

Carers NSW 2012 Carer Survey



Final Report

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1. Executive Summary

The aim of the biennial Carers NSW Carer Survey is to collect information about carers in NSW to inform the organisation's advocacy for carers. The survey was available as a paper questionnaire as well as online and was promoted to members, carer support groups, service providers and contacts of Carers NSW. In contrast to previous surveys, this year the survey focused on four key issues:

- Carer recognition
- The mental health and wellbeing of carers
- Knowledge and expectations of person centredness and individualised funding
- Former carers

The Carers NSW 2012 Carer Survey was completed by 1919 respondents, more than double the respondents compared to the 2010 survey. Similar to previous surveys, 84 per cent of respondents were female. In terms of cultural diversity, 15 per cent spoke a language other than English at home, 17 per cent identified as being from a culturally and linguistically diverse (CALD) background and 3 per cent identified as Aboriginal and/or Torres Strait Islander. Roughly half of respondents lived in an urban/metropolitan area with 37 per cent in regional areas and 11 per cent in rural or remote areas. Significantly, only 55 per cent of respondents were members of Carers NSW, which represents an increase in the number of non-members completing the survey.

The questionnaire contained a section focusing on carer recognition, with the aim of measuring awareness of the NSW *Carers (Recognition) Act 2010* (the Act) and the extent to which the Act has been implemented. The results indicated that most carers have little or no knowledge of the Act but would like to learn more. When carers were asked to comment on carer recognition generally, the most common responses were that they were not sure and/or would like to know more about carer recognition and the Act. Other common themes included cynicism about the benefits of the Act and the continuing need for more or better services.

Results from the health and wellbeing section revealed caring had negatively affected the mental health of half of carers. Forty per cent said that they had needed or need mental health services or support, most commonly from their GP. Talking to friends and family was the most popular coping strategy for carers (75 per cent), followed by exercise/relaxation techniques and respite/time-out. When asked what they think would most improve their mental health and wellbeing, regular breaks from caring was the most popular response, followed by financial and other support.

Knowledge and understanding of person centredness and individualised funding was limited, as almost two thirds of respondents had either not heard of, or did not understand, these concepts. However, more than half of carers said that they would take the option of managing individualised funding themselves if it were available. The most common types of support carers felt they might need if they were to manage their own funding were an information session and assistance from a support person or organisation to plan and purchase supports.

Roughly half of carers believe that person centred approaches and individualised funding would lead to improvements for carers and/or the person they care for in terms of control over services,

choices in how to live their life and the degree to which their needs are met. However, many carers were concerned about how these changes could affect finding and organising services.

The survey also asked former carers about their experiences and support needs. For most respondents, the reason their caring role ended was that the person they cared for died (70 per cent), or the carer could not cope any more (15 per cent). Two thirds of former carers needed emotional support when their caring role ended, with legal advice and financial support the next most common responses. Forty per cent felt they did not receive the support they needed when their caring role ended, while 60 per cent had their needs met, or had their needs met to some extent. When asked how the end of their caring role could have been made easier, the most common theme was the need for more or better support from services, followed by emotional support.

Carers NSW thanks the carers who completed the survey for giving up their time and sharing their experiences. The information and insights gained from the survey are extremely valuable for Carers NSW continued advocacy on behalf of carers. The following report provides more information about the survey process and a detailed analysis of the results.

2. Aims and Objectives of Carers NSW 2012 Carer Survey

The biennial Carers NSW Carer Survey aims to collect information about carers in NSW to inform the organisation's systemic advocacy. Given that the previous Carer Survey had only been completed 18 months ago, Carers NSW decided to break from the usual survey format and focus on four current critical issues:

- Carer recognition
- The mental health and wellbeing of carers
- Knowledge and expectations of person centredness and individualised funding
- Former carers

While Carers NSW has previously used the survey to collect information about carer demographics and health and wellbeing, previous surveys had not focused on the impact and perception of reforms in carer recognition and person centredness. The Carers NSW 2012 Carer Survey was also the first time there had been a specific section for former carers to collect information about carers' experiences and needs after their caring role ends. This means that while some data can be compared to previous surveys, in many cases this will be the first time such information has been collected.

The questionnaire was also designed to provide information to the NSW Government and other agencies regarding the impact of particular reforms, including carers' perceptions of person centredness to support the implementation of these reforms in a way that recognises, includes and supports carers.

Carers NSW will return to the usual survey format for the next survey to allow continued and consistent tracking of carer demographics, health and wellbeing and access to services.

3. Survey Methodology

3.1 Survey design

The Carers NSW 2012 Carer Survey was available as a paper questionnaire as well as an online survey developed using Survey Monkey. Just over half of respondents completed the online survey, while the remainder completed the paper version. These were then entered into Survey Monkey by Carers NSW staff.

The survey contained 52 questions and included closed-ended questions and five open-ended questions to elicit comments from carers. Comments were coded according to themes using Survey Monkey in order to allow further analysis. Skip logic was used to determine eligibility for the survey by ensuring that the respondent lived in NSW and was currently in a caring role or had been in a caring role in the past. If respondents were not eligible they were excluded from the remainder of the survey and any analysis of the results. It was also used to ensure that respondents were only asked certain questions if relevant, for example, some questions only applied to former carers or carers in paid employment.

There were five sections:

- Section 1: About you, the carer
- Section 2: Carer recognition
- Section 3: Your mental health and wellbeing
- Section 4: The introduction of person centred approaches
- Section 5: Former carers

Section 1 was for all carers and former carers to complete and collected demographic information. Sections 2, 3 and 4 were for current carers only. Respondents who indicated that they had a caring role in the past were directed to Section 5. 114 carers were able to complete all sections as they had both a current and a past caring role.

3.1.1 Data collection and sampling

Paper questionnaires were distributed with the Carers NSW bi-monthly newsletter *Carers News* to over 4,500 members of Carers NSW. A link to the online survey was promoted on the Carers NSW website. A number of stakeholders were also asked to promote the survey through their websites and newsletters, including the Working Carers Gateway and the Council of Social Service of New South Wales (NCOSS). Copies of the paper survey and the link to the online version were distributed to service providers and other contacts by staff of Carers NSW. Carers NSW also received a number of requests for surveys from organisations and individuals to distribute to support groups, clients and friends.

The survey was completed by almost 2,000 carers. The sample of carers and former carers who completed the Carers NSW 2012 Carer Survey was more representative of the carer population in NSW than previous surveys. However, as over half of respondents were members of Carers NSW, our sample was more likely to be informed about the issues examined and to be receiving services than the general carer population. Other organisations and service providers played a key role in

promoting the survey to clients and contacts, and therefore it is likely that respondents were more likely to be receiving services than the general carer population. For these reasons, the results of the survey may be more positive than for the general carer population.

Carers under the age of 18 were not permitted to complete the survey meaning that the views and experiences of younger carers were excluded. Nonetheless, for the purposes of the survey this sample was representative of a range of caring situations and groups. This issue will be examined further in the data analysis section of this report.

3.1.2 Data recording and analysis

The Carers NSW 2012 Carer Survey was fully or partially completed by 1,936 respondents, more than double the response to the 2010 survey. More than half of respondents completed the online survey; the remainder completed the paper questionnaire. Several respondents were excluded due to the survey being received after the extended cut-off date or due to a lack of information being provided. Respondents who had begun to answer the survey but did not live in NSW or were not current or former carers were also excluded as they were not eligible to complete the survey.

Carers NSW staff assisted with entering the information from the paper surveys into Survey Monkey. Once entered, data was analysed using Survey Monkey and Microsoft Excel, and the open ended responses were coded according to themes.

To enable comparison across different population groups, output data is presented as valid percentages, that is, the percentage was calculated by dividing the number of respondents by the total number of respondents per question. This means that carers who chose not to answer a question, or who were excluded from the question based on the skip logic, were not included in the total.

Excluding questions where the skip logic prevented many respondents from answering questions (such as all questions in the former carer section), roughly three quarters of questions had a response rate of 90 per cent or higher. Those questions with a lower response rate tended to be open ended or asked respondents about specific initiatives (for example person centred approaches) which many respondents had not heard of previously.

3.2 Enticements

Respondents did not receive any enticement to complete the survey. The number of responses received indicates that carers felt strongly about the need to raise their concerns and share their experiences.

3.3 Ethical issues

As with the 2008 and 2010 Carers NSW Carer Surveys, carers under the age of 18 were excluded.

4. Data Analysis

4.1 Demographic information

Almost 2,000 carers completed the 2012 Carer Survey, more than double the number who completed the survey in 2010. Demographic features of the respondents include:

- 84 per cent of respondents were female
- 52 per cent of respondents were aged between 45-64 inclusive, while 27 per cent were aged over 65
- 17 per cent identified as being from a culturally and linguistically diverse (CALD) background, with roughly half listing a European country as their country of origin, with Italy, Germany and Poland among the most popular
- 15 per cent spoke a language other than English at home, with Italian, Chinese and Arabic the most common languages listed
- 3 per cent identified as Aboriginal and/or Torres Strait Islander
- 52 per cent of respondents lived in an urban/metropolitan area, 37 per cent lived in a regional area and 11 per cent in a rural or remote area
- 29 per cent selected bachelor degree or higher as their highest level of education, while 21 per cent selected high school year 10 or equivalent
- 55 per cent were members of Carers NSW.

Despite the increase in the number of respondents, the demographics of respondents remained similar across the survey series, with the exception of the proportion of non-members of Carers NSW completing the survey which increased from 17 per cent in 2010 to 46 per cent in 2012.

Question 8 asked carers whether they were engaged in paid work or study, in addition to their informal caring role (see Figure 1). Carers were able to select all that applied. Forty per cent selected paid work, while 35 per cent responded that they did not work or study. Significantly, 10 per cent selected 'No, but I would like to', which supports other research and anecdotal evidence that many informal carers would like to engage in paid work or study. These results show that balancing work and care was an issue for approximately two thirds of respondents. This issue will be examined further in Section 2.

Question 10 asked whether respondents 'currently look after, or give help, support or assistance to a family member or friend, because they have a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or are frail' (see Figure 2). As mentioned previously, those who selected 'no' or did not answer this question were excluded from the remainder of the survey and from analysis of the results, while those who had cared in the past were directed to Section 5 for former carers.

For those who indicated that they were currently caring for one or more individuals, Question 10a asked whether they were the primary carer, to which 92 per cent of carers responded that they were the primary carer.

