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Carers NSW 2018 Carer Survey

Summary Report

ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

www.carersnsw.org.au

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

ABOUT CARERS

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/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 904,400 carers (ABS, 2015), and to replace the care they provide the NSW Government would have to spend more than \$17 billion each year.¹ Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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Prepared by the Policy & Research Team
October 2018

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Available online at: <http://www.carersnsw.org.au/research/survey>

¹ Carers NSW estimate based on Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*.

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List of abbreviations

%SM	Percentage of Scale Maximum
ABS	Australian Bureau of Statistics
CALD	Culturally and Linguistically Diverse
GP	General practitioner
JSS	Job Satisfaction Subscale
K10	Kessler Psychological Distress Scale
LOTE	Language other than English
MSPSS	Multidimensional Scale of Perceived Social Support
N	Number of respondents
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PAC	Positive Aspects of Caregiving
PWI	Personal Wellbeing Index
SDAC	Survey of Disability, Ageing and Carers
SPSS	Statistical Package for the Social Sciences

Foreword

The biennial Carers NSW Carer Survey provides Carers NSW with a critical opportunity to hear from carers across New South Wales about what matters most to them. At a time of immense change in the disability, aged care, mental health and carer support sectors, solid evidence about carers' needs and experiences is more important than ever. I am therefore pleased to present the summary report for the Carers NSW 2018 Carer Survey. This summary report contains key insights about the carer population in New South Wales and highlights the successes and challenges carers are experiencing as they engage with the service system and with paid employment.

I would like to extend a special thank you to the members of the 2018 Carer Survey Reference Committee, whose expert advice and valuable contribution of time and skill supported us to build on the strengths of the 2016 Carer Survey and introduce new questions to produce timely evidence to support the work of Carers NSW and the sector. Thank you to Helen McFarlane (NSW Department of Family and Community Services), Louise Farrell (NSW Health), Professor Michael Fine (Macquarie University), Dr Lyn Phillipson (University of Wollongong), Cathy Duncan (University of Wollongong), Dr Hugh Bainbridge (UNSW Australia), Dr Myra Hamilton (UNSW Australia), Cathy Thompson (UNSW Australia) and Selen Akinci (Multicultural Communities Council of Illawarra) for all their work. The expert advice and support of our former colleague Dr Timothy Broady (UNSW Australia) is also much appreciated.

Carers NSW wishes to acknowledge the work of Zoi Triandafilidis and Sarah Judd-Lam in leading the design and delivery of the 2018 Carer Survey and in producing this summary report. Thank you also to Jessica Lay and Madelaine Berglind, student interns, for their support with data entry, coding and analysis, and to the volunteers who assisted with data entry for the survey: Amanda Sharma, Penny Graham, Jessica MacCulloch, Gavin Mathew and Garima Aneja.

Finally, and most importantly, I would like to acknowledge and thank every carer who took the time to participate in the 2018 Carer Survey. We value your time and are grateful for your openness in sharing your views and experiences with us.

In contributing to the evidence base regarding carers in New South Wales, the Carers NSW 2018 Carer Survey will enable Carers NSW and our partners and stakeholders to continue supporting carers and advocating for improved carer recognition and support.



Elena Katrakis
CEO
Carers NSW
October 2018

Executive summary

The biennial Carers NSW Carer Survey collects information about carers in New South Wales (NSW) to provide an evidence base that informs the organisation's direction, support, and systemic advocacy for all carers across NSW. The 2018 Carer Survey built on the success of the 2016 Carer Survey in order to collect data regarding carers' lived experiences across a range of domains. This summary report provides an initial overview of survey results, with particular topics to be explored in greater depth in future publications.

The 2018 Carer Survey was completed by a total of 1,830 respondents, including 1,706 current carers and 124 former carers. The majority (79%) of respondents were female, and almost half (46%) were aged between 45 and 64 years. Most respondents (86%) were the main providers of care for those they supported (primary carer), and more than one third (37%) had experienced a long-term illness or disability themselves within the previous 12 months.

In line with previous Carers NSW Carer Surveys, this sample cannot be considered representative of the wider NSW carer population, thus limiting the generalisability of its findings. However, a wide range of caring experiences were evident across the sample, including relatively strong representation from culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander, LGBTI+² and rural and regional communities. More detailed analysis will therefore be possible within these sub-groups.

The findings presented in this summary report raise important implications for governments, service providers, employers and the broader community at a time of considerable change for carers in NSW. They will be used to direct additional data analysis and dissemination and to inform ongoing service delivery, advocacy and research work conducted by Carers NSW and its partners and stakeholders.

2018 Carer Survey: Key findings

- Consistent with previous surveys, the typical respondent was a female primary carer aged between 45 and 64 years, educated beyond high school and not in paid work.
- The typical care recipient was an adult son, aged 18 to 64 years, with a physical disability, only able to be left alone for a few hours and requiring 60+ hours per week of care.
- Around half of respondents (53%) were living on a household income of less than \$50,000 per year, and 40% reported difficulty in meeting their living expenses in the last 12 months.
- Around half of respondents (51%) provided 60+ hours of care per week, and almost one in three carers (31%) had been caring for over 20 years.
- Carers were most likely to be included in decision making and support planning when accessing services for the people they care for, but were less likely to be asked about their own needs.
- Carer support services had a relatively low uptake overall, and demand for increased support was high.
- Carers in paid employment reported that their caring interfered with their jobs more than their jobs interfered with their caring.
- Respondents had higher levels of psychological distress than the average carer in NSW (according to the 2015 SDAC).

² Lesbian, gay, bisexual, transgender, intersex and other sexuality, sex and gender diverse

Methodology

The biennial Carers NSW Carer Survey aims to collect information about carers in NSW to inform the organisation's direction, support and systemic advocacy for all carers across NSW. Building on a tradition of carer surveys dating back to the 1974 *Dedication* report by the Council on the Ageing, which led to the establishment of Carers NSW, Carers NSW has conducted a biennial survey of carers across NSW since 2002. Since 2014, the Carers NSW Carer Survey has been developed with the input of an expert reference committee made up of sector representatives and leading researchers in the field of caring, and has been conducted with university ethics approval.

