percentages breakdown)



The findings on incomes of care recipients were similar. The overwhelming majority (70%) of care recipients received government benefits and allowances (mainly in the form of disability support pension, age pension and veterans' affairs pension). Only 3.4% indicated income from paid work. Eighty-seven care recipients (13.5%) received no income and were completely reliant on their carers for financial support. The findings for the 'secondary' care recipients were similar, as illustrated in Graphs 7 and 8 below.

Graphs 7 and 8: Incomes for Care Recipient 1 and Care Recipient 2



Box 1: Carers comments on their work participation

“No superannuation, financial retirement fund...at times I feel I have no say in my own life as my caring role ties me down and dictates what needs to be done” (male carer, 49 yo, caring for a spouse with a disability)

“Flexibility in the workplace – need to often take mum off to appointments and go to her aid on short notice – this means I need to just drop out of work or use all my annual leave on looking after mum. When I am not earning anything it makes it hard on our finances” (female carer, 58 yo, caring for elderly parents)

“Management where I work doesn’t seem to understand the challenges faced being a carer, trying to focus for 40 hrs per week. They have carers leave, but don’t want to approve it. Take your leave first” (male carer, 37 yo, caring for a child with a disability)

“Sympathetic work environments would help so we don’t feel bad having to take time off all the time” (male carer, 42 yo, caring for elderly parents)

“The lack of superannuation for us is a big issue, and the need to buy equipment to make my husband’s and my life easier as it is hard to get funding without a case manager” (female carer, 57 yo, caring for a partner with dementia)

“Caring for someone is very expensive, especially when I can’t work. Funding should be given regardless of income” (female carer, 45 yo, caring for her elderly mother)

“Better assistance for full-time working carers to maintain work/life balance and carer’s responsibilities” (female carer, 58 yo, caring for her husband with mental illness)

4.5 Use of formal services

Section 4 (Questions 34 to 36) was devised to gauge the level and type of support and services carers received.

Participants were asked to indicate assistance from formal services they receive separately to the services provided to their care recipients, to clearly distinguish between services provided to the carer and services to the care recipient. The findings are illustrated in Graph 9 below.

Graph 9: Formal care services used by carer

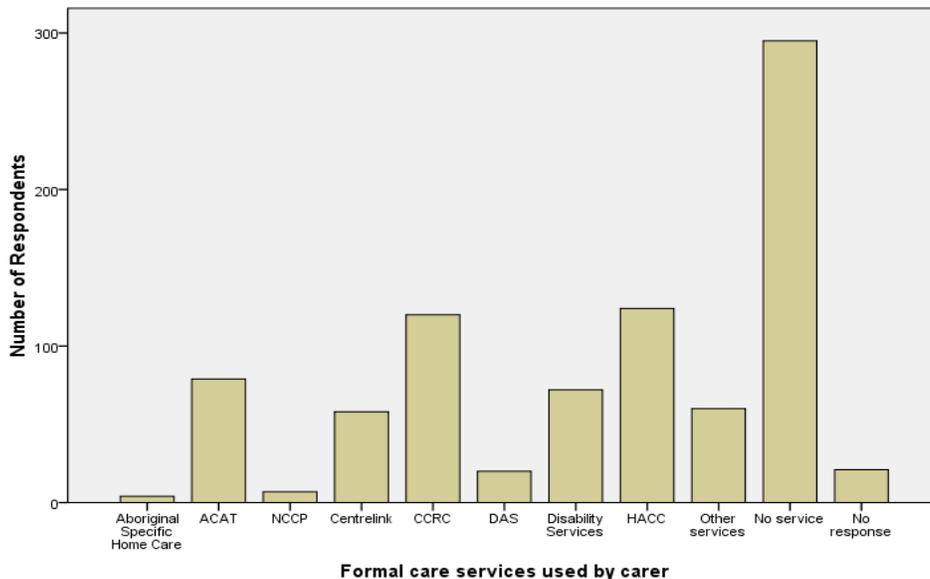
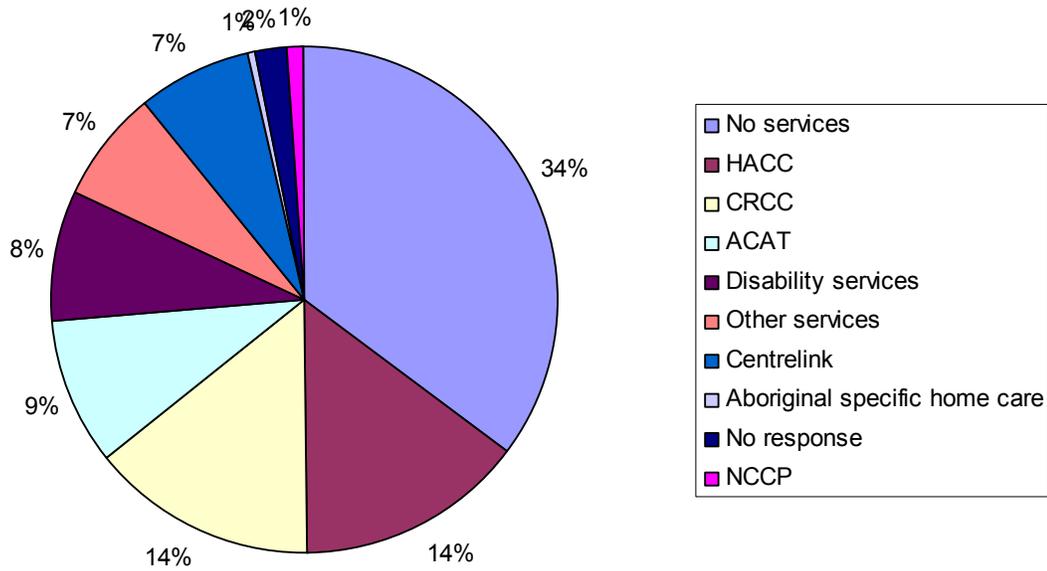