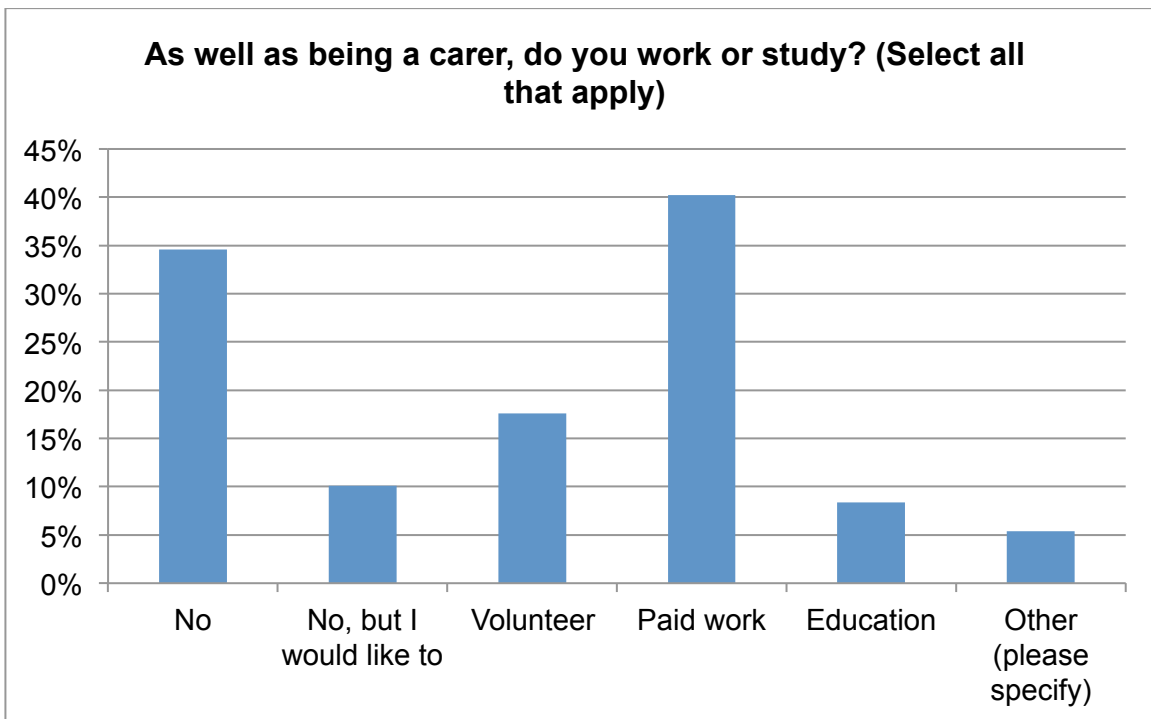


Figure 1: Graph for Question 8 ‘As well as being a carer, do you work or study? (Select all that apply)’

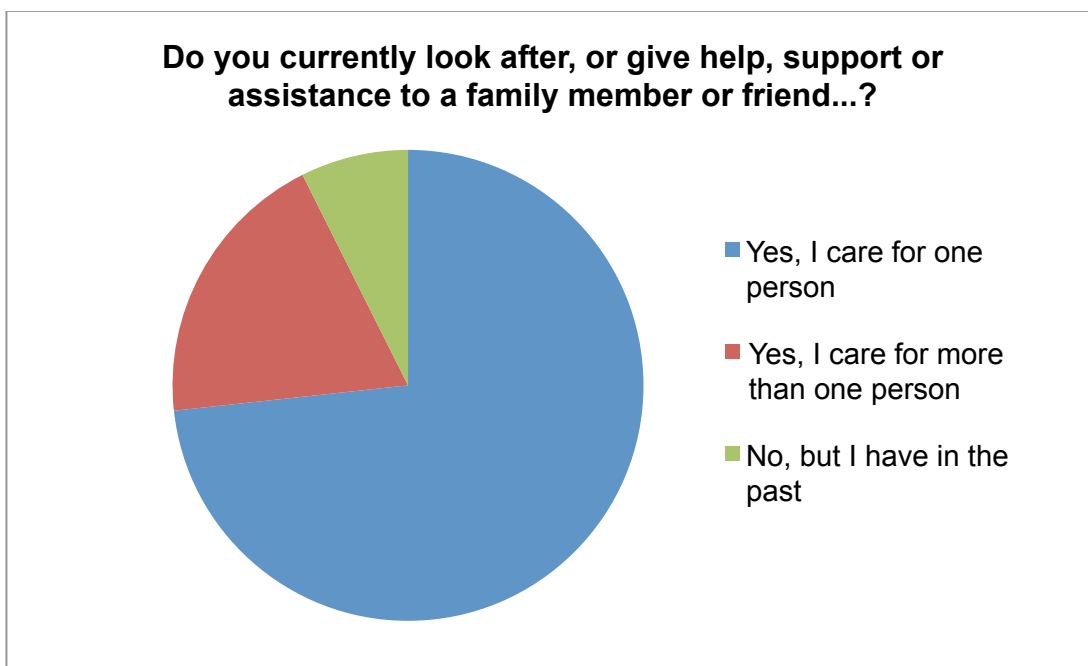


Figure 2: Graph for Question 10 ‘Do you currently look after, or give help, support or assistance to a family member or friend, because they have a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or are frail?’

Table 1 compares some of the characteristics of survey respondents with the findings of the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) 2009 for NSW. This demonstrates that the demographic profile of the carers who completed the survey does not exactly reflect that of carers in NSW generally. Therefore, Carers NSW will need to continue to promote the survey to diverse groups of carers and male carers in order to better

reflect the demographics of the carer population in NSW. However, the characteristics and views of respondents are still indicative of the views and characteristics of many carers.

Table 1: Comparison of Carers NSW 2012 Carer Survey respondent profile with Australian Bureau of Statistics (ABS), (2011) Disability, Ageing and Carers, Australia: State tables for New South Wales.

	ABS data (NSW)	2012 Carer Survey
Proportion female	55 per cent	84 per cent
Aged over 65	20 per cent	27 per cent
Primary carer	31 per cent	92 per cent
Membership of Carers NSW	Less than 1 per cent	55 per cent
Total population	849,700	1919

The questionnaire also asked carers about which sectors the person(s) they cared for used services from. More than half of respondents were caring for a person using disability services, with one third receiving services from the health sector. Figure 3 shows the percentages of carers accessing services from other sectors.

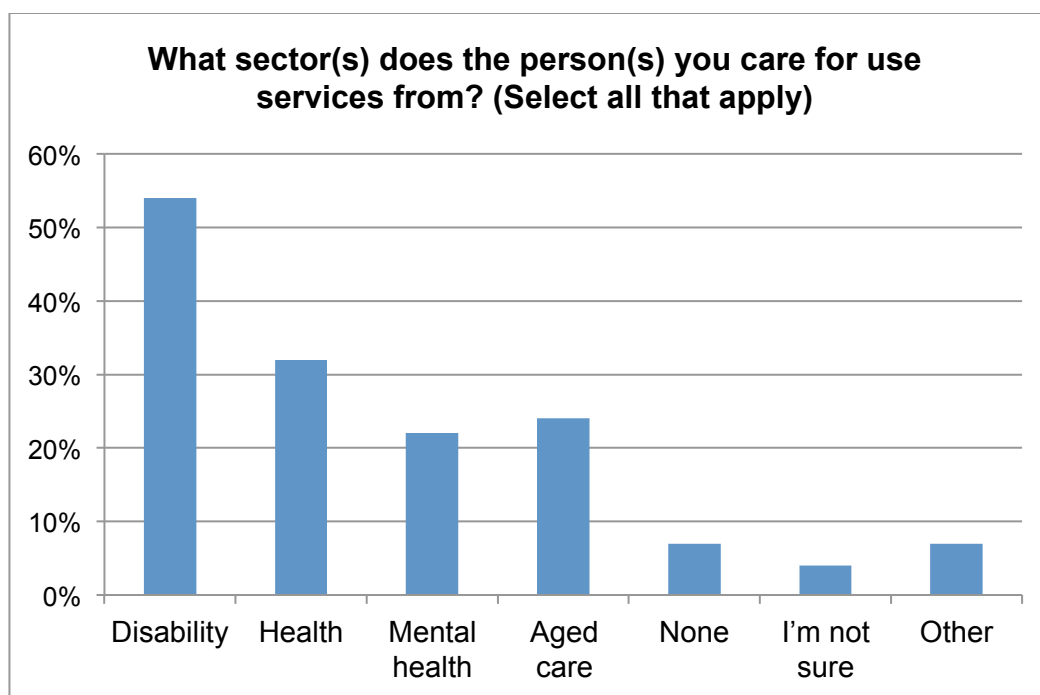


Figure 3: Graph for Question 32 'What sector(s) does the person(s) you care for use services from? (Select all that apply)

4.2 Carer recognition

The questionnaire contained a section focusing on carer recognition, with the aim of measuring awareness of the *Carers (Recognition) Act 2010* (the Act) and also the extent to which the Act has been implemented. The findings show that there is a need for more information about the legislation for carers as only a small proportion of carers understood what the Act meant for carers, although most were interested in learning more about it. The poor ratings for many services in terms of upholding the Act also reveal a lack of awareness and commitment to the Act and the

principles of carer recognition among service providers and the community. The comments revealed that the views of carers about carer recognition vary widely, from cynicism to support to lack of understanding.

4.2.1 Knowledge of the NSW Carers (Recognition) Act 2010

Questions 11, 12 and 13 asked carers whether they had heard of the Act, the NSW Carers Charter (contained in the Act) and the NSW Carers Advisory Council (established by the Act). Carers who answered that they had heard of the Act, Charter or Council were then asked an additional question to determine their level of understanding.

- 35 per cent (616) of respondents had heard of the Act, but of those only 235 felt they understood the Act.
- A similar number of respondents (634) had heard of the Carers Advisory Council, and of these one third felt that they knew what it did.
- Respondents were much less likely to have heard of the NSW Carers Charter, with only 17 per cent claiming to have heard of it, and of these only 99 respondents felt they were familiar with the contents of the Charter. Interestingly, less than half of those who claimed to understand the Act also understood the Charter which is central to the Act.
- Carers who had heard of the Act were much more likely to have heard of the Charter and the Carers Advisory Council.
- Members of Carers NSW were more than twice as likely to have heard of the Act or the Charter compared to non-members, and almost twice as likely to have heard of the Carers Advisory Council.

Interestingly, there was a decrease in the proportion of carers who had heard of the Act compared to the 2010 survey, where 44 per cent of respondents said they had heard of it. The higher proportion of respondents who had heard of the Act may be due to the timing of the previous survey, which was distributed within a few months of the Act being passed by the NSW Government. It may also reflect the increase in non-members completing the survey, who were less likely to be aware of the Act.