Procedure

The 2018 Carer Survey was developed by the Carers NSW Policy & Research Team under the guidance of the Carers NSW Board and Executive and the 2018 Carer Survey Reference Committee, which was made up of the following expert members:

- Helen McFarlane, Manager, Strategy, Design & Stewardship -Carers (Department of Family and Community Services)
- Louise Farrell, Director, Priority Programs Unit, Health and Social Policy Branch (NSW Health)
- Professor Michael Fine, Honorary Professor, Department of Sociology (Macquarie University)
- Dr Lyn Phillipson, NHMRC-ARC Dementia Fellow, Australian Health Services Research Institute (University of Wollongong)
- Cathy Duncan, Research Fellow, Australian Health Services Research Institute (University of Wollongong)
- Dr Hugh Bainbridge, Senior Lecturer, School of Management (UNSW Australia Business School)
- Dr Myra Hamilton, Senior Research Fellow, Social Policy Research Centre (UNSW Australia)
- Cathy Thompson, Research Fellow, Social Policy Research Centre (UNSW Australia)
- Selen Akinci, Senior Project Officer, Partners in Culturally Appropriate Care (Multicultural Communities Council of Illawarra)

Ethics approval for the 2018 Carer Survey was sought in partnership with Dr Lyn Philipson, a member of the Reference Committee. Approval was granted in February 2018 by the University of Wollongong Human Research Ethics Committee (Health and Medical) (2018/015).

The survey was made available online through Survey Monkey and promoted to carers across NSW from 1 May 2018 until 30 June 2018, however the online survey remained open until 6 August 2018 due to an initially slow response rate. A paper questionnaire version was distributed from 15 May 2018, with final copies being accepted until 10 August 2018 to account for mailing delays.

The online survey was promoted on the Carers NSW website and social media, and through the Carers NSW monthly *eBulletin* and *Research Community News*. The survey was also advertised through a range of stakeholder networks and other organisations with which Carers NSW staff have regular contact. As with previous surveys, paper questionnaires were distributed with the Carers NSW bimonthly newsletter, *Carers News*, in May 2018 to approximately 6,000 members. Approximately, 1,750 additional paper questionnaires were distributed on request to organisations, support groups, at events, and to individuals.

Completed paper questionnaires were entered into Survey Monkey by the Policy & Research Team with the support of several trained volunteers and student interns. The final dataset was exported and cleaned, coded, and analysed using SPSS 22, by the Policy & Research Team, with the assistance of student interns and support from Dr Timothy Broady. Further analysis will be undertaken and published in future by the Policy & Research Team and named investigators from the 2018 Carer Survey Reference Committee.

Survey instrument

The 2018 Carer Survey questionnaire built on the framework established in previous Carer Surveys, and consideration was given to ensuring that results could be compared to previous surveys, and could continue to be compared in future surveys. Therefore, the same five focus areas were included in the 2018 questionnaire:

- Section 1: The caring relationship
- Section 2: Services and supports
- Section 3: Paid work
- Section 4: Health and wellbeing
- Section 5: Carer demographics

However, several changes were made to the 2018 questionnaire to improve the quality of the data, reflect recent changes to the service systems carers access, reflect up-to-date, best practice approaches to research, and generate new information to address identified gaps in the literature and current policy challenges. The revised questionnaire was piloted with a total of six carers, including Carers NSW staff with caring responsibilities and Carers NSW Carer Representatives.³ This feedback was used to further refine and finalise the questionnaire. The paper version of the survey questionnaire is included in Appendix A.

Respondents

A total of 2,146 people responded to the 2018 Carer Survey, however, 316 responses were excluded from the final sample. Three screening questions were included in the questionnaire to ensure all respondents were living in NSW and caring for a family member, friend or neighbour who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing. A total of 78 respondents were excluded from completing the survey on the basis of their responses to these screening questions.⁴ For ethical reasons, only carers aged 16 years and over were invited to participate, with one further response being screened out for being under this age limit. An additional 237 responses were excluded from analysis because they did not submit a completed survey.⁵

This resulted in a final sample of 1,830, 1,706 of whom were current carers, and 124 former carers. 971 (53%) completed the online version and 859 (47%) completed the paper version. More than half of the sample (54%) were members of Carers NSW, or the Carers NSW Young Carer Program (0.8%). A slight majority (53%) completed the survey online, with just fewer than half (47%) completing the paper questionnaire, an increase from 2016, where only 808 paper based responses were included in the final sample.

A comparison of response rates to the 2018 and the 2014, 2016 Carer Surveys is shown in Table 1. The total number of responses in 2018 was lower than in 2016 and 2014, however, the proportion of valid responses was greater. The rate of current carers who responded to the survey was similar to previous years. The rate of former carers was significantly less than 2016. This discrepancy is likely to be due, in part, to the structure of the 2018 survey which forced respondents to identify as *either* a current or a former carer, while in the 2016 and 2014 surveys, former carers were identified differently.

³ Carers NSW Carer Representatives are specially trained carers who are offered opportunities to speak up for carers to help improve the system for all carers and the people they care for.

⁴ This included 24 from people who did not live in NSW, 29 who indicated that they had not cared for someone with the identified conditions, 18 who were paid care workers, and 7 who were formal volunteers.

⁵ A *complete* survey was defined as a paper survey which had been submitted, and an online survey where the respondent had completed the last compulsory question in the online survey – the third question in Section 3.

Table 1. Comparison of response rates to the 2014, 2016, and 2018 Carer Surveys

	2018 Carer Survey		2016 Carer Survey		2014 Carer Survey	
	N	%	N	%	N	%
Total responses	2,146	-	2,519	-	2,228	-
Valid responses	1,830	85	2,081	83	1,797	81
Online responses	971	53	1,273	61	1,072	60
Paper responses	859	47	808	39	723	40
Former carers	124	7	657	32	146	8
Current carers	1,706	93	1,958	94	1,684	94
Carers NSW members⁶	1,010	55	1,120	57	829	49

Limitations

Several limitations apply to the methodology outlined in this section. Most notably, this is not a representative survey, and caution should be used when generalising findings to the broader population of carers in NSW. The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) is the most reliable source of generalisable population level data regarding carers in NSW. Convenience sampling was used to recruit participants, as the survey was promoted on an opt-in basis via a wide range of communication channels. Given that a number of regular communication channels were utilised to engage members, clients and other stakeholders, the resulting sample is likely to over-represent carers who identify as carers and already have contact with supports and services. Hidden carers and carers who are not in receipt of support or who are socially isolated are much less likely to have responded to the survey, and due to response bias, it can be assumed that people with more positive or negative experiences would have been more likely to respond.

In the development phase, it was also identified that, due to the length of the questionnaire and the formal English required in order to elicit accurate responses, carers who lacked confidence in reading and writing English were likely to be excluded. In order to address this gap, the Policy & Research Team conducted six focus groups with CALD carers from new and emerging and low literate communities in May to June 2018. A summary of findings from the focus group is available at <http://www.carersnsw.org.au/research/projectsandpublications> and data from the focus groups will be analysed in greater depth in future publications, alongside survey data regarding CALD carers.