Chart 5: Formal services used by carer (percentage breakdown)



Surprisingly, a large number of carers surveyed (34%) indicated that they receive no services. This finding corresponds with 28% of care recipients who also did not receive services. Of the services used, the most common ones were Home and Community Care (HACC) services, services provided by Commonwealth Respite and Carelink Centres and Aged Care Assessment Teams. Amongst the category of 'other services' used the most commonly cited were respite services provided by non government or community organisations.

In addition to the types and level of services carers currently use, Question 36 asked carers to indicate the types of services they would like to receive to further assist their caring role. Almost one quarter of survey respondents indicated respite (24%) was a priority, followed by carer support groups (15%) and community care services (13%). The results are shown in Graph 10 and Chart 6.

Graph 10: Types of services carers would like to receive to further assist in their caring role

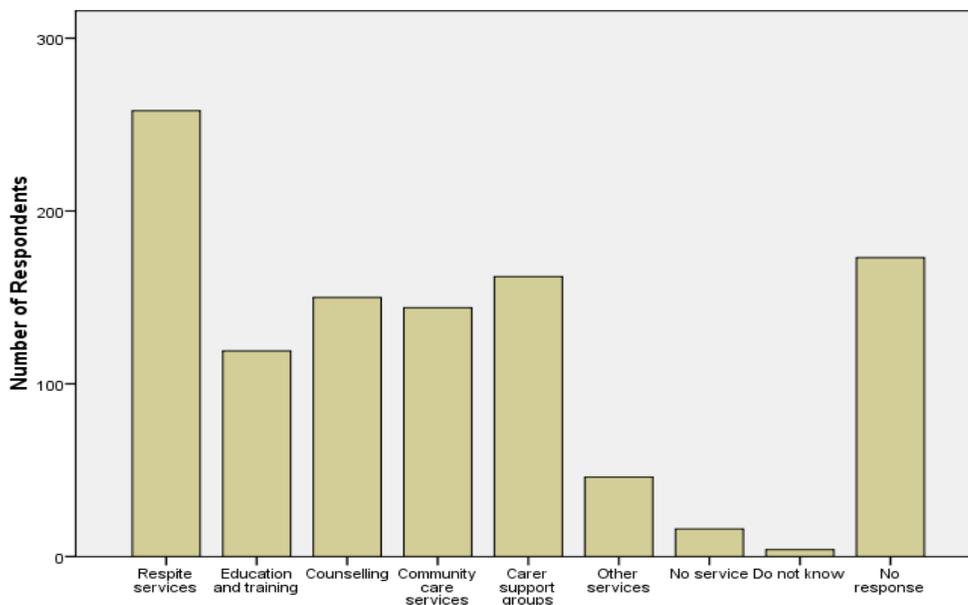
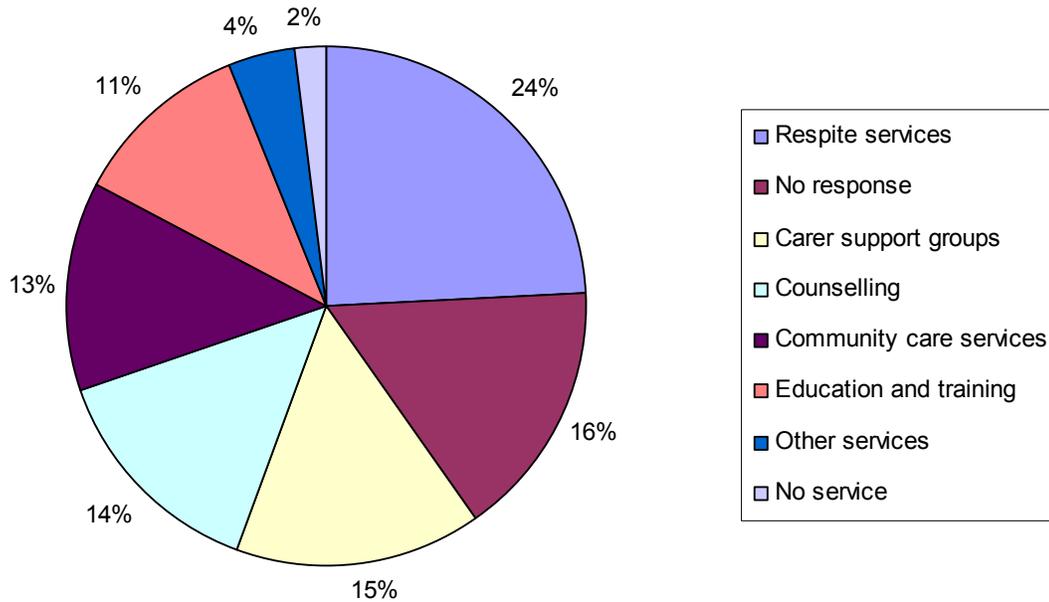