Question 22 asked where carers had heard of the Act and/or the Carers Advisory Council. The Carers NSW member newsletter, *Carers News*, was the most common source of information about the Act, and was nominated by approximately half of those respondents who had heard of the Act. The key role of *Carers News* in raising awareness of carer recognition legislation partly explains why members had higher levels of awareness and understanding of the Act.

Of particular note was the response to Question 20, which asked whether carers would like to know more about the Act. 81 per cent of respondents said they would like to know more about the *Carers (Recognition) Act 2010* which indicates significant demand for more information and education about the Act.

4.2.2 Evidence and experiences of carer recognition

Very few carers (four per cent) claimed to have seen any evidence of the Act or the Charter being put into practice in question 14. The remainder selected ‘no’ or ‘not sure’, while 69 carers commented on a range of issues, including recently receiving more services and examples of carer recognition or lack thereof in relation to employment.

Questions 15 and 16 were designed to measure the extent to which the principles of the NSW Carers Charter were being upheld by services and more generally.

Question 15 asked carers to rate whether in the last year the organisations that supported them and/or the person that they cared for upheld the principles of the NSW Carers Charter (see Figure 4). The most highly rated item was ‘respected your relationship with the person(s) you care for’, with 35 per cent selecting ‘always’. The item ‘told you about services to help you as a carer’ had the lowest average rating, with 35 per cent selecting ‘rarely’ or ‘never’.

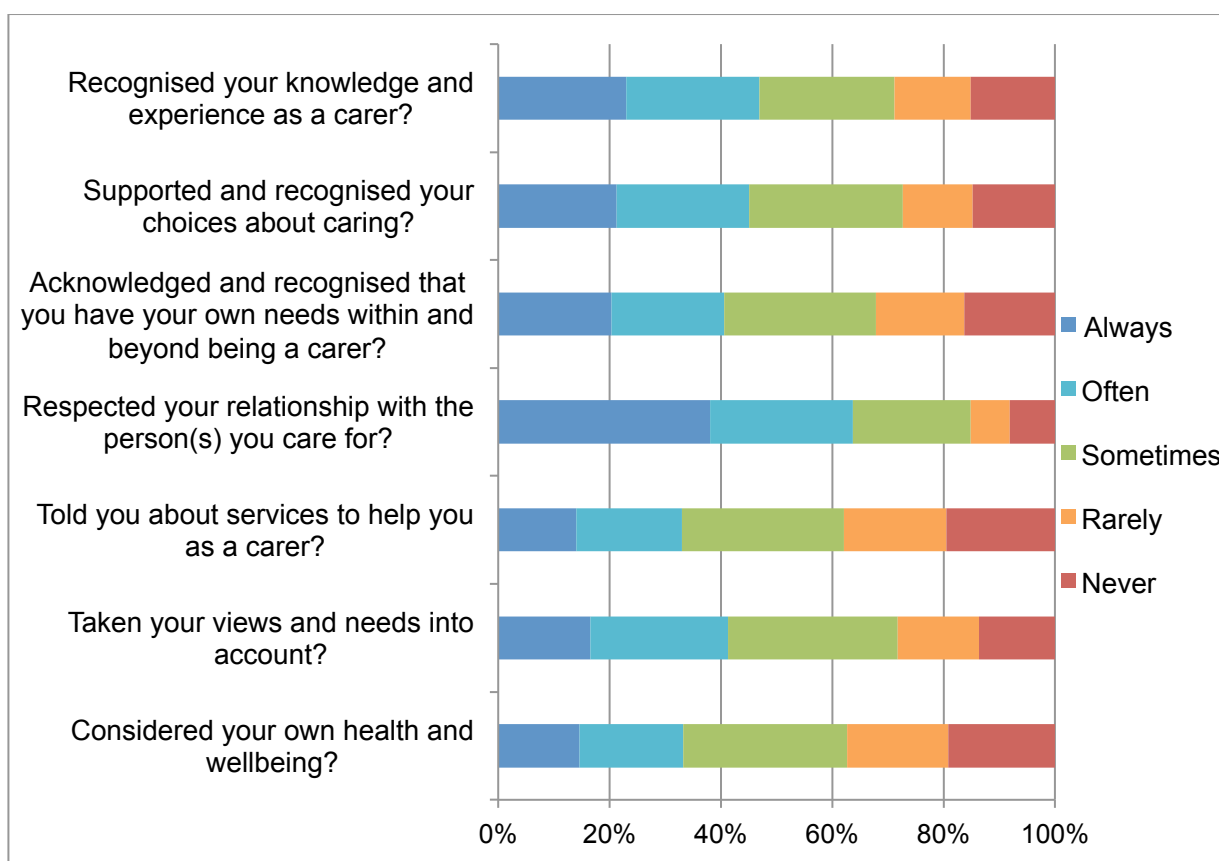


Figure 4: Graph for Question 15 ‘In the last year, have the organisations that support you and/or the person(s) you care for:’ (NB ‘N/A’ category excluded from graph)

Question 16 asked respondents to rate whether they believed that in the last year other principles of the Charter had been upheld in NSW generally (see Figure 5). Carers were most positive in regard to the item ‘The contribution carers make was recognised and supported’, with almost one third of respondents agreeing or strongly agreeing with this statement. The most negatively rated item was ‘Carers enjoyed the same rights, choices and opportunities as others’, with which more than half of respondents disagreed or strongly disagreed.

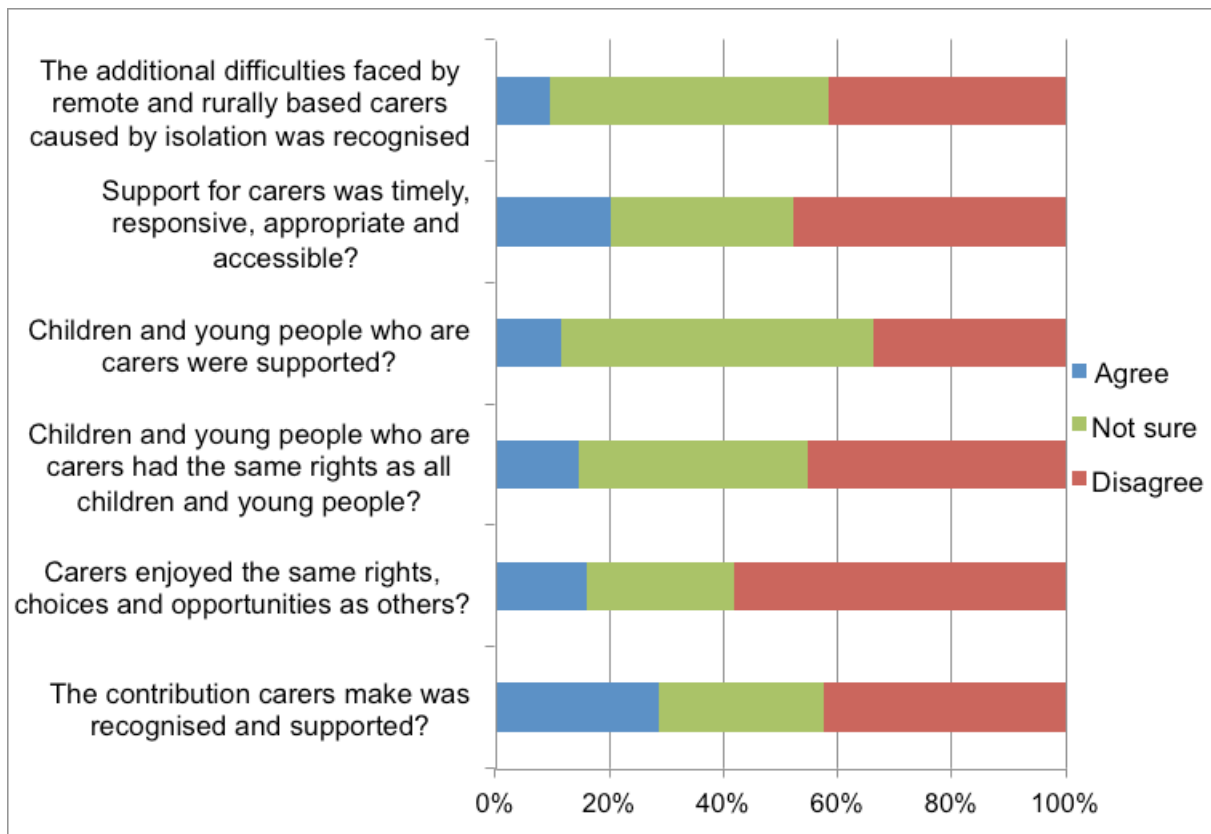


Figure 5: Graph for Question 16 ‘In the last 12 months, do you think that in NSW:’ (NB categories for ‘strongly agree’ and ‘strongly disagree’ combined with ‘agree’ and ‘disagree’ respectively)

Carers living in rural and remote areas felt that the additional challenges they faced were often not recognised, as 59 per cent disagreed or strongly disagreed that ‘The additional difficulties faced by remote and rurally based carers caused by isolation was recognised and acknowledged’. In other sections of the survey carers from regional and rural areas often commented on the lack of services available and the additional difficulties this created for them and their families.

Further analysis of responses to Questions 15 and 16 by the sector the person receiving care used services from, revealed slight differences in responses depending on the sector. Carers of a person receiving aged care services were slightly more positive in rating several items compared to other respondents, including being more likely to feel that the organisations supporting the person they cared for took their views and needs into account, and told them about services to help them as a carer and that the contribution carers make was recognised and supported. Carers of a person receiving mental health services were more likely to feel that their knowledge and experience was recognised as a carer.

Question 17 asked if carers felt that recognition of carers in NSW had improved over the past year, with 45 per cent answering ‘yes’ and 55 per cent selecting ‘no’. 566 respondents commented in response to this question, with 164 respondents using the space to take the middle ground or explain that they were not sure.

More services are improving but they still often don't understand that carers are often in an inflexible situation. Frequently support is only possible if a list of preconditions is achieved and this may not fit the disability.

...There is also a lot of patronising and disempowering behaviour that is not useful to me as a carer. The whole industry needs to reframe its support objective towards one that enables carers to feel whole rather than simply an appendage of the other's illness. Another 'client'!

I've only been a carer (officially) for less than a year.

Other comments referred to a lack of support from services (98), the role of the media (41) or criticised the Act as 'lip service' (31).