It should also be noted that during analysis a limitation was identified in regards to the questions about services and supports accessed by the care recipient. The questionnaire directed respondents caring for people in the under 65 and over 65 age categories to different questions based on the eligibility criteria for aged care and disability services. While it was assumed that care recipients aged 65 years and older would only be accessing aged care services, and those aged under the age of 65 years would only be accessing supports through the NDIS, it became apparent that some care recipients represented exceptional circumstances and were receiving services through systems for which they did not meet the official age criteria. The responses to these questions may therefore be slightly underestimated.

⁶ Includes Carers NSW members and members of the Carers NSW Young Carer Program

Results

This section outlines the initial results from all five sections of the 2018 Carer Survey.⁷ Further analysis examining the relationship between variables and the particular experiences of various sub-groups of carers will be undertaken in future and reported in subsequent publications.

Respondent profile

Highlights

- Consistent with previous surveys, the typical respondent was a female primary carer aged between 45 and 64 years, educated beyond high school and not in paid work.
- The sample was not representative of the wider NSW carer population.
- A range of carers from different cultural backgrounds, of different sexualities, ages, and socioeconomic status responded to the survey.
- Most carers used the internet on a mobile phone and/or computer.
- Around half of respondents (53%) were living on a household income of less than \$50,000 per year, and 40% reported difficulty in meeting their living expenses in the last 12 months.
- Nearly one in five respondents under the age of 65 indicated that they did not know how they would fund their retirement, or had not thought about it.

Selected demographic characteristics comparing results from the Carers NSW 2018 Carer Survey with population level estimates from the 2015 SDAC (ABS, 2015, 2017) and with the Carers NSW 2016 and 2014 Carer Surveys are summarised in Table 2. Compared to the average carer in NSW (according to the 2015 SDAC), respondents to the 2018 Carer Survey were older, more likely to be a primary carer, more highly educated, less likely to be employed and more likely to have a disability themselves. Compared to the last two Carer Surveys, the number of respondents who were primary carers was lower in 2018, and the average age was higher. The levels of education and employment among respondents were fairly similar overall (discrepancies in the high school categories may have been due to these options being worded and framed differently) (Table 2). These key demographic differences must be considered when interpreting findings from other sections of this survey.

Table 3 presents demographic characteristics showing the diversity of respondents. Although most carers identified as Australian, and spoke only English, 11% of respondents were identified as being CALD.⁸ After Australian, the five most commonly identified cultural backgrounds were; English/British, Italian, Chinese, New Zealand, German. The five most common languages other than English (LOTE) spoken at home were; Italian, Spanish, Cantonese, German, and Auslan. With regard to sexuality, 2% of carers identified as bisexual, 1% as lesbian, gay, or homosexual, 0.1% as queer, and 2% identified different identities. Approximately half (52%) of respondents reported living in Greater Sydney, with the five most common regions outside of Greater Sydney being Mid North Coast, Illawarra, Central

⁷ N.B. Some reported percentages do not add up to 100% due to rounding or missing data. Some results refer to valid percentage and some to total sample percentage depending on the purpose of the question. Qualitative analysis has not yet been completed so in-depth analysis of open-text responses will be reported elsewhere.

⁸ CALD respondents were defined as carers who identified with cultural backgrounds not associated with main English-speaking countries (Australia, United Kingdom, Republic of Ireland, New Zealand, Canada, United States of America and South Africa), **AND** spoke a language other than English (including Auslan/sign languages).

Coast, Newcastle and Lake Macquarie, and Coffs Harbour - Grafton.⁹ Most carers (91%) were not currently enrolled in any formal education (Table 3).

Table 2. Demographic characteristics of sample, compared to previous surveys and ABS (2015, 2017) data

		Carers NSW 2018 Carer Survey (%)	Carers NSW 2016 Carer Survey (%)	Carers NSW 2014 Carer Survey (%)	SDAC 2015 (NSW) (%)
Total carers		1,830	1,958	1,684	904,400
Primary carer		86	93	92	31
Gender	Female	79	81	84	56
	Male	16	16	15	44
	Self-described*	0.1	-	-	-
Age	<45 years	13	17	20	37
	45-64 years	46	48	52	41
	65+ years	36	29	27	22
Education	Bachelor or higher	33	31	31	21
	Certificate/diploma	33	35	36	31
	High school	12	17	7	13
	< High school	15	12	24	30
Employed		34	37	43	51
Disability**		37	33	32	31

*2 respondents chose to self-describe their gender, 1 as "Mother and Father" and the other as "TransWoMan"

**Percentage of carers who had experienced any long-term illness or disability themselves during the last 12 months

Table 3. Demographic characteristics showing the diversity of respondents

		N	% of total sample
Cultural background			
Australian		1373	75
Aboriginal and/or Torres Strait Islander status	Aboriginal	48	3
	Torres Strait Islander	2	0.1
LOTE		231	13
CALD		202	11
Sexuality	Lesbian, gay, or homosexual	22	1
	Straight or heterosexual	1466	80
	Bisexual	30	2
	Queer	2	0.1
	Different identity*	35	2
Region	Greater Sydney	863	47
	Other area in NSW	791	43
Current education enrolment	Not enrolled	1558	85
	High school	8	0.4
	TAFE apprenticeship	56	3
	University	55	3
	Other	44	2

*Examples of 'Different identities' include; asexual, pansexual, NA, NIL, and No

A new question about respondents' internet usage was included in the 2018 survey in order to ascertain the digital literacy of carers in NSW. Respondents were asked about devices used to access the internet in the last 3 months, with mobile phones and computers being used by the majority of carers, and tablets by more than half (Figure 1). Less than 1% of carers said they had not used the internet in the past 3 months, which is significantly lower than the 22% of primary carers who reported not accessing the internet in the 2015 SDAC (ABS, 2015).

⁹ The regions represent Statistical Areas – Level 4 (ABS, 2016).

Respondents were also asked about their finances, with the majority of carers (53%) reporting that their annual household income was less than \$49,999 (Figure 2). Approximately 15% of survey respondents declined to disclose their household income. Most (63%) of the carers with household incomes under \$49,999 per year were receiving the Carer Payment, Age Pension, Disability Support Pension or Newstart Allowance, compared to 27% of all respondents. Overall, most respondents (58%) were receiving Carer Allowance and just under one quarter (23%) were receiving Carer Payment. Around 18% were receiving some other payment, most often the Age Pension (10%), Disability Support Pension (3%), and Newstart (1%).