Chart 6: Types of services carers would like to receive to further assist in their caring role (percentage breakdown)



The need for more, better organised respite and accessible and responsive services, in general, were also reflected in qualitative responses carers provided. The wide range of responses indicated simply 'more respite' to specific respite models and services, as well as comments about quality and appropriateness of respite. Qualitative data was grouped in common themes and categories as shown in Graph 11.

Graph 11: What would make your caring role easier or better

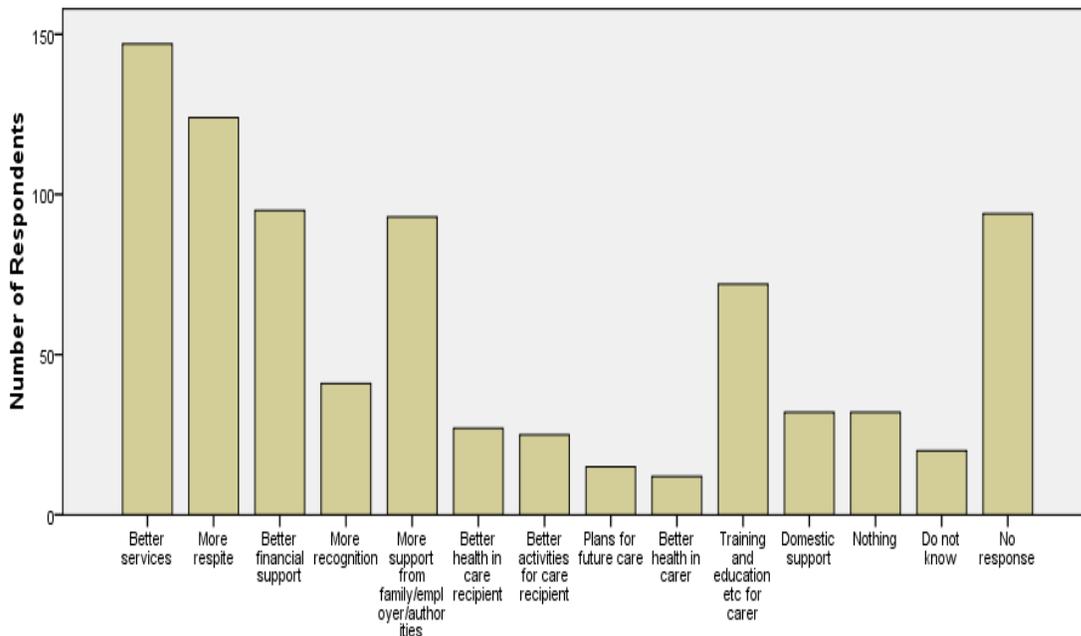
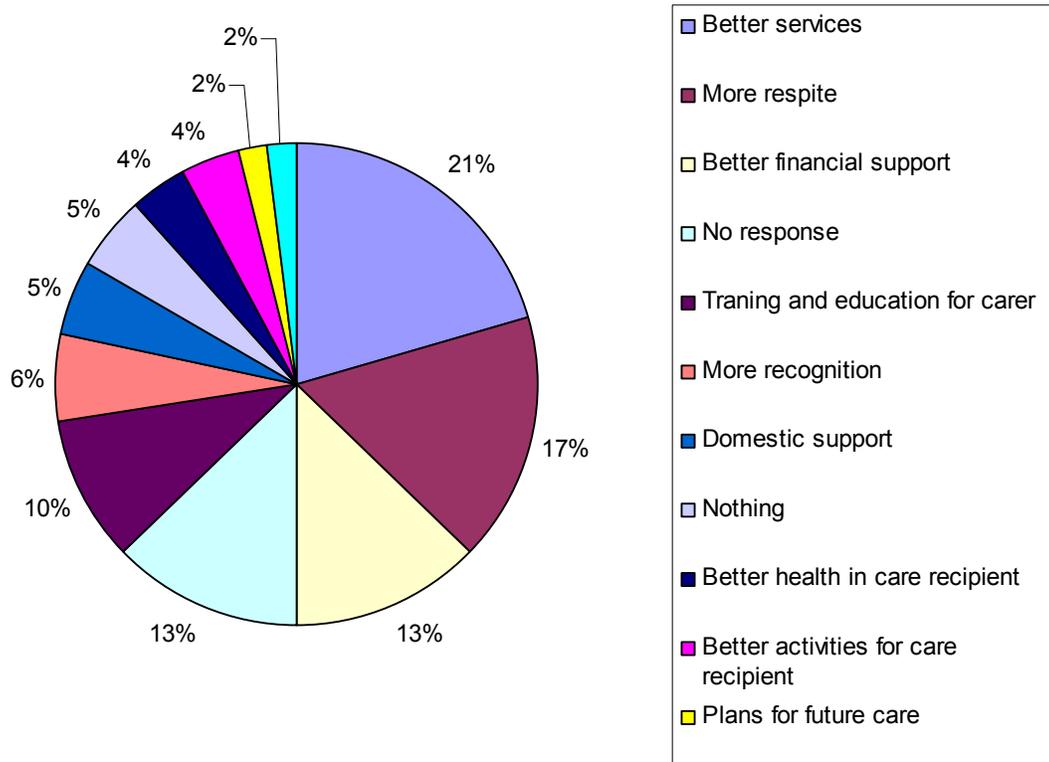