Seriously, No! I have just come out of hospital neither I nor my husband's needs were considered we are in a rural area, registered with local HACC. I booked transport months ahead it was cancelled to run HACC staff to a meeting. I was treated like I wasn't even there in the hospital which is 2 hours from where we live. A very long stay.

I have been a carer for three years consecutively. It seems worse, harder to access, a bigger labyrinth.

As I said before, the worst offence with carer recognition is actually getting no service at all!!!!!! That's the starting point. I am exhausted but I have to keep working to pay the mortgage...

Statements of recognition appear in newspapers etc. but this is very superficial. Real recognition implies changed behaviour and that is most uncommon in the community. My municipal council for instance has been extremely difficult and tardy in addressing basic access and safety for disabled and their carers. Recognition is at the 'lip service' stage.

There is a vast gap between rhetoric from government and others, and actual benefit to carers and the future of those for whom we care.

There has been stories etc. in the media and politics sometimes talks about improving carers situations.

Over the past year, I have found the mass media to be more cooperative in increasing recognition of carers in NSW. In particular, favourable media coverage during carers week, in my opinion was successful in achieving this objective.

Question 21 asked carers to comment on carer recognition more broadly, with the most common type of response (65) being that they were not sure and/or would like to know more about carer recognition and the Act. The themes that emerged were similar to those for Question 17, with many respondents being quite negative or again referring to 'lip service', and commenting on the need for more or better services.

What is it? Love to know more.

I am not after recognition. It would be nice to be able to find out more about the practical side. What services/help is available. It's like everything is top secret and you don't find out about anything unless you go searching which is often the last thing on your mind when you are exhausted and just trying to get through the day.

Yes – is this 'Act' just a 'feel good' document or can it really be enforced? What are the legal advantages for carers? Is there any legal aid or advocacy to assist in this?

I have a severely physically disabled son and everything has been a battle from when he was born. I had to fight to get him into our local schools with his siblings. It has been one constant battle. This has been doubly hard as well as dealing with his disabilities and all that involves.

'Flexible' respite hours need to be looked at to be more 'flexible'.

The information gained from the survey clearly demonstrates that there is a need for much greater awareness of the Act and its implications among service providers and government agencies, and a shift in the culture of health professionals and service providers to consider the needs of carers. Professionals and services also need to acknowledge carers' knowledge and expertise and recognise carers as partners in care.

Since the survey was conducted, the NSW Government has begun an awareness campaign to improve awareness and understanding the Act and the Charter which will hopefully address this issue. However, organisations also need to have greater knowledge of services available to carers such as the Carer Line, respite services and the National Carer Counselling Program (NCCP).

Implications for carer recognition arising from the Carers NSW 2012 Carer Survey

There is a need to address carer recognition in NSW through:

- Increased awareness and understanding of the NSW *Carers (Recognition) Act 2010* and the NSW Carers Charter among carers, service providers and the broader community.
- Increased information and education for carers around the Act and their rights.
- Further improvements to the quality of services and support provided to carers in line with the requirements of the NSW Carers Charter by changing the culture of service providers and the health system to also focus on the needs of informal carers and increasing awareness of support available for carers.
- Increased support for carers in rural and remote areas.

4.2.3 Carer recognition and work

Questions 18 and 19 sought information about the experiences of the 713 carers who indicated that they were in paid employment. The survey found that 87 per cent reported that their employer knew they had caring responsibilities, and three quarters felt that their workplace supported them to combine working and caring.

Flexible working hours was the workplace practice that helped the most respondents (385) to combine caring and work, followed by carers' leave (320). Many respondents commented about other practices, or problems they had faced at work. Reduced hours or casual or part time work were other common practices which helped respondents to combine caring and work, while being self-employed, taking leave (including personal, family, annual and unpaid leave) and having an understanding employer or manager were also common.

I work casually so if I need time off I don't work but I also don't get paid.

Casual worker – unpaid leave – happily granted when necessary.

Hours of employment support caring. Understanding employer.

Employment reduced from full time to part time for 2 days only at 5 hours per day due to lack of government out of home respite support.

Resigned from full time work and have taken a part time 1 day a week job to get flexibility I need.

I had a reduction in my working hours so I could continue to work and still provide care and there is some flexibility to change my working hours from time to time although I don't feel very comfortable doing that.

I started my own business to give me the flexibility that I need to work and be a carer.

Starting my own company and working for myself.

Co-operative and supportive co-workers. Additional annual leave days (reduces annual salary but means extra time available as needed).

Carers leave is taken from personal leave so when you are sick as a worker you have less leave due to taking carers leave.

My employer is very good and recently offered three months unpaid leave – I find this depends on the boss you have. Earlier I had a boss who was good verbally but when it came to support it was zilch, while my current boss is very supportive with respect to time.

Assistance depends purely on who is the person in charge at the time.

Evening hours – my husband works early mornings so we cover our caring responsibilities that way.

Several carers commented on the difficulties they had encountered in combining work and care:

I had to fight to be treated fairly...The point I am making is, that it is all arbitrary until the Act enshrines legally enforceable obligations. Please don't try to tell people their life will be different because of the Act. It is not true. You ought to be fighting for it to become legally enforceable.

Worst thing I ever did was tell them and I am in Government. Worst lip service, not supported by Government. I work more hours but can go in at 7 and leave before 5pm.

Despite some negative responses and concerns, responses to Questions 18 and 19 reveal that a high proportion of working carers are able to balance working and caring and feel supported by their current employer. While this finding is positive, anecdotal evidence and comments from the survey suggest that many carers are unable to continue working in their job or career of choice when their caring role begins or intensifies. In most cases, this involves a carer reducing their hours of work, taking on a less skilled role or working casually. This also means a reduction in income which can have serious consequences for carers at a time when costs may be increasing due to the needs of the person being cared for. This is particularly difficult for carers who may be the primary income earner in a household. Therefore, there is a need for further research into how carers could be better supported to remain in their job or career of choice as much as possible.

Implications for carers and the workplace arising from the Carers NSW 2012 Carer Survey

There is a need to improve workplace support of carers through:

- The development and promotion of case studies of employers supporting carers to balance their paid work and caring role.
- Further research into how carers can be supported to continue working in their job or career of choice as much as possible.
- The development of support strategies for carers to return to work while continuing their caring role, or after their caring role has ended.

4.3 Mental health and wellbeing

This section explored the health and wellbeing of carers, and the support that carers need to cope with their caring role. Carers tended to be positive about their health, as shown by responses to Questions 23 and 24 which asked carers to rate their health and mental health respectively. There were similar results for both questions as almost two thirds of respondents rated their health and/or mental health as 'good', 'very good' or 'excellent', and approximately 7 per cent rated one or both of these as 'poor'. This largely positive response contrasts with research such as the 2007 study of carer wellbeing by Deakin University, which found that carers reported the lowest wellbeing of any group surveyed in Australia. However, this difference may be a result of a number of factors, such as a more extensive analysis of wellbeing in the Deakin University study.

Responses to Question 25 reveal that caring affected the mental health of most carers. Half of respondents felt that caring had negatively affected their mental health, while 16 per cent believed caring had a positive impact.

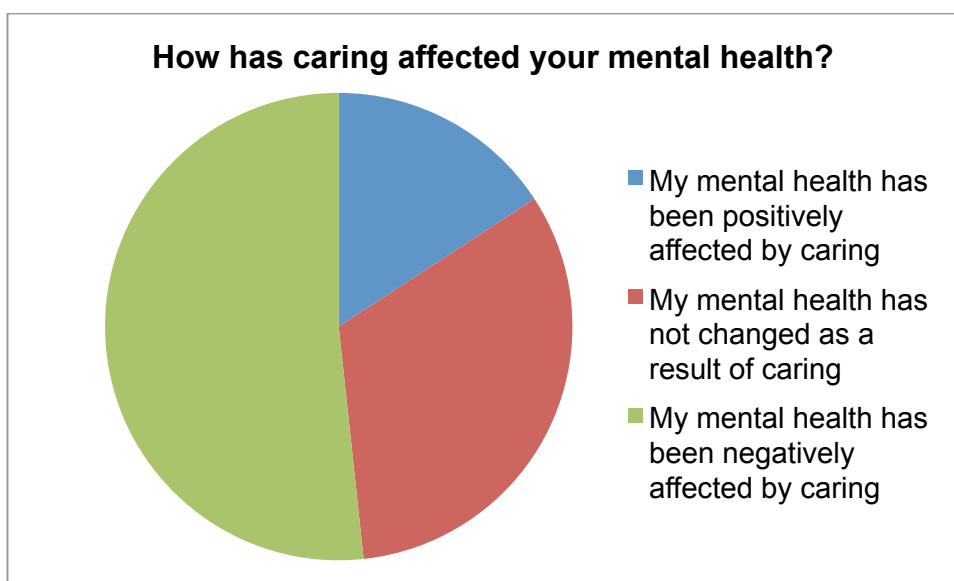


Figure 6: Graph for Question 25 ‘How has caring affected your mental health?’

4.3.1 Services and support

Questions 26 to 29 addressed the services and support that carers needed. Forty per cent of respondents said that they had needed or need mental health services or support, and of those two thirds had been able to get the services or support they needed. The most common type of support selected was GP (348), followed by support from family/friends, psychologist and counsellor.

For the 221 respondents who felt they had needed mental health services or support but had not been able to access this, the most common reasons were that their caring responsibilities took priority and the cost of accessing services.

4.3.2 Coping strategies

Question 30 asked carers about the coping strategies they have used since becoming a carer, with respondents able to select multiple options (see Figure 7). Talking to friends and family was the most popular strategy, selected by three quarters of respondents, followed by exercise/relaxation techniques (45 per cent) and respite/time-out (42 per cent). One quarter of respondents selected stress or anxiety medication while 15 per cent selected alcohol or drugs.

Further analysis suggests that carers with additional responsibilities, such as employment or multiple caring roles, are more likely to be struggling with their caring responsibilities and to be using medication, alcohol or other drugs to cope. For instance, the results revealed that carers using stress or anxiety medication or alcohol or other drugs were more likely to rate their health as fair or poor, and more likely to feel that their mental health had been negatively affected by caring. Working carers were more likely to use alcohol or other drugs as a coping strategy, while carers for more than one person were more likely to use medication and alcohol or other drugs.