Figure 1. Devices carers use to access the internet¹⁰

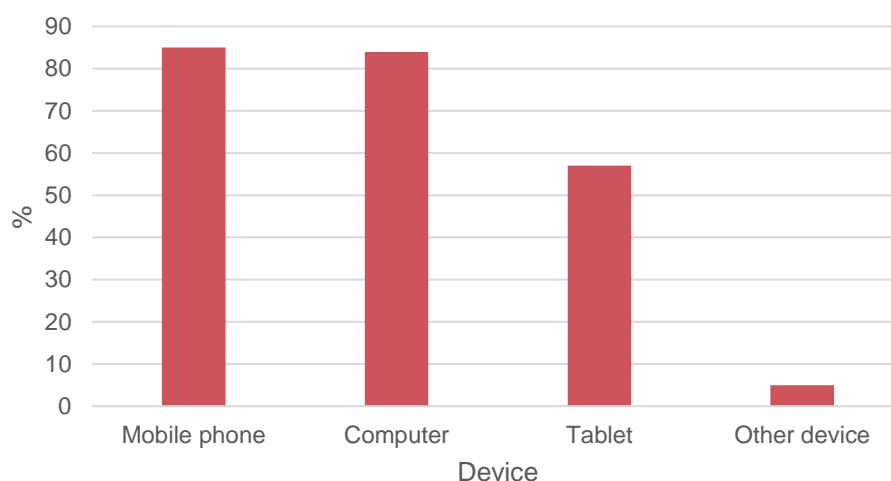
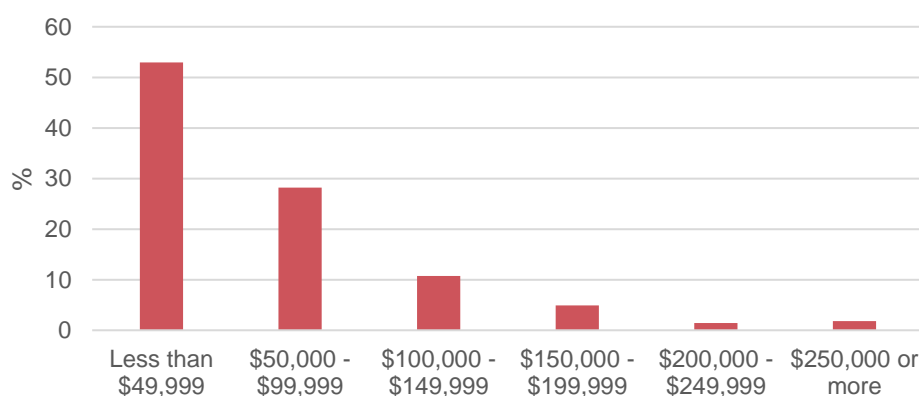


Figure 2. Annual household incomes of carers



New questions about financial hardship and retirement plans were included in the 2018 Carer Survey in order to determine impacts of caring on respondents' current and future financial security. Respondents were asked about the ease with which they were able to meet the necessary cost of living expenses in the past 12 months. One quarter (25%) of carers reported that it was easy, while 35% responded that it was neither difficult nor easy. However, 40% of carers indicated that meeting the necessary cost of living expenses was difficult.

When asked how they did or would fund their retirement, most carers selected a government pension and superannuation. Nearly one in five respondents under the age of 65 indicated that they did not know how they would fund their retirement, or had not thought about it. These results suggest that many carers are, and/or will be, affected by financial hardship as a result of their caring role.

¹⁰ This question was a 'select all that apply' question, therefore the percentages exceed 100%.

The caring relationship

Highlights

- The typical respondent was caring for one person with no assistance from other family members or friends.
- The typical care recipient was an adult son, aged 18 to 64 years, with a physical disability, only able to be left alone for a few hours and requiring 60+ hours per week of care.
- Nearly one in four carers reported caring for more than one person.
- Around half of respondents (51%) provided 60+ hours of care per week, and more than one in four carers (27%) had been caring for over 20 years.

A total of 7% of respondents indicated they were not currently caring, but had in the past. The 93% of respondents who identified as a current carer reported caring for a combined total of 2,124 people – an average of 1.3 care recipients per carer. Carers were most likely to be the sole carer, and to not receive any assistance from other family members or friends (56%) (Table 4).

Table 4. Characteristics of the caring relationship

		%
Carer status (n=1,830)	Current	93
	Former	7
Care arrangements (n=2,116)	Sole carer	56
	Shared care	44
Number of care recipients (n=1,634)	One	76
	Two	20
	Three or more	4

Care recipients' ages ranged from less than 1 year old, to over 100 years old,¹¹ and were most likely to be aged 18 to 64 years. Most carers (60%) were caring for a male, 45% for a female. Carers were most commonly caring for their sons/daughters (45%), spouses/partners (30%), and parents/parents in law (21%). Demographic characteristics of care recipients is summarised in Table 5.

Table 5. Demographic characteristics of care recipients

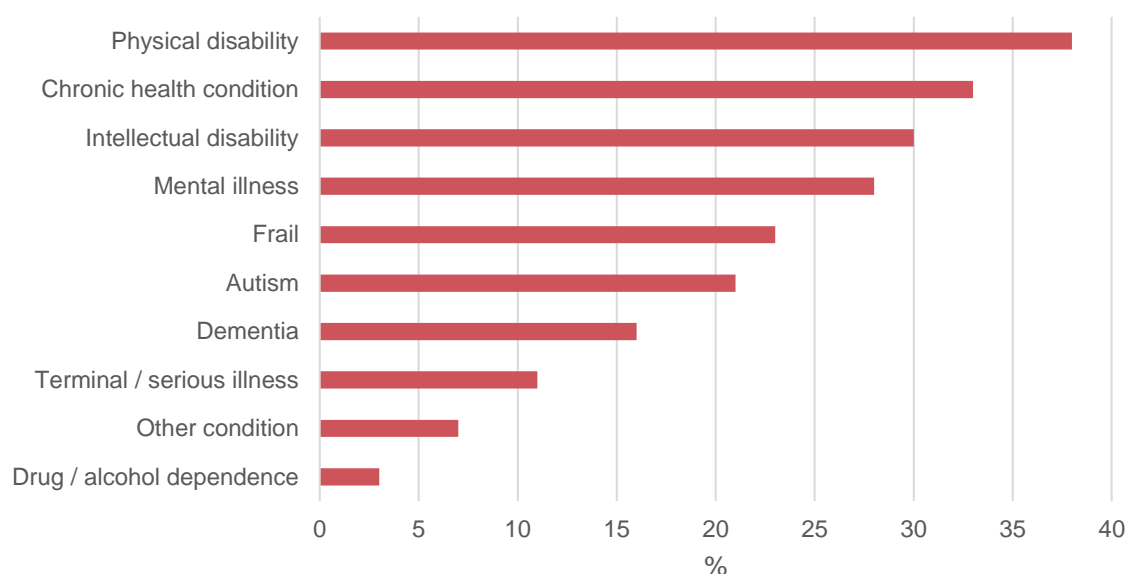
		%
Gender (n=2,133)	Female	45
	Male	60
	Self-described*	0.2
Age (n=2,081)	0-6 years	3
	7-17 years	15
	18-64 years	45
	65+ years	39
Relationship to care recipient (n=2,135)	Parent/parent in law	21
	Spouse/partner	30
	Son/daughter	45

*2 were not stated, and 1 was a transgender male.