Chart 7: What would make your caring role easier or better (percentage breakdown)



Thirty-eight per cent of carers indicated that better services and more respite would make their caring role better and easier, followed by better financial support (13%), and counselling and education for the carer (10%). Evident also were comments related to carer recognition and domestic support, and better health and activities for the care recipient. (See Box 2.)

These results indicated that many carers feel they are inadequately supported by formal services designed to assist them to continue caring in the community. Awareness of programs and services was apparent. However, various complaints about existing services and comments about access to services (and their availability) were common. This was characteristic of carers of people with a mental illness.

The need for community services and general support was also continually expressed in survey responses. This category encompasses many types of support for both the carer and person they care for, primarily including assistance at home, but also meal delivery and community transport.

The need for financial assistance was apparent but did not take precedence over the need for respite services. Less than a quarter of carers (13%) indicated that financial support would make their role better or easier. Throughout the survey the need for better financial support was apparent but less significant than the need for services. This may indicate that, although carers face financial hardship, the need for more services and support and the frustration faced in trying to get these services outweighs financial concerns. However, it also must be noted that for many restricted access to services may be a result of inadequate financial support.

Box 2: Carers comments on improvements for their caring role

“Better financial support from the government. Many of us carers don’t have any superannuation and we can’t plan anything for our uncertain future. The Carer Payment rate should be increased from 25% of average weekly earnings, to 35%. It means an increase of the base rate of this payment. The Carer Allowance should be increased to at least \$200 a fortnight”³ (male carer, 56 yo, caring for a spouse with a disability)

“I feel blessed to enjoy a level of support from my mum and children which is incredibly rare in my experience with other carers, many of whom feel totally isolated and struggle” (female carer, 57 yo, caring for an elderly father)

“Provide a non-means tested concession card for people with chronic illness, who are unable to work and are supported by their working partner. The current system does not consider the huge medical/pharmacy burden”⁴ (female carer, 47 yo, caring for a child with a disability)

4.6 Social isolation

Carers are more likely than the general population to have little face-to-face contact with friends and relatives outside the household, especially when caring for someone with high level care needs (Edwards et al, 2007). Carers in general also have the lowest level of wellbeing with single parent carers being affected the most by the negative impacts of caring (Deakin University, Australian Unity and Carers Australia, 2007).

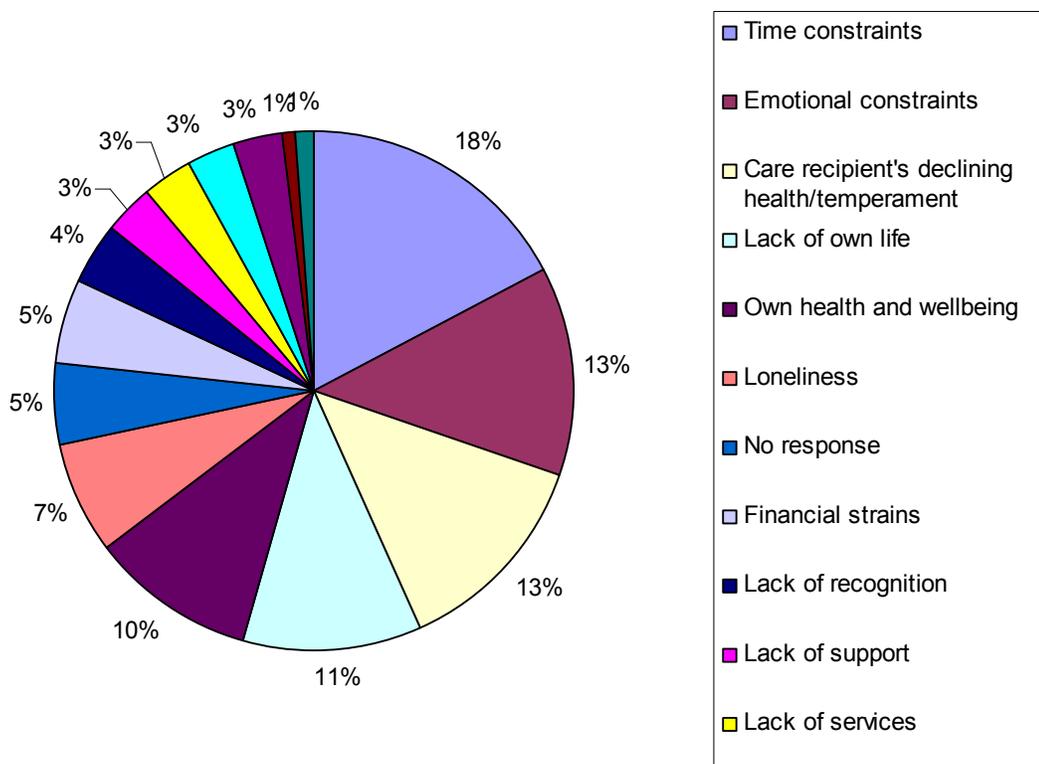
The Carers NSW Survey 2008 did not have a separate category about social isolation so it has not been possible to ‘quantify’ and measure its occurrence, although many carers expressed their feelings of loneliness and the burdens of social isolation.