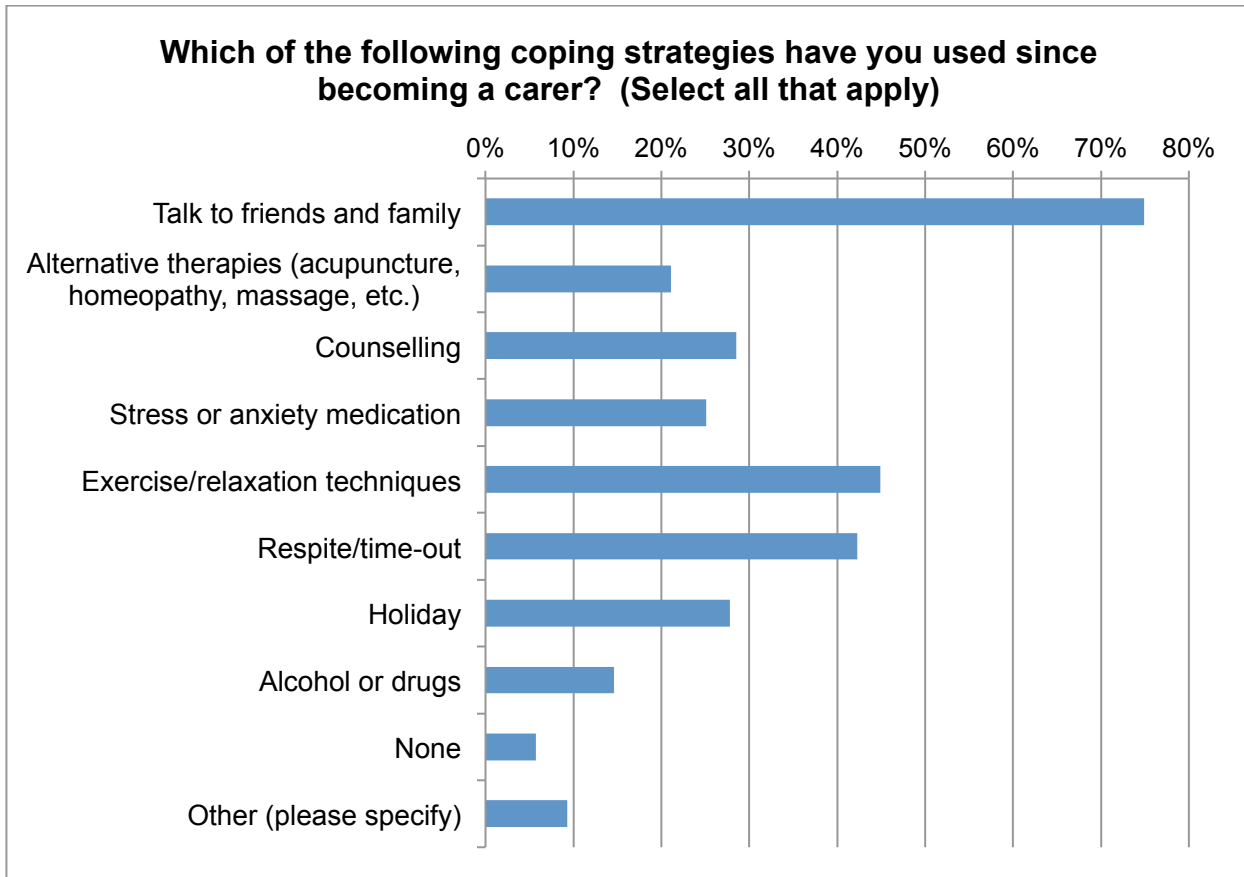


Figure 7: Graph for Question 30 *‘Which of the following coping strategies have you used since becoming a carer?’ (Select all that apply)*

Carers NSW was also interested in what carers think would most improve their mental health and wellbeing (see Figure 8). The most common response was regular breaks from caring (61 per cent), followed by more financial support, more practical support and more support from services, selected by almost half of respondents. The strong desire for the opportunity for regular breaks from caring reflects similar concerns in the 2010 Carer Survey, where one third of respondents selected ‘increase in funding for respite services’ as the single most important issue that they would like the NSW Government to focus on.

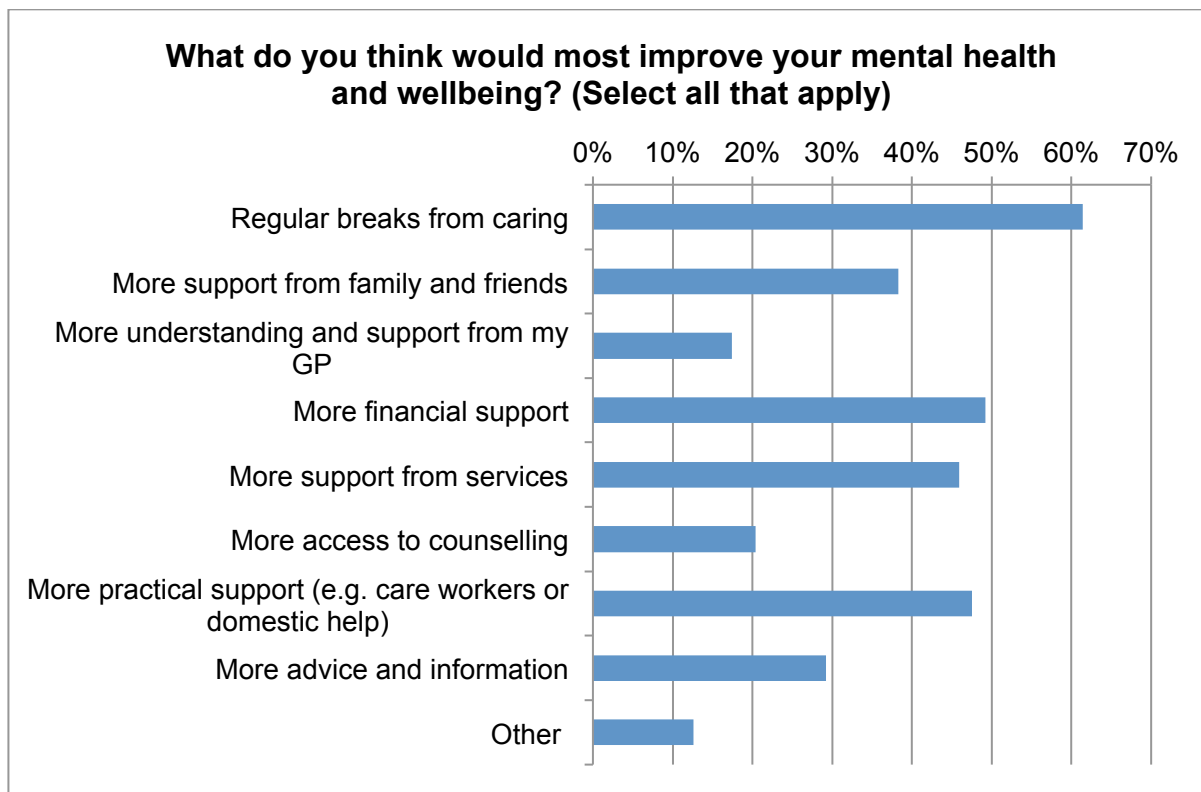


Figure 8: Graph for Question 31 *‘What do you think would most improve your mental health and wellbeing?’ (Select all that apply)*

Implications for carer mental health and wellbeing arising from the Carers NSW 2012 Carer Survey

There is a need to support better outcomes for carer mental health and wellbeing through:

- More services and support for carers and the people they support.
- Improved access to respite services for carers to facilitate regular breaks from caring.
- Increased support for carers including increased financial support and more practical support.
- Further research into the use of stress and anxiety medication, alcohol and other drugs by carers as a coping strategy.

4.4 The introduction of person centred approaches

Given the significant changes occurring in the disability system and more broadly, Section 4 focused on the introduction of person centred approaches and individualised funding to find out how carers feel about these initiatives, and what they know about them. The findings revealed that carers had low levels of understanding of these reforms but, as with carer recognition, they would like to know more. Carers also raised a number of concerns about the potentially negative impact of these changes, while others hoped it would mean a better life for them and for the person they care for.

In Questions 33 and 34, carers were asked if they had heard of and understood person centredness and individualised funding. One third of respondents had heard of person centredness, and of these just over one third felt that they understood what is meant by a person centred system.

According to responses to Question 35 and 36, 40 per cent of respondents had heard of individualised funding, slightly higher than for person centredness. Of these 38 per cent felt they knew what individualised funding was. This means that almost two thirds of respondents had not heard of, or did not understand, the concepts of person centredness and/or individualised funding.

Further analysis of the responses to Questions 33 to 36 reveals that carers of a person(s) receiving services from the disability sector, and to a lesser extent the health sector, are more likely to know about person centredness and individualised funding. This is not surprising, as in NSW person centred approaches and individualised funding are primarily being promoted and discussed in the disability sector. The NSW Government has conducted a number of consultations with people with a disability and their carers about person centred approaches and has introduced a number of initiatives which employ the principles of person centredness and/or incorporate individualised funding.

Those who received no services were the least familiar with person centredness and individualised funding, while those caring for a person accessing mental health or aged care services also had less awareness.

Carers who identified as being from a culturally and linguistically diverse background (CALD) were less likely to have heard of person centred approaches (22 per cent) or individualised funding (27 per cent) than other carers.

The questionnaire included a brief explanation of both these concepts in order to assist carers to answer subsequent questions.

4.4.1 Individualised funding

More than half of respondents said that they would take the option of managing individualised funding themselves if it were available, while one third were unsure (see Figure 9). Those who selected 'no' or 'not sure' were asked why they would not want to manage individualised funding. The most common reason selected was that it sounded too complicated, followed by feeling they don't have the time.

All carers were asked about what kind of support they may need in order to manage individualised funding, and selected all that applied from a range of options. The most commonly selected was an information session (57 per cent), followed by support person/organisation to assist with planning, purchasing etc. (41 per cent). Only 11 per cent said they would not need any assistance, while 21 per cent were not sure.