¹¹ The online survey only allowed respondents to enter care recipients' ages up to 100 years, however, some of the paper respondents reported that they cared for someone over the age of 100 years.

Respondents were asked to identify the conditions, disabilities or illnesses for which care recipients needed their care. Respondents were most likely to provide care for someone with physical disability (38%), a chronic health condition (33%), or intellectual disability (30%) (Figure 3).

Figure 3. Care recipients' conditions/disabilities/illnesses¹²



Most care recipients could not be left alone for more than a few hours (34%), and 28% could not be left alone at all (Table 6).

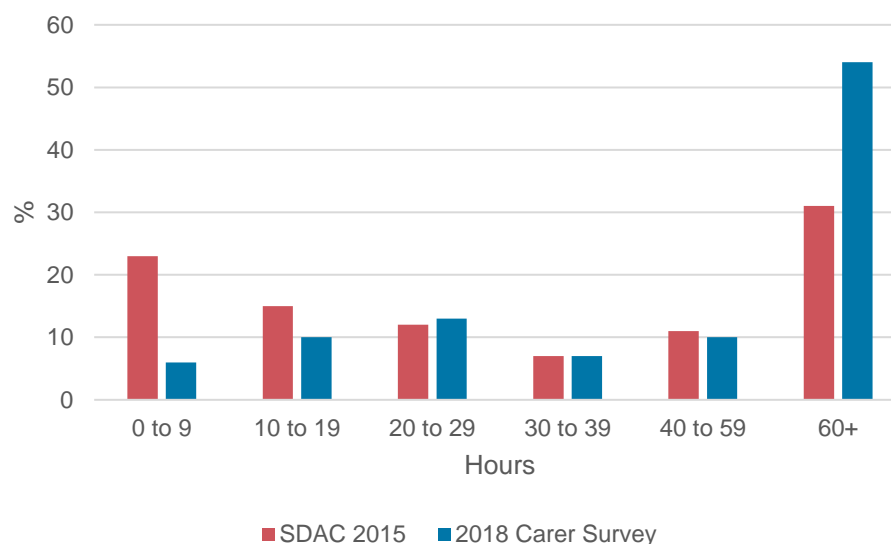
Table 6. Length of time care recipient can be left alone

		%
How long care recipients can be left alone (n=2,109)	Not at all	28
	Less than 1 hour	13
	Few hours	34
	One day	12
	Few days	9
	More than a few days	4

¹² This question was a 'select all that apply' question, therefore the percentages exceed 100%.

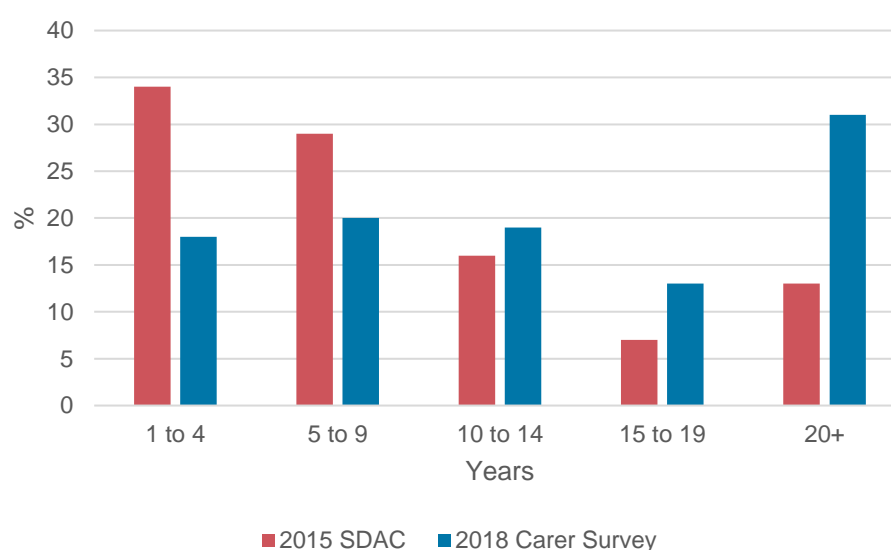
The majority of carers (51%) reported that they spent 60 or more hours per week providing care to the care recipient. Figure 4 compares the hours of care primary carers provide, showing that the primary carers responding to the 2018 Carer Survey were more likely to be providing a significant amount of care than the primary carers captured by the 2015 SDAC (ABS, 2015).

Figure 4. Comparison of hours of care provided by primary carers reported in SDAC 2015 and the 2018 Carer Survey



The number of years respondents had been caring for care recipients ranged from less than one year, through to 63 years, with the mean being 15 years. Significantly, almost one in three carers (31%) had been caring for over 20 years. Similar to the hours of care provided, primary carers responding to the 2018 Carer Survey had a significantly longer duration of care compared to the primary carers captured by the 2015 SDAC (ABS, 2015) (Figure 5).