The data collected from qualitative responses to Question 39 (“What is the most difficult part about being a carer?”) was illustrative of the negative impacts of caring. Amongst these, social isolation was the most common concern for carers. Social isolation also had an impact on carers’ personal relationships. For example, 141 carers indicated that the hardest part of being a carer was the emotional burden, followed by loneliness (79 carers) and strain on other relationships (32 carers). One-hundred-and-eleven carers had concerns about their own life and wellbeing, and a further 187 wished they had more of ‘their own time’ (see Chart 8 below).

³ From 20 September 2009 a new Pensioner and Beneficiary Living Cost Index (PBLCI) will be a tool used in the calculation of the base rate of the pension for age, disability, carer, widow and veteran service pensioners. These payments will also be benchmarked against wages, as measured by Male Total Average Weekly Earnings (MTAWE), and will effectively increase from 25 to 27.7% of MTAWE for a single person.

⁴ Pharmaceutical Safety Net Arrangements may not be sufficient for carers of families with high medical and pharmaceutical costs.

Chart 8: Most difficult part about being a carer (percentage breakdown)



Box 3: Carers' comments on social isolation

“Social network for carers and care recipient. Isolation being the biggest problem” (male carer, 75 yo, caring for an elderly spouse)

“...the stress of caring and social isolation, particularly for us people from CALD background” (male carer from Former Yugoslavia, 56 yo, caring for a spouse with disability)

“No-one understands unless they live it – a lot of people keep away from us. Isolation is sometimes a problem. Lack of money is a huge pressure and difficulty and it really affects everything” (female carer, 45 yo, caring for a teenage son with a disability)

“...the constant barrage of repetitive questions and the social isolation caused by it...you find out who your friends are” (male carer, 73 yo, caring for his elderly wife)

“Feeling alone, afraid and at times like it’s too much for caring on my own. Feeling like other people – relatives, friends really have no idea what it is like for me and my husband” (female carer, 61 yo, caring for a spouse and a son with disabilities)

4.7 Carers from regional and rural areas

Just over half of respondents (51%) were living in the greater Sydney metropolitan area (comprising the NSW Department of Ageing, Disability and Home Care (DADHC) Metro North and Metro South administrative regions). Around 44% of respondents were living in regional and rural areas of NSW (corresponding to DADHC Hunter, Northern, Southern and Western regions), including the regional cities of Wollongong, Newcastle and Dubbo.

Although a cross tabulation of the data has not been undertaken to test the relationship between living in rural and remote areas and access to services, the evidence collected from qualitative data shows that access to services is limited in rural and remote areas. This poses significant difficulties for carers living outside major cities, particularly if they are carers of a person with mental illness or intellectual disability.

Box 4: Comments from carers from regional and rural NSW

“More affordable and accessible counselling, especially in regional areas. Affordable computer courses in short block that would fit in with respite. TAFE courses not an option because of length of day and long term commitment” (female carer, 66 yo, caring for a husband diagnosed with dementia)

“...to have services made available in country areas not just to Orange and Dubbo but further west in farming areas...” (male carer, 58 yo, caring for his wife diagnosed with mental illness)

“Mental health services are well below standard west of Orange and Dubbo. What with the drought and pressures of life in the bush. I know these are stretched to the limit as we lost our support worker because he just had too many clients...” (male carer, 58 yo, caring for his wife diagnosed with mental illness)

4.8 Carers of people with mental illness

Research on carers of people with mental illness revealed that carers generally report the range of health, financial and other problems associated with caring for a person with a mental illness (Edwards et al, 2008). Research conducted by the Mental Health Council of Australia and Carers Australia through focus groups with carers, mental health service providers and stakeholders in each state and territory indicated that individual carers on average contribute 104 hours a week caring for a person with mental illness (MHCA and Carers Australia, 2000).

A survey conducted by SANE Australia in 2007 revealed that the majority (70%) of carer respondents had never received any form of training or education to carry out their role, and over a half (54%) had not accessed carer support services of any kind (SANE Australia, 2007).