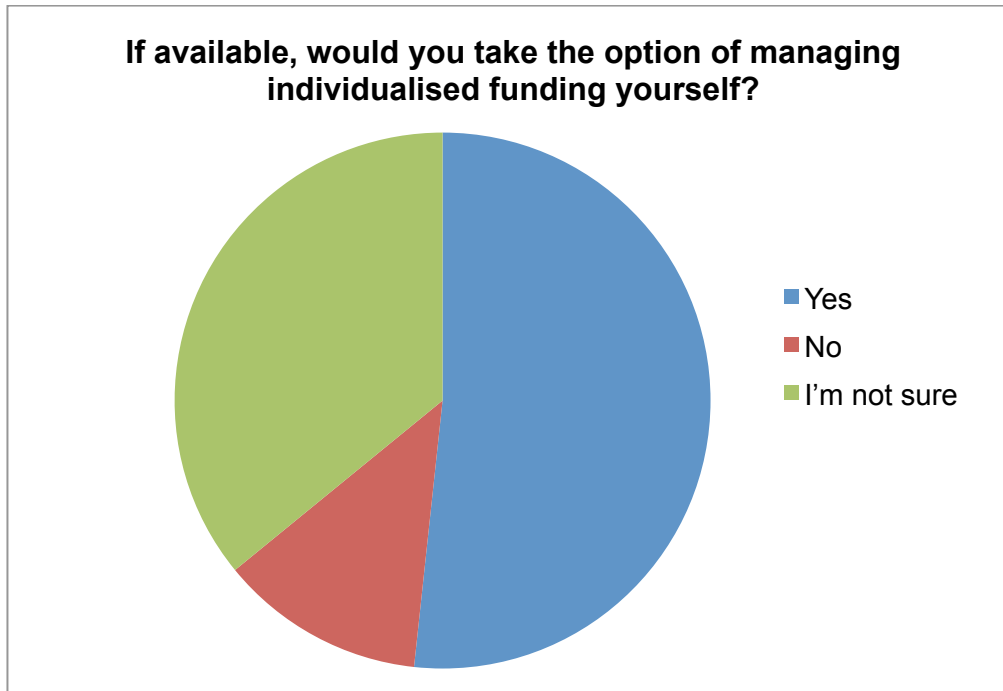


Figure 9: Graph for Question 37 *'If available, would you take the option of managing individualised funding yourself?'*

4.4.2 How carers expect person centredness and managing their own funding to affect services and support

Questions 39 and 40 asked carers to rate how they expected person centredness and managing their own funding to affect a range of factors:

- The control you have over services?
- The control the person(s) you care for has over services?
- The choices you have in how you live your life?
- The choices the person(s) you care for has in how they live their life?
- The degree to which your needs are met?
- The degree to which the needs of the person(s) you care for are met?
- Finding and organising services?

Over 500 respondents did not answer questions 39 and/or 40, due in part to their lack of knowledge or understanding of these concepts, as many explained in their comments to Questions 33-36.

4.4.3 Control over services

Carers were asked about how person centredness and managing their own funding would affect the control they, and the person they care for, have over services. Approximately 55 per cent of respondents felt that the control they have over services would improve, and 46 per cent believed that the control the person they care for has over services would improve. The lower rating for the person receiving care may reflect situations where the carer believes the person receiving care is not in a position to control services, for example, carers of young children.

4.4.4 Choices in how to live life

The results for how carers expected person centredness and managing their own funding to affect the choices both they and the person they cared for had in life were also similar. Fifty-four per cent of respondents expected that the degree of choice they have in how to live their life would be a little or a lot better for both, while 51 per cent believed that the choice the person they care for has in how they live their life would improve.

4.4.5 The degree to which needs are met

Just over half of respondents expected that person centredness and/or managing their own funding would improve the degree to which their needs and/or those of the person they care for would be met. This result follows a similar pattern to the items discussed previously.

4.4.6 Finding and organising services

Finding and organising services was the only factor for which the responses varied significantly from the others. Although approximately 40 per cent believed that finding and organising services would improve, 11 per cent of respondents believed this would be worse and almost one third didn't know. The poorer ratings for this statement may reflect the fact that the carer may have increased responsibility for finding and organising services themselves.

4.4.7 Overall feeling about the introduction of person centredness and individualised funding

More than 1,000 carers responded to Question 41, which asked them about their overall feeling about the introduction of person centredness and individualised funding. One third of the comments were broadly positive, around one fifth of comments were mixed and a small number were negative.

Excited... looking forward for a life of choices for my daughter!!

I feel that it is an excellent opportunity to be hands on support the people I care for to a greater extent. It will also empower them to be involved in the decision making process, this way they will feel they have some control over their future needs.

PLEASE implement this. I can choose the right path for the people I care for. WE NEED THIS.

Person centredness is often meaningless/theoretical and makes no real difference. Individualised funding is a necessary improvement in disability and it is disgraceful that Australia/NSW has been so slow in introducing it.

I like the idea however as we live in a rural area there are such limited services available that it would not make much difference.

Depends how much the funding is and how much help we're given in choosing the best services to meet our son's needs.

More work for me to do on top of what I am currently doing as a carer.

I will still be begging for care for my child. It will make no difference to accessing supported housing. I will still be unable to return to the workforce as by 2017 I will be too old.

I don't understand the parameters so sense that I'm going to do more frustrating organisation for less funding. Sounds good, probably isn't.

Implications for the implementation of person centredness and individualised funding arising from the Carers NSW 2012 Carer Survey

There is a need to significantly increase the capacity and willingness of carers to engage with person centredness and individualised funding through:

- The provision of targeted and comprehensive information to carers about person centredness and individualised funding.
- The provision of capacity building opportunities to support capacity of carers to engage with person centredness and individualised funding.
- Establishing robust practices of carer recognition, inclusion and support in the implementation of person centredness and individualised funding using the *NSW Carers Charter* as a framework.
- Establishing an online forum, publishing case studies and facilitating mentoring relationships to assist carers to share their experiences of person centredness and individualised funding.

4.5 Former carers

The last section of the survey was for people who had had a caring role that had ended. This was the first time Carers NSW had included a section specifically for former carers. Almost half of those who completed the former carer section were currently caring for at least one person, so they completed both the current and former carer sections. The results from the survey indicate that former carers need better support when their caring role ends, in particular emotional support, and recognition of their continued caring role even when the person they care for enters residential care.

The demographic profile of those who had a caring role that ended varied slightly from the profile of other respondents. In particular, former carers had an older age profile and were less likely to be in paid employment. They were also less likely to identify as CALD or to speak a language other than English at home. The length of time that the respondents had been caring for ranged from a few months to 40 years. For some, their caring role had ended some time ago, while for others their caring role had ended more recently.

Question 44 asked why their caring role had ended. The most common reason was that the person they cared for died (70 per cent), followed by 'I couldn't cope any more' (15 per cent), and the

person being cared for moving away or choosing a different source of care (7 per cent each). 'Moving away' included moving into residential aged care or supported accommodation. As the end of the caring role of most former carers was due to the death of the person cared for, following their death they would have experienced grief for the loss of a family member or friend. This is in addition to other losses which are specific to carers, such as the loss of identity and role as a carer, isolation, poor physical and mental health and financial difficulties.

It is worth noting that while 'moving away' was an option for the reason that a carer's caring role had ended, Carers NSW recognises that caring relationships can continue when the person being cared for is living separately from the carer, including in residential care. In such situations carers may continue to provide emotional support, assistance with personal care or advocacy, or provide care over weekends. Many former carers were critical of the fact that they were no longer considered carers once the person they cared for entered residential aged care, despite maintaining their caring role.

As with respondents currently in a caring role, former carers were also asked to rate their health. Similar to current carers, almost two thirds considered their health to be 'good', 'very good' or 'excellent', although the ratings for former carers were slightly more positive than current carers.

4.5.1 Coping with caring and the end of the caring role

While many former carers had coped well while they were carers and after their caring role ended, many others had struggled and had not received the support they needed. Questions 46 to 48 asked former carers to rate how they coped and the impact of caring or the end of their caring role at three different stages: when they were a carer, when their caring role ended and currently. The first item asked how former carers had coped at each stage. Despite the challenges, a high proportion of respondents felt that they had always or often coped well, with 59 per cent coping well when they were a carer and 61 per cent coping well currently. However, when their caring role ended respondents were less likely to feel they coped well, with only 40 per cent coping well always or often during this period.

Those who coped well always or often when their caring role ended were more likely to have coped well when caring and also to be coping well currently. They were less likely to feel that they needed any support when their role ended or now, while also being more likely to have received the support that they needed. They were also less likely to feel that they needed support currently. From this data, it is difficult to conclude whether the support that carers who coped well received had helped them to cope better than other former carers, or whether there were other factors.

4.5.2 Supporting carers when their caring role ends

Questions 49 asked former carers what kind of support they needed when their caring role ended. Two thirds of carers selected emotional support, followed by legal advice and financial support (almost one third each) as shown in Figure 10. Furthermore, 59 respondents used the space to nominate other kinds of support, or to comment on how they were still caring for others.

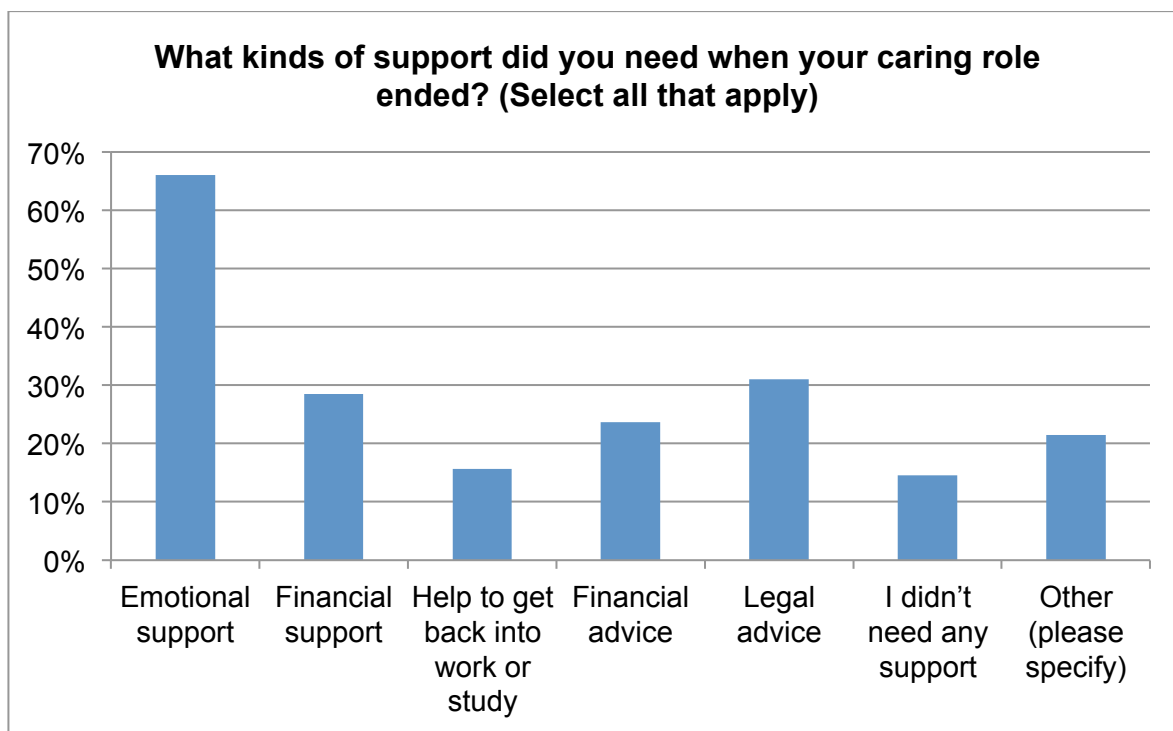


Figure 10: Graph for Question 49 ‘What kinds of support did you need when your caring role ended?’ (Select all that apply)