Figure 5. Comparison of duration of care provided by primary carers reported in SDAC 2015 and the 2018 Carer Survey



Services and support

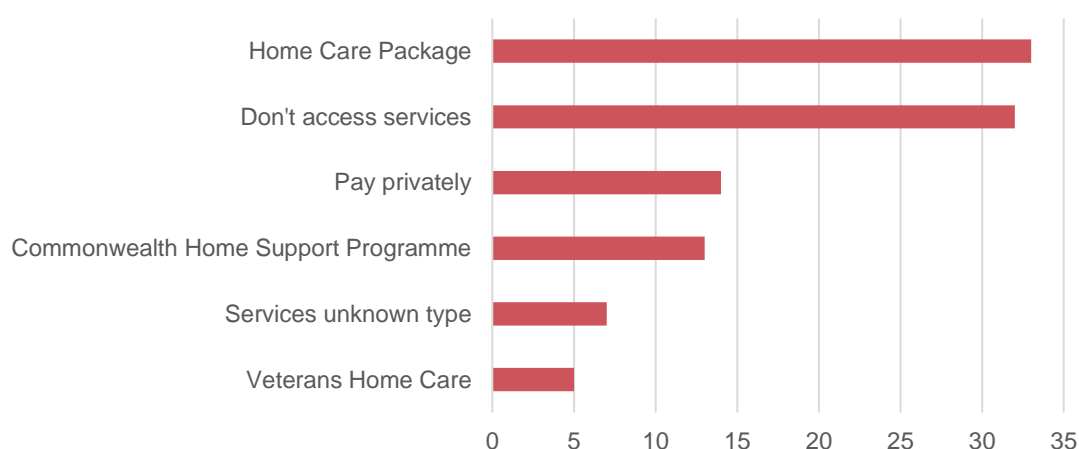
Highlights

- Carer inclusion was relatively common across the NDIS and aged care service planning and decision making, but being asked about carer needs was considerably less common.
- Large numbers of respondents reported being able to take a break as a result of NDIS supports and aged care services, however there was not widespread agreement that these supports enabled carers to look after their health or go back to work.
- Typically, care recipients under the age of 65 had experienced an increase or no change in the amount of support they were accessing since the introduction of the NDIS; however carers were more likely to have experienced no change, or a decrease in the support they were accessing.
- The majority of carers of people under the age of 65 had experienced an increase in the amount of time they spent organising support for the care recipient.
- Carer support services had a relatively low uptake overall.
- Respite and online forums were used most frequently, while counselling was the least frequently used carer support type.
- Online forums were the only support type where more carers were satisfied than dissatisfied with their current use; in most cases carers wanted more access to respite, support groups and counselling than what they were currently accessing.

Aged care services

A total of 756 respondents (41% of the full sample) were caring for someone over the age of 65 years. These carers were most likely to report that the person they were caring for was accessing services funded out of a Home Care Package (33%), followed by privately funded services (14%) and services provided by the Commonwealth Home Support Programme (13%). Nearly one third (32%) of respondents to this section indicated that the person they cared for did not access any aged care services (Figure 6).

Figure 6. Aged care services accessed by the person they care for¹³



¹³ This question was a 'select all that apply' question, therefore the percentages exceed 100%.

The majority (80%) of respondents agreed that aged care services had included them in decision making, however just under half (43%) reported being asked about their needs as a carer (Figure 7).

Approximately half of respondents (51%) agreed that aged care services had enabled them to take a break from their caring role, with 40% agreeing that aged care services supported them to look after their own health needs (Figure 8). Nearly half of respondents (45%) disagreed, however, that aged care services had enabled them to stay in, or go back to, paid work (Figure 8).

Question 21. Have you had any difficulties accessing aged care services for the person you care for?

“After hours on the phone, [we] gave up and [now] pay for services.”

“Living in a rural area limits the services available to my mother. If we have a problem with the service provider we don’t always have the luxury of accessing another as there isn’t one available.”

Figure 7. Carer inclusion in aged care services

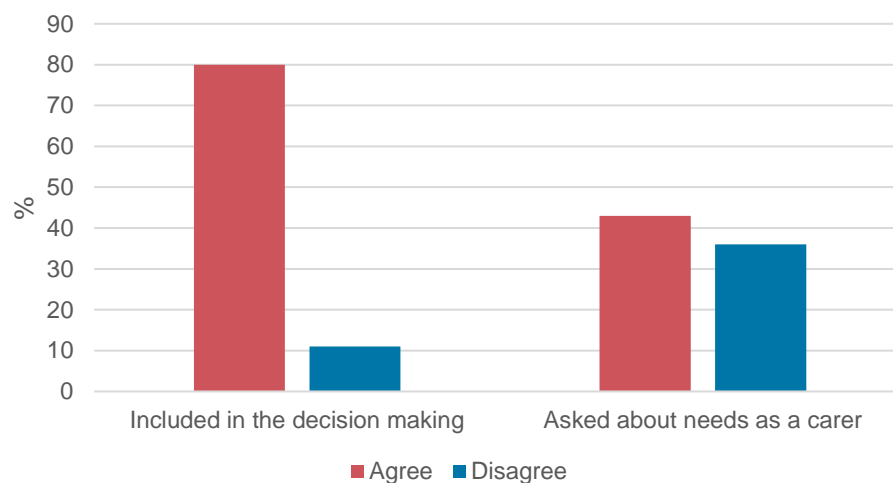
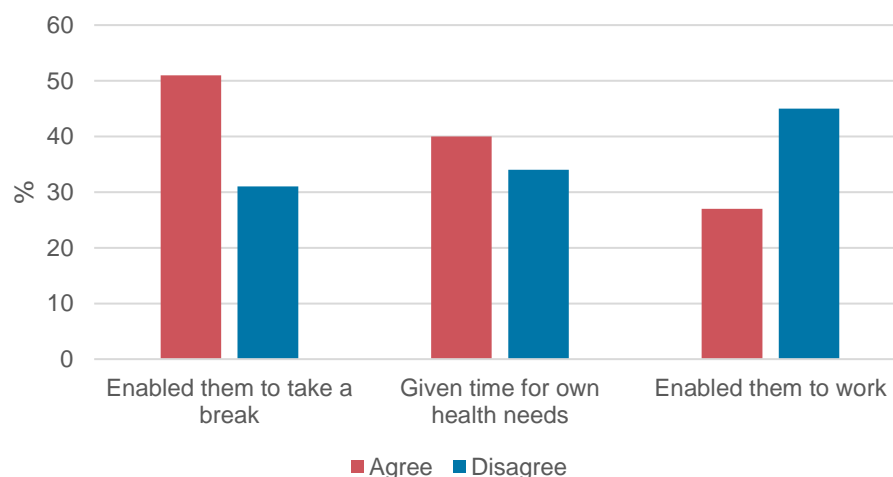


Figure 8. Impact of aged care services on carers



National Disability Insurance Scheme (NDIS)

A total of 713 survey respondents (39% of the full sample) indicated that they were caring for an NDIS participant. The majority (72%) of respondents to this section agreed that they had been included in the planning process, while just over one third (38%) indicated that they had been asked about their needs as a carer (Figure 9). Respondents were fairly evenly split (40% agreed, 44% disagreed) regarding the effect of NDIS supports on their ability to take a break. However, around half (49%) of respondents disagreed that supports from the care recipient's NDIS plan supported them to look after their own health, and just over half (55%) disagreed that NDIS supports enabled them to stay in, or go back to, paid work (Figure 10).