In the Carers NSW Survey 2008, 169 respondents (26%) identified that they were carers of someone with a mental illness. It is difficult to determine if this is representative of the proportion of carers caring for someone with a mental illness in NSW due to broad definitions of mental illness in general, and possible existence of multiple conditions as indicated by respondents in the Carers NSW Survey 2008.

4.9 Carers' own perception of their caring role

Section 5 (Questions 38 to 40) asked participants to give their comments on certain aspects of their caring role. Specifically they were asked to describe positive and negative impacts of caring and what would improve their caring role (Question 40). A large number of respondents (560 or 87%) had definite answers to this question.

Responses have been recorded and analysed to count frequencies, taking into account the need to preserve the richness and uniqueness of an individual carer's response. Overall results regarding the impact of caring are summarised in Tables 2 to 4 below.

Tables 2-4: Positive and negative impacts of caring

Best part about being a carer	Number of comments
Care recipient looked after well/can stay in own home/has a quality of life	162
Reward/fulfilling/proud/care recipient is grateful	84
To still be able to care/help/support loved one	61
Nothing	55
Time with care recipient/developed closeness	46
To see improved health/happiness in care recipient	41
To receive love from care recipient/to love care recipient	36
It is my duty (or responsibility) to care	21
Changed my outlook on life/I have learnt about disabilities	20
To give back to person who previously has looked after me	14
Other	7
I see myself as a parent, not a carer	6
Support and friendship from other carers	5
Don't know	3

The most difficult part about being a carer	Number of responses
Time constraints	187
Emotional constraints	141
Care recipient's declining health/temperament	140
Lack of own life	123
Carer's own health and wellbeing	111
Loneliness	79
Financial strains	56
Lack of recognition	38
Lack of support	37
Lack of services	33
Strain on other relationships	32
Future care	30

No difficulties	10
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Things that would make caring easier/better	Number of responses
Better services	147
More respite	124
Better financial support	95
More training and education or counselling for carer	41
More recognition	41
Domestic support	32
Nothing	32
Better health of care recipient	27
Better activities for care recipient	25
Plans for future care	15
More sleep/better health of carer	12

4.10 Other issues of concern to carers

The majority of comments in this section were incorporated into prior data, as they expanded on or reiterated concerns by participants addressed elsewhere in the survey. Many respondents thanked and acknowledged Carers NSW for working to improve the support available to carers in NSW.

A number of single comments did not fit into the above categories. These were:

- the system is too complex to deal with
- issues of superannuation for women carers
- criteria too stringent for the Carer Payment
- more sensitivity and understanding from Centrelink
- assistance to take an occasional holiday
- the need to educate GPs and specialists about carers
- the need for referrals and support at the start of the caring journey
- the need for simpler and streamlined access and services.

4.11 Recommendations to the NSW Government about how to best support carers

Each year Carers NSW provides a budget submission to the NSW Government with a set of recommendations about how to best support carers in NSW. The data collected from this survey has informed the Carers NSW 2009/2010 Budget Submission and its recommendations.

Respondents were asked to number the recommendations from the Carers NSW 2008/2009 Budget Submission in priority order, with number 1 being the most important and number 9 being the least important. The frequencies are represented in Graph 12 and Table 6 below.