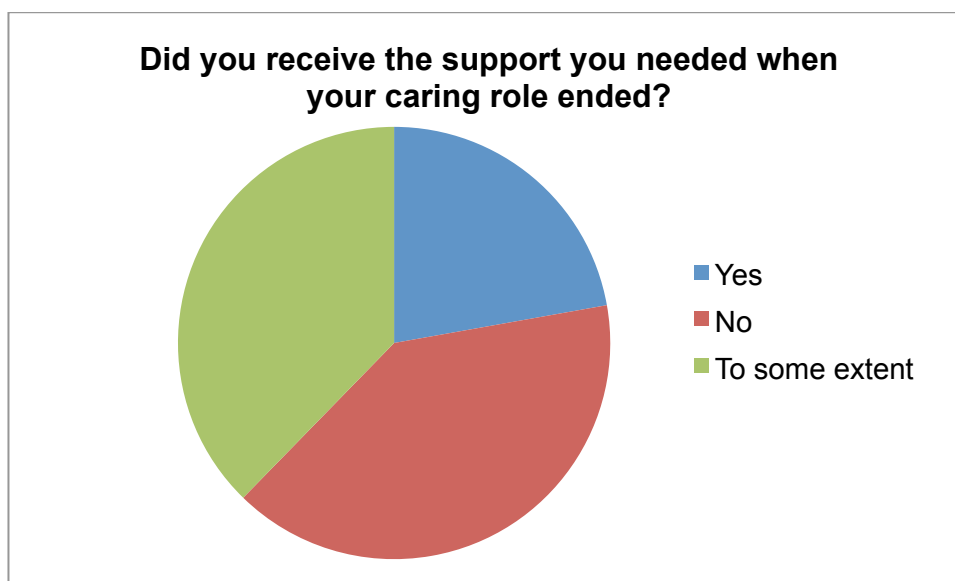


Figure 11: Graph for Question 50 ‘Did you receive the support you needed when your caring role ended?’

Question 50 asked respondents whether they received this support when their caring role ended. 40 per cent felt they did not receive the support they needed when their caring role ended, while 60 per cent had their needs met, or had their needs met to some extent (see Figure 11).

Former carers who answered that they did not receive the support they needed for Question 50 were more likely to have poorer health, and significantly more likely to need support currently. On the other hand, those carers who received the support they needed were more likely to report better health and less likely to require support currently, meaning that timely support for former

carers can help them to cope and adjust to their new role. These findings suggest that further research is needed in this area.

In response to Question 51 which asked what kinds of support they need now, more than half of respondents selected emotional support while one third felt that they didn't need any support (see Figure 12).

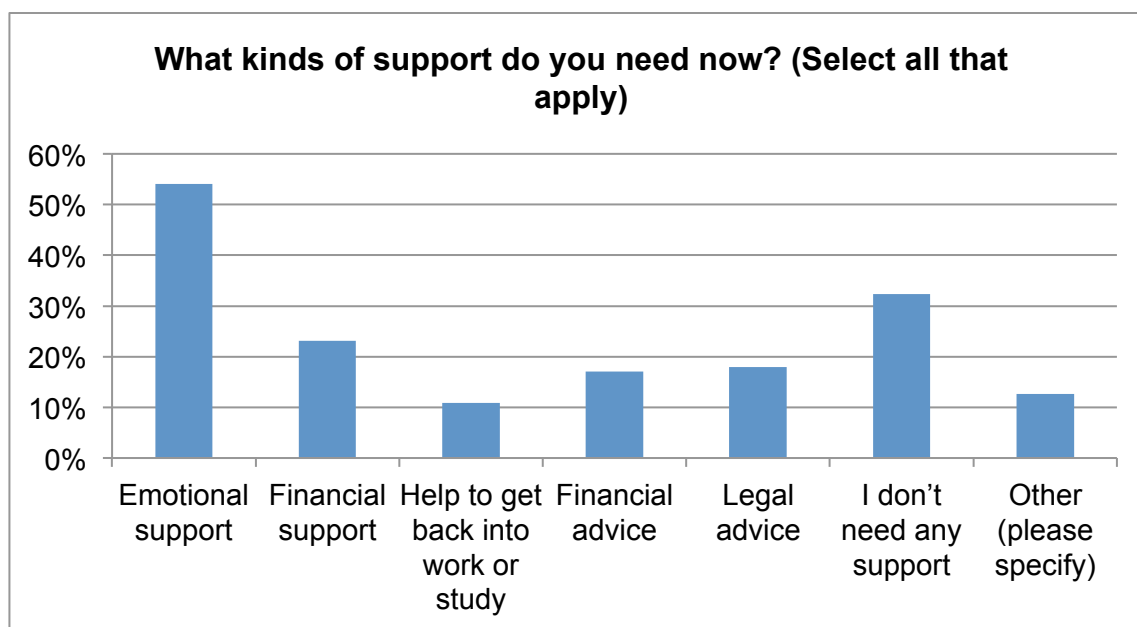


Figure 12: Graph for Question 51 'What kinds of support do you need now?' (Select all that apply)

The final question asked former carers how the end of their caring role could have been made easier for them. This was an open ended question, and the 183 comments were coded according to themes, with some comments falling into multiple categories.

The most common theme was the need for more or better support from services, followed by emotional support. Other comments related to financial support, recognition of their caring role and more informal support. A small number of comments also mentioned how the carer continued to provide care, either for the person they cared for in residential care, or for other family members.

It could have been made easier if I wasn't so physically and emotionally and financially depleted, that another option such as somewhere else for the person I was caring for to go, could be given before I was at the total end of my tether.

Better cooperation and attitude from staff at my daughter's accommodation services. They need to be aware of the loss and grief experienced by parents who make a decision to prepare their adult child for the future without them. Service providers often think its 'good riddance' without understanding how hard it is to part and hand over someone precious and trust.

Some sort of debriefing. Help filling out government forms. Given a short holiday, even a weekend. A course on how to deal with change, now in a nursing home. The caring role

doesn't stop when a person goes into a nursing home but the Carers Allowance does. My health is broken and it will take a while to rebuild my health.

When I ended my caring role I was very depressed and I had to prove to Centrelink I was looking for work every 2 weeks. I was 58 and no one wanted me at that age. I gave up a good job to care for my parents and I was treated like dirt by Centrelink- they made it very hard for me.

The fact that at that stage (and up to the current day) I still had two members of my immediate family with disabilities meant that I got no chance to really grieve, process as 'life just went on..'

I could have used support with respite and practical house work support whilst my father was ill, I could have used counselling support, legal and financial advice when my caring role ended.

Implications for recognition and support of former carers arising from the Carers NSW 2012 Carer Survey

There is a need to significantly improve outcomes and experiences of carers at the end of their caring role through:

- Improved access to support for carers with multiple caring roles for whom one caring role may have ended.
- Improved support for carers when their caring role ends in order to improve their health and wellbeing and help them to adjust to their new role.
- Increased awareness of the impact of caring on former carers.
- Provision of early intervention and support for carers before they reach breaking point and are unable to cope any longer.
- Provision of support for carers of persons who have entered residential care, especially those who continue to provide some form of care.
- Raise awareness of support available for former carers, in particular emotional support, such as the National Carer Counselling Program (NCCP).
- Improved access to legal advice and financial support for carers when their caring role ends.
- Improved support for carers to return to work after their caring role has ended.

4.6 Conclusion

Carers NSW appreciates the time taken by carers to complete the survey and share their thoughts and experiences. The information gained from the survey is valuable for Carers NSW role in advocating for the needs of all carers and provides important evidence for the need for more and better support and information for carers.

5. References

Australian Bureau of Statistics (ABS) (2011), Disability, Ageing and Carers, Australia: State tables for New South Wales, Canberra.

Carers Australia, Australian Unity, and Deakin University (2007), Australian Wellbeing Index Survey 17.1, *The Wellbeing of Australians: Carer Health and Wellbeing*, Melbourne.

Carers NSW (2010), *Carers NSW Survey 2010 and Focus Group Consultations Final Report October 2010*, Sydney.

6. Appendix: Carers NSW 2012 Carer Survey Questionnaire

Carers NSW 2012 Carer Survey



Questionnaire

INTRODUCTION

ABOUT THE SURVEY

Dear Carer,

Carers NSW invites you to take part in our carer survey. Carers NSW is an organisation for people who provide unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, terminal illness, chronic condition or who is frail.

We are conducting this survey to get more information about carers in NSW. This information helps us to identify and advocate for what carers want and need.

This year's survey is different to previous surveys. Sections two, three and four are for current carers only. There is also a fifth section which is just for people who are no longer carers, or who have had a previous caring role which ended. This section will help us to collect information about carers' experiences and needs after their caring role ends.

To complete the survey:

- Fill in this form and send it to Carers NSW in the reply paid envelope by **30 April 2012**
OR
- Go to our website at www.carersnsw.asn.au and do the survey online by **30 April 2012**

Important information:

- This survey is for carers aged 18 years and over.
- All the information you provide is confidential.
- You will not be identified in any publication of results, although we may quote your response in a way that cannot identify you.

If you have any questions, need help to complete the survey, or would like to order more copies, please contact the Carers NSW Policy Team on 02 9280 4744.

For more information about Carers NSW Carer Counselling or other services please call the Carer Line on 1800 242 636 (Monday to Friday, 9 am–5 pm). Free call except from mobiles.

SECTION 1

ABOUT YOU, THE CARER

1. Are you: Female Male _____
2. How old are you? _____ years old
3. Are you from an Aboriginal and/or Torres Strait Islander background? (Tick all that apply)
 Yes, Aboriginal background Yes, Torres Strait Islander background No
4. Are you from a culturally or linguistically diverse background?
 Yes, country of origin _____ No
5. Do you speak a language other than English at home?
 Yes, I speak _____ No

6. What is your highest level of education?

- Bachelor degree or higher Advanced Diploma or Diploma
 Certificate High school year 12 or equivalent
 High school year 10 or equivalent Other, please specify _____

7. Where do you live?

- Urban/metropolitan area Regional area Rural or remote area

8. As well as being a carer, do you work or study? (Tick all that apply)

- No No, but I would like to
 Volunteer _____ hours per week Paid work _____ hours per week
 Education _____ hours per week Other _____

9. Are you a member of Carers NSW?

- Yes No

10. Do you currently look after, or give help, support or assistance to a family member or friend, because they have a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or are frail?