Figure 9. Carer inclusion in the NDIS

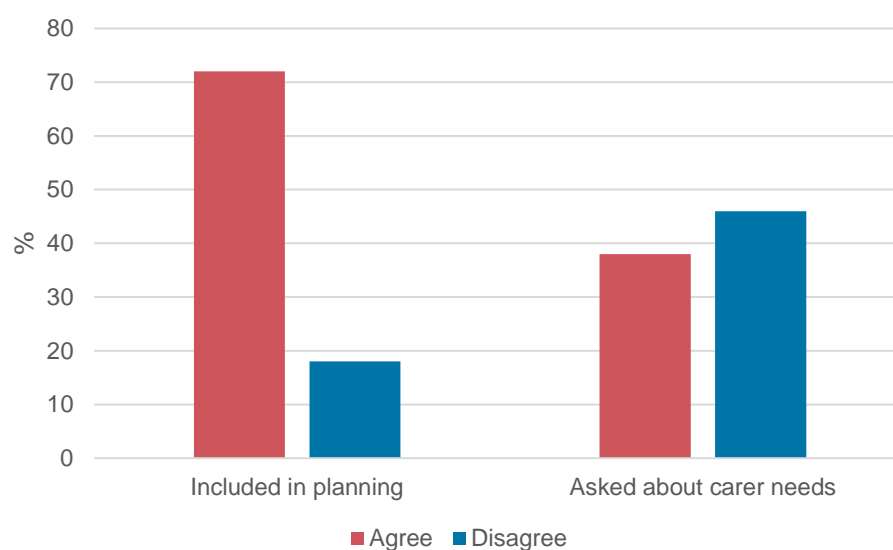
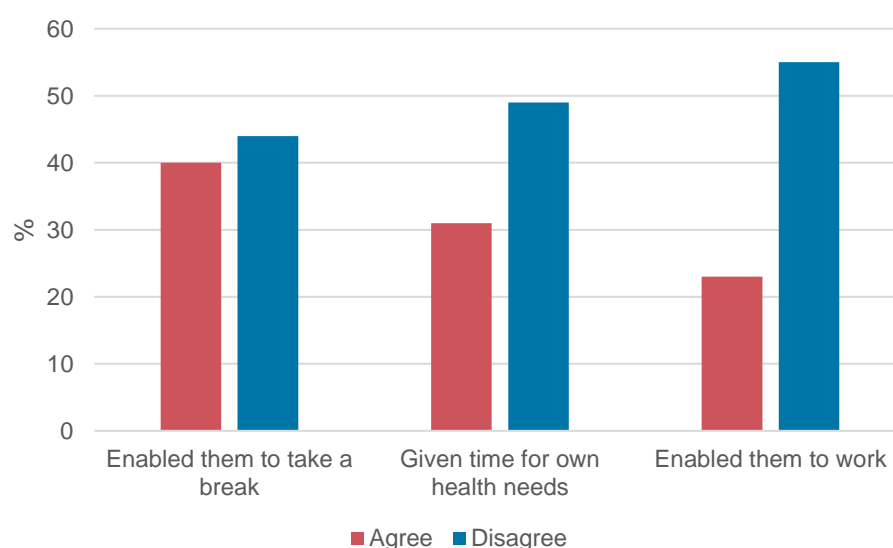


Figure 10. Impact of NDIS on carers



Respondents were fairly evenly split between having experienced an increase in support for the person they care for (40%), or experiencing no change in the past two years (38%) (Figure 11). However, just over half of respondents (52%) indicated no change in the amount of carer support they were accessing (Figure 11). The largest reported change was 61% of carers reporting an increase in the amount of time spent per week organising support for the people they care for (Figure 12).

Question 25. Have you had any difficulties accessing the NDIS?

“It has been an emotional nightmare let alone massively time consuming and frustrating”

“...[it] has been time consuming and stressful, and at my age, 78, more than I can be expected to handle”

Figure 11. The amount of support the person they care for has access to

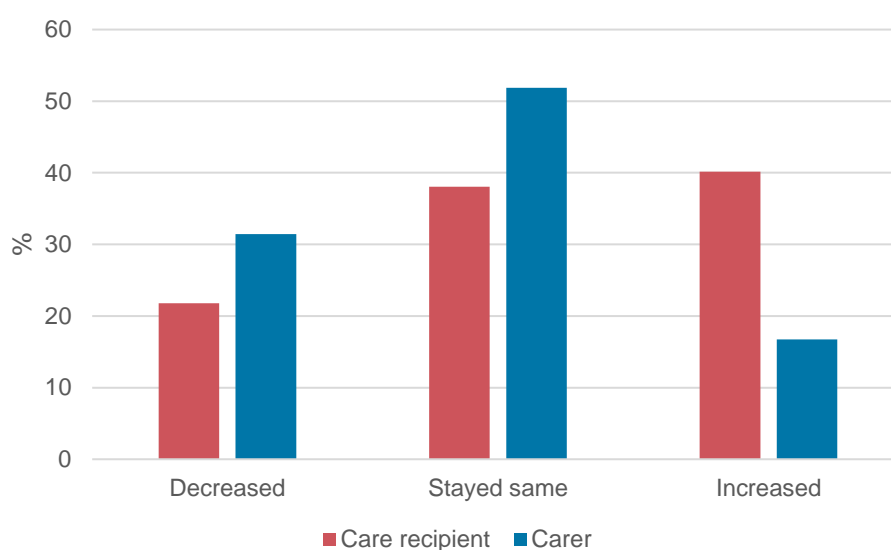
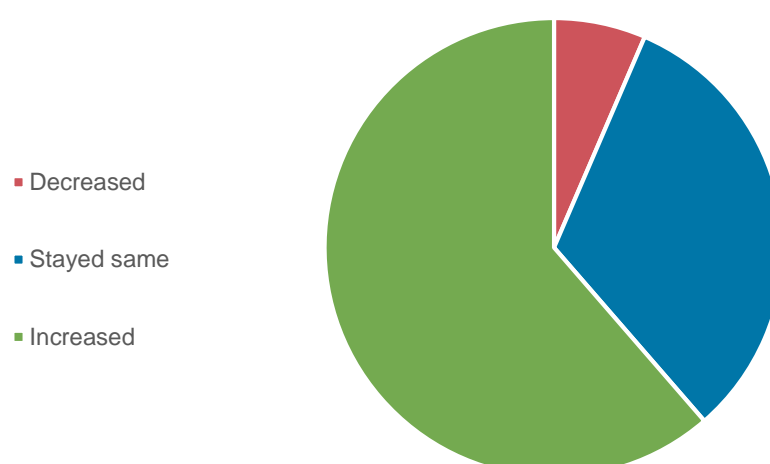