Graph 12: Rating of recommendations

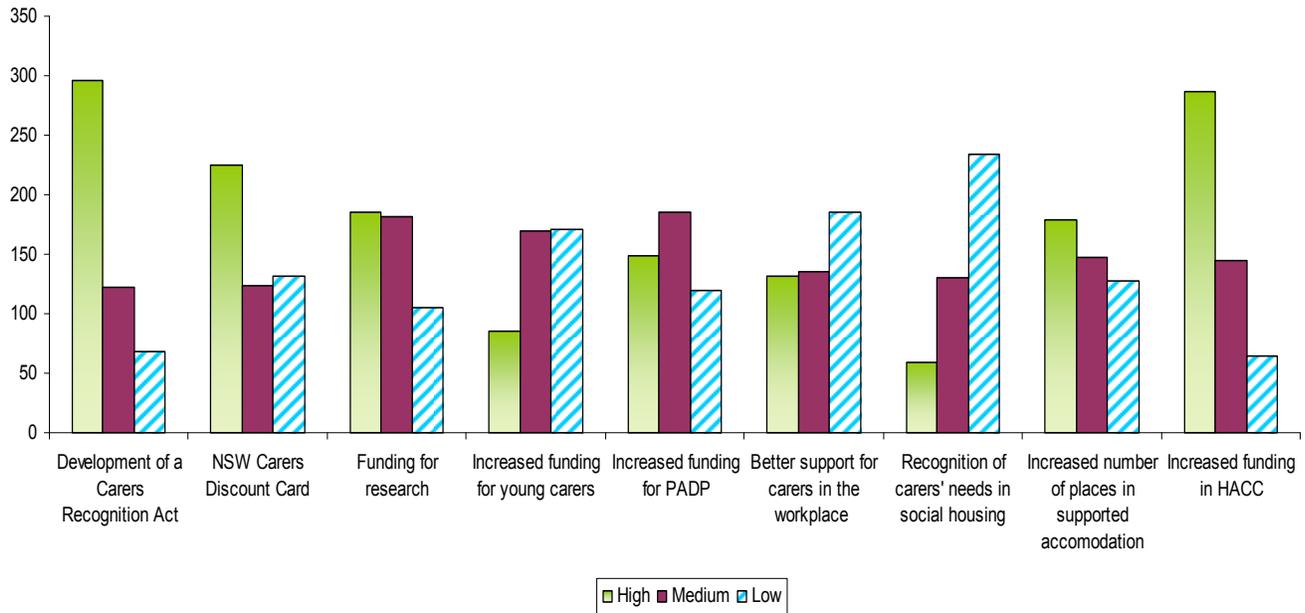


Table 5: Analysis of recommendations

Recommendation/priority	Priority 1	Priority 2	Priority 3	1+2+3= high
Development of a Carers Recognition Act	147	77	72	296
Increased funding in HACC	128	96	63	287
Development of a NSW Carers Discount Card	69	75	81	225
Funding for research	36	70	79	185
Increased number of places in supported accommodation	75	59	45	179
Increased funding for PADP	36	57	56	149
Better support for carers in the workplace	48	38	46	132
Increased funding for young carers	13	36	36	85
Recognition of carers' needs in social housing	9	14	36	59

Table 6 above shows that the three most important recommendations to governments (in order of priority) are **the development of a Carers Recognition Act, a funding increase in HACC and the introduction of the NSW Carers Discount Card**. These recommendations correspond with carers wishes for better services, recognition in the community and to ease the financial burden of caring.

However, some carers expressed the view that all suggested recommendations are equally important and it is hard to isolate some recommendations over others. They suggested that overall carers need recognition in society which, in their opinion, will translate into increased and better services, and improved financial standing.

“All [recommendations] are important and I cannot rank any as being more [or less] important” (female carer, 58 yo, caring for a husband with a physical disability)

Carers also had the opportunity to provide additional recommendations to governments. These responses were grouped into common themes for analysis and are listed in order of frequency below. Multiple responses were received.

Table 6: Additional recommendations

Additional recommendations to governments suggested by carers	Number of responses
<i>Services</i> – more appropriate, accessible, flexible, affordable, safe	167 (23%)
<i>Financial</i> – improved financial support, including utilities discount and help with costs of care and medical costs	155 (21%)
<i>Recognition of carers</i> and their contribution to the society	64 (8%)
<i>Support</i> – appropriate/safe/better quality/accessible	23 (3.2%)

Box 5: Carers comments on additional services

“I am lucky as I have family to call in for respite – it would be difficult if this support was not available” (male carer, 58 yo, caring for aged parents)

“...to lessen criteria to receive Carer Payment. At present these are too stringent and do not take into account the toll carers pay by giving support constantly” (female carer, 72 yo, caring for elderly mother who is 91 yo)

“Services should be flexible and geared to the support needs of the person requiring care. That will in turn help the carers. Carers though should be able to ask for services that they need as well” (female carer, 62 yo, caring for her mother-in-law)

“Recognition of other family members and the essential role they have in caring for the disabled family member. For example; having more than one nominated carer with Centrelink (but only one payment per family) who can share the responsibility of care without having to contact Centrelink, especially as we age and may need to give our children the “power of attorney” responsibilities for our welfare (female carer, 55 yo, caring for a daughter with an intellectual and physical disability, living in regional NSW)

“A better recognition and make it free services” (male carer, 72 yo, caring for an elderly spouse)

“My husband and I are unable to live together at the moment because he has a mental illness and I have suffered an emotional collapse trying to look after him. I no longer receive a Carer Payment because of that separation. I felt it was like a compensation for the superannuation I am unable to earn because I still can’t work” (female carer, 53 yo, caring for a spouse diagnosed with a mental illness)

5. Conclusion

The most significant findings of this survey are:

- The carer population surveyed is predominantly female in older age groups (55 years of age and older), owner occupiers, largely reliant on government benefits and allowances and, to a smaller extent, on superannuation and income from work. The population surveyed is almost equally spread between metropolitan Sydney (and larger regional centres) and rural and regional areas.
- The main types of assistance that carers need are improved services, more respite, better financial support to assist with the increased costs of caring, and recognition of carers by governments and in the community. Although financial assistance was important, it did not take precedence over the need for respite and services.
- The main difficulties experienced by respondents were time constraints and the lack of their own life, health concerns, declining health of care recipient, loneliness and financial strains.
- The top three recommendations to the NSW Government by respondents were the formal development of a Carers Recognition Act, increased funding for Home and Community Care services and the introduction of the NSW Carers Discount Card.
- A higher level of statistical analysis is likely to indicate additional determinants about carer respondents and their caring role.

These findings provide further evidence to support existing knowledge about issues faced by carers. Throughout the responses to the survey the need for formal services and respite to complement the role of carers was apparent. Financial strains were seen as an important issue. The implications of these findings for government and community and aged care sectors are significant as carers are the lynchpin of the community and at-home based care.