- Yes. I care for one person Yes. I care for more than one person
 No No, but I have in the past
(Please go to Section 5 on page 7 which is for former carers only)

10a. If yes, are you the primary carer/main provider of care and support to the person(s) you care for?

- Yes No

SECTION 2 **CARER RECOGNITION**

11. Have you heard of the *NSW Carers (Recognition) Act 2010*?

- Yes No

11a. If yes, do you understand what the *NSW Carers (Recognition) Act 2010* means for carers?

- Yes No I'm not sure

12. Have you heard of the NSW Carers Charter?

- Yes No

12a. If yes, are you familiar with the contents of the NSW Carers Charter?

- Yes No I'm not sure

13. Have you heard of the NSW Carers Advisory Council?

- Yes No

13a. If yes, do you know what the NSW Carers Advisory Council does?

- Yes No I'm not sure

14. Have you seen any evidence of the *Carers (Recognition) Act 2010* or NSW Carers Charter being put into practice?

- Yes No I'm not sure

If yes, what: _____

15. In the last year, have the organisations that support you and/or the person(s) you care for:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER	N/A
Considered your own health and wellbeing?						
Taken your views and needs into account?						
Told you about services to help you as a carer?						
Respected your relationship with the person(s) you care for?						
Acknowledged and recognised that you have your own needs within and beyond being a carer?						
Supported and recognised your choices about caring?						
Recognised your knowledge and experience as a carer?						

16. In the last 12 months, do you think that in NSW:

	STRONGLY AGREE	AGREE	NOT SURE	DISAGREE	STRONGLY DISAGREE
The contribution carers make was recognised and supported?					
Carers enjoyed the same rights, choices and opportunities as others?					
Children and young people who are carers had the same rights as all children and young people?					
Children and young people who are carers were supported?					
Support for carers was timely, responsive, appropriate and accessible?					
The additional difficulties faced by remote and rurally based carers caused by isolation was recognised and acknowledged?					

17. Do you think recognition of carers in NSW has improved over the past year?

Yes No

Comment: _____

18. If you are in paid employment:

I am not in paid employment (go to question 20)

Does your employer know you have caring responsibilities?

Yes No

Does your workplace support you to combine working and caring?

Yes No

Do you work for local government, or a government department or agency?

Yes No

19. What workplace practices, if any, have helped you to combine caring and work? (Tick all that apply)

Carers leave

Flexible working hours

Working from home

Other _____

None

20. Do you want to know more about the *NSW Carers (Recognition) Act 2010*?

Yes No

21. Do you have any comments you would like to make about the *NSW Carers (Recognition) Act 2010*, NSW Carers Advisory Council or carer recognition more broadly?

22. Where did you hear about the *NSW Carers (Recognition) Act 2010* and/or the NSW Carers Advisory Council?

- I hadn't heard of them until today
- Carers NSW website
- Carers NSW newsletter
- Newspaper or television report
- Internet, *where?* _____
- Another organisation, *which one?* _____
- Word of mouth
- Other _____

SECTION 3

YOUR MENTAL HEALTH AND WELLBEING

23. In general, would you say your health is: (Select one)

- Excellent
- Very Good
- Good
- Fair
- Poor

24. In general, would you say your mental health is: (Select one)

- Excellent
- Very Good
- Good
- Fair
- Poor

25. How has caring affected your mental health? (Select one)

- My mental health has been positively affected by caring
- My mental health has not changed as a result of caring
- My mental health has been negatively affected by caring

26. Have you needed, or do you need, mental health services or support?

- Yes
- No

27. Have you been able to get the services or support you need?

- Yes
- No
- I haven't needed any services or support (go to question 28)

27a. If yes, what services and support have you used? (Tick all that apply)

- GP
- Counsellor
- Psychologist
- Psychiatrist
- Support from family/friends
- Support group
- Carers NSW Carer Line or Carers NSW counsellor
- Other _____

27b. If no, why not? (Tick all that apply)

- Cost
- Service not available
- Don't have time
- Caring responsibilities take priority
- Didn't know where to go
- Other _____

28. Where would you go to get support for your mental health needs? (Tick all that apply)

- GP
- Counsellor
- Psychologist
- Psychiatrist
- Family/friends
- Through the organisation(s) that support the person(s) I care for
- Carers NSW Carer Line or Carers NSW counsellor
- Other _____
- Don't know

29. If you have used a Carers NSW counsellor, was the counselling: (Select one)

- Very helpful Somewhat helpful Not that helpful at all N/A

30. Which of the following coping strategies have you used since becoming a carer? (Tick all that apply)

- Talk to friends and family Alternative therapies (acupuncture, homeopathy, massage, etc.)
 Counselling Stress or anxiety medication
 Exercise/relaxation techniques Respite/time-out
 Holiday Alcohol or drugs
 None Other _____

31. What do you think would most improve your mental health and wellbeing? (Tick all that apply)

- Regular breaks from caring More access to counselling
 More support from family and friends More support from services
 More understanding and support from my GP More practical support (e.g. care workers or domestic help)
 More financial support More advice and information
 Other _____

SECTION 4

THE INTRODUCTION OF PERSON CENTRED APPROACHES

This section is about the trend towards person centredness, which may change the way you and the person(s) you care for are supported in the future.

32. What sectors does the person(s) you care for use services from? (Tick all that apply)

- Disability Health Mental health Aged care
 Other _____ None I'm not sure

33. Have you heard of person centredness?

- Yes No I'm not sure

34. Do you understand what is meant by a person centred system?

- Yes No I'm not sure

In a person centred system, the rights of people with a disability, and their families and carers, to make choices about their own lives are respected. Instead of the government telling people with a disability what support service they will receive, they can decide what services they want. People with a disability, their families and carers can decide how these services are delivered, how often, and by what service provider.

35. Have you heard of individualised funding?

- Yes No I'm not sure

36. Do you know what individualised funding is?

- Yes No I'm not sure

Individualised funding means that individuals and their families have their own 'package' of funds and control over how it is used. There are examples of individualised funding in some disability programs. In these programs, individuals are allocated a funding amount based on their assessed needs and can choose their services and service providers.

37. If available, would you take the option of managing individualised funding yourself?

- Yes No I'm not sure

37a. If no, why not? (Tick all that apply)

- I'm happy with things as they are It sounds too complicated
 I don't feel I have the skills I don't feel I have the time
 Other _____

38. Some carers might feel that they need training or other support to manage individualised funding. If you were to manage your own funding, what would you need? (Tick all that apply)

- No assistance or support Information session
 Book keeping course Computer course
 Other training _____ Financial advice
 Legal advice Support person/organisation to assist you with planning, purchasing etc.
 Additional respite/services to give you more time I'm not sure
 Other _____

39. How do you expect person centredness to affect:

	A LOT WORSE	A LITTLE WORSE	NO CHANGE	A LITTLE BETTER	A LOT BETTER	DON'T KNOW
The control you have over services?						
The control the person(s) you care for has over services?						
The choices you have in how you live your life?						
The choices the person(s) you care for has in how they live their life?						
The degree to which your needs are met?						
The degree to which the needs of the person(s) you care for are met?						
Finding and organising services?						

40. If you decided to manage your own funding, how do you think it would affect:

	A LOT WORSE	A LITTLE WORSE	NO CHANGE	A LITTLE BETTER	A LOT BETTER	DON'T KNOW
The control you have over services?						
The control the person(s) you care for has over services?						
The choices you have in how you live your life?						
The choices the person(s) you care for has in how they live their life?						
The degree to which your needs are met?						
The degree to which the needs of the person(s) you care for are met?						
Finding and organising services?						

41. What is your overall feeling about the introduction of person centredness and individualised funding?

Thank you for completing this survey. Your input is greatly appreciated.

This section is for former carers. Please only complete this section if you have had a caring role that ended.

42. How long were you a carer? _____ years _____ months

43. When did your caring role end? _____ years _____ months ago

44. Why did your caring role end?

- I chose not to be a carer anymore
 The person(s) I cared for recovered
 The person(s) I cared for moved away
 I couldn't cope any more
 The person(s) I cared for chose a different source of care
 The person(s) I cared for died

45. In general, would you say your health is: (Select one)

- Excellent
 Very Good
 Good
 Fair
 Poor

46. When you were a carer:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER	N/A
Did you cope well?						
Did you find it demanding being a carer?						
Did you feel well supported as a carer?						
Did you feel alone?						
Did you feel supported by family or friends?						
Did caring have a positive effect on your physical health?						
Did caring have a negative effect on your physical health?						
Did caring have a positive effect on your emotional wellbeing?						
Did caring have a negative effect on your emotional wellbeing?						
Did you experience financial difficulties?						

47. When your caring role ended:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER	N/A
Did you cope well?						
Did you find it difficult to cope?						
Did you feel well supported?						
Did you feel alone?						
Did you feel supported by family or friends?						
Did it have a positive effect on your physical health?						
Did it have a negative effect on your physical health?						
Did it have a positive effect on your emotional wellbeing?						
Did it have a negative effect on your emotional wellbeing?						
Did you experience financial difficulties?						

48. Currently:

	ALWAYS	OFTEN	SOMETIMES	RARELY	NEVER	N/A
Do you cope well as a former carer?						
Do you feel well supported?						
Do you feel alone?						
Does your past caring role have a positive effect on your current physical health?						
Does your past caring role have a negative effect on your current physical wellbeing?						
Does your past caring role have a positive effect on your current emotional health?						
Does your past caring role have a negative effect on your current emotional wellbeing?						
Do you experience financial difficulties as a result of being a carer?						

49. What kinds of support did you need when your caring role ended? (Tick all that apply)

- Emotional support
- Financial support
- Help to get back into work or study
- Financial advice
- Legal advice
- I didn't need any support
- Other _____

50. Did you receive the support you needed when your caring role ended?

- Yes
- No
- To some extent

51. What kinds of support do you need now? (Tick all that apply)

- Emotional support
- Financial support
- Help to get back into work or study
- Financial advice
- Legal advice
- I don't need any support
- Other _____

52. How could the end of your caring role have been made easier for you?

Thank you for completing this survey. Your input is greatly appreciated.