Figure 12. The amount of time spent organising support for the person they care for



Health services

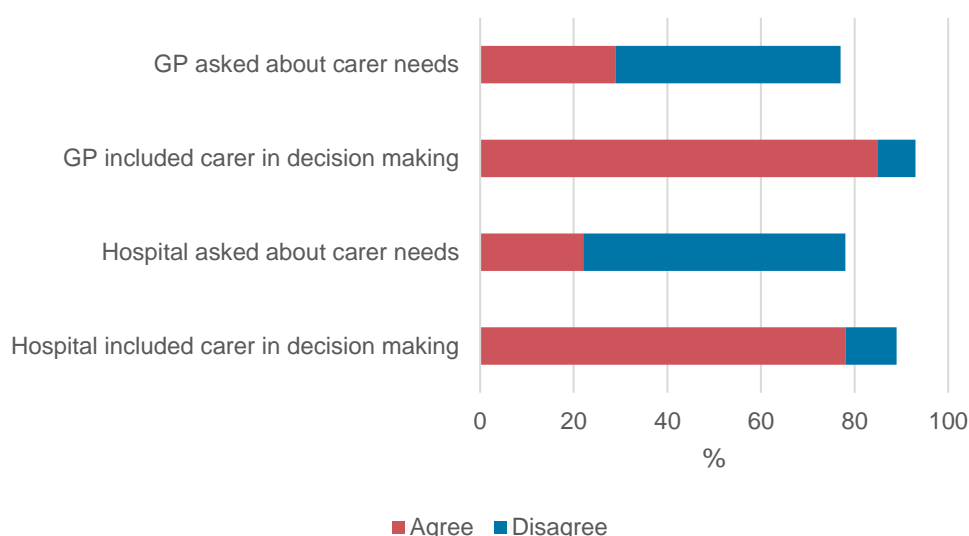
Carers were asked about their experiences when the person they care for visits the family doctor or general practitioner (GP), and the hospital. The majority of carers agreed that they were included in decision making by GPs (85%) and at hospitals (78%), however, very fewer carers reported being asked about their needs as a carer (Figure 13).

Question 27. Do you have any suggestions for how health services can improve the way they work with carers?

“Start listening to the carers. We are the ones that know them best.”

“We need to be kept informed - and given more information about how best we can support the people we care for.”

Figure 13. Carer inclusion by health services



Carer support services

Carers were asked about their usage of the four main current types of carer support: respite, carer support groups, counselling, and online forums (Figure 14). Less than half of carers in this survey indicated that they were using each of these services. Of these services, respite was the most commonly used (43% of respondents), although 37% of those using respite reported that they would like to use more (Figure 15). The carer supports carers used most frequently were respite and online forums (Figure 16).

The frequency with which respondents accessed online forums was on par with their demand for these supports, while large numbers of carers indicated that they would like to use respite, support groups and counselling more than they were currently (Figure 15).

Question 30. Tell us about your experience accessing carer supports.

“When you are a carer running on low batteries you don't have the energy to source support for yourself. All your energy goes into caring.”

“To be honest I'm too tired to try to find this help.”

“They are available in my area and very helpful.”

“There is nothing to help carers where I live or if there is no one will tell me when I ask.”

Figure 14. Carers' use of carer support services

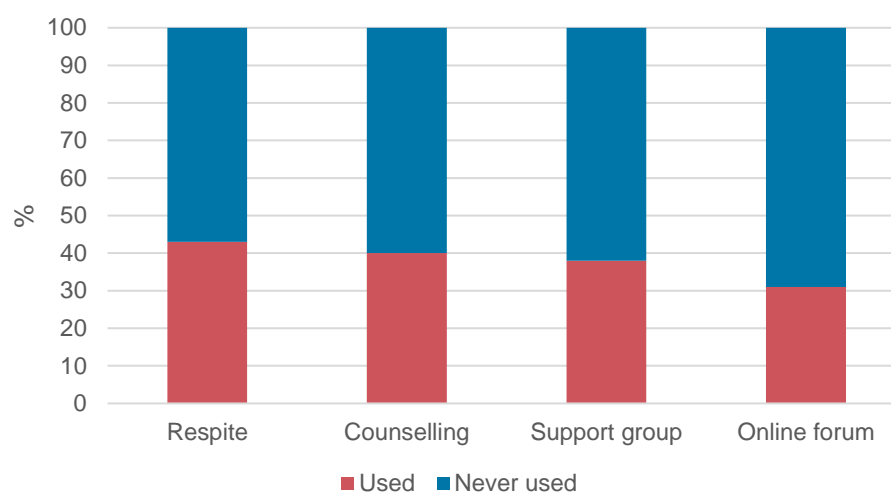


Figure 15. Use of and demand for identified carer support types

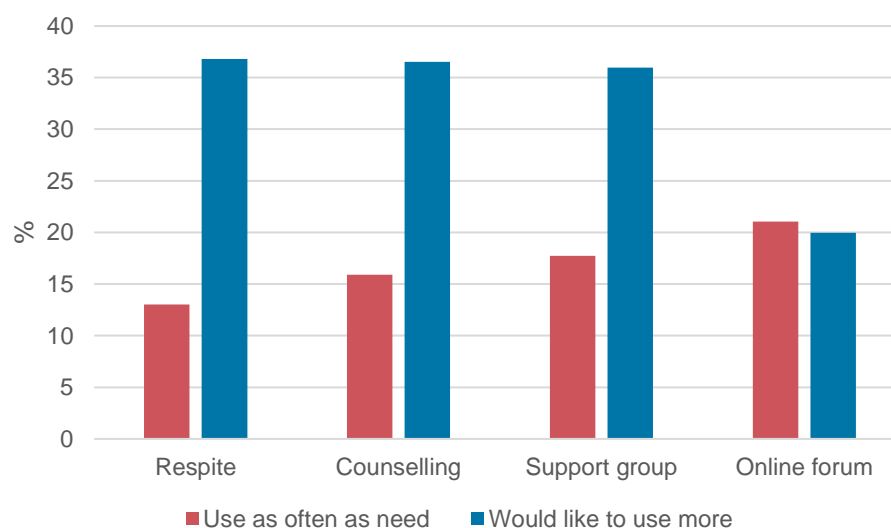