From this survey it is evident that carers feel undervalued and unrecognised. Only a small number of carers expressed their satisfaction and fulfilment with their caring role, apart from family obligations and the love they feel for the care recipient.

6. Policy Implications

The result of the Carers NSW Survey 2008 identified several policy implications for consideration by Carers NSW, the NSW Government and the community sector:

- Greater efforts need to be made to improve awareness of carers in the wider community, and amongst service providers and health professionals. It is therefore not surprising that the formal recognition of carers in the form of a Carers Recognition Act received a large amount of support by carers who participated in the survey.
- The provision of services to carers continues to be an issue for carers and care recipients, in terms of accessibility, appropriateness and availability. The greatest need is for more respite services, general community services, services provided within Home and Community Care programs and supported accommodation.
- The provision of a NSW Carers Discount Card received a large amount of support among participants. This is likely to indicate the need for financial support and assistance with the increased costs of caring.
- The *NSW Carers Action Plan 2007-2012* outlines a whole of government policy commitment to recognising and supporting carers over a five year period. It includes strategies to increase the

respect and recognition of carers, reach out to family members who may not see themselves as a carer, improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work and caring. The findings of the Carers NSW Survey 2008 confirm that the priorities outlined in the Carers Action Plan are crucial and their timely implementation is necessary for fundamental improvement of the carers' quality of life.

7. Comments and Carers NSW Survey 2008 recommendations

Most of the recommendations about the survey design from respondents of the Carers NSW Survey 2004 were incorporated in the 2008 survey.

Further investigations could also be made into the demographics of carers in NSW as those surveyed were mainly 65 and older (which is not representative of all carers in NSW). Suggested reasons for this finding are:

- Carers who are not in the workforce may be more likely to have time to complete and return surveys
- Historically, older carers are members of Carers NSW
- Carers of workforce age may tend to respond to online surveys. This was reflected in the number of working carers who filled in the survey via Carers NSW website. 63 of the 84 carers filled in the survey via Carers NSW website were in the workforce either full-time or part-time.

The under-representation of Aboriginal and CALD respondents to the survey is also a consideration for Carers NSW in future carer surveys. NSW has the largest population of Aboriginal people of any state or territory in Australia. 148,200 people in NSW identify as Aboriginal, representing 2.1 per cent of the NSW population (ABS, 2008b). There are approximately 10,600 Aboriginal carers in NSW (ABS, 2008b).

Although the survey was sent to all Aboriginal carers in the Carers NSW contact database and to the members of Koori Interagencies, only 12 carers (or 1.8%) responded to the survey. It is also necessary to note that a large number of surveys were returned because the Aboriginal carer changed address or moved out of the area. Another possible reason for such a small number of replies is the small number of Aboriginal members of Carers NSW. A strategy for reaching Aboriginal carers needs to be developed for future surveys.

There is an estimation that 186,000 carers in NSW are from culturally and linguistically diverse backgrounds (MDAA, 2007). The number of CALD carers who participated was 81. Such a small number of CALD respondents was reflective of Carers NSW membership and the fact that CALD carers were also more likely to be hidden and less linked with support services (Cardona et al, 2006). Another possible barrier for participation in the Carers NSW Survey 2008 for CALD carers was the lack of translated surveys in languages other than English. As with Aboriginal carers, a thorough outreach plan and surveys translated in several community languages should be developed for the next Carers NSW carer survey.

In future Carers NSW carer surveys the use of Aboriginal and CALD carer focus groups could be a valuable tool to elicit more information about their caring roles and be used to test previous research findings.

8. References

Australian Bureau of Statistics (2008a). Year Book Australia, 2008, Australian Bureau of Statistics, Canberra

Australian Bureau of Statistics (2008b). A Profile of Carers in Australia 4448.0, Australian Bureau of Statistics, Canberra

Australian Bureau of Statistics (2004). 2003 Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra

Access Economics (2005). The Economic Value of Informal Care, Access Economics Report for Carers Australia, Canberra

Cardona B, Chalmers S and Neilson B (2006). Diverse strategies for diverse carers: the cultural context of family carers in NSW, Centre for Cultural Research, University of Western Sydney for the NSW Department of Ageing, Disability and Home Care, Sydney

Deakin University, Australian Unity and Carers Australia (2007). Special Report: the wellbeing of Australians: carer health and wellbeing. Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, Australian Unity, Melbourne

Edwards B, Higgins D and Zmijewski R (2007). The Families Caring for a Person with Disability study and the social lives of carers, *Family Matters*, no.76, pp 8-17

Mental Health Council of Australia and Carers Australia (2007). Carers of People with Mental Illness Project Report, Canberra

Multicultural Disability Advocacy Association (September 2007). CALD Carers and the NSW Carers Action Plan, Sydney

NSW Health (2007). NSW Carers Action Plan 2007-2012, Sydney.

SANE Australia (2007). SANE Research Bulletin 5: Family Carers and Mental Illness, available at: http://www.sane.org/images/stories/information/research/0701_info_rb4.pdf

Appendix A: see attached Carers NSW Survey 2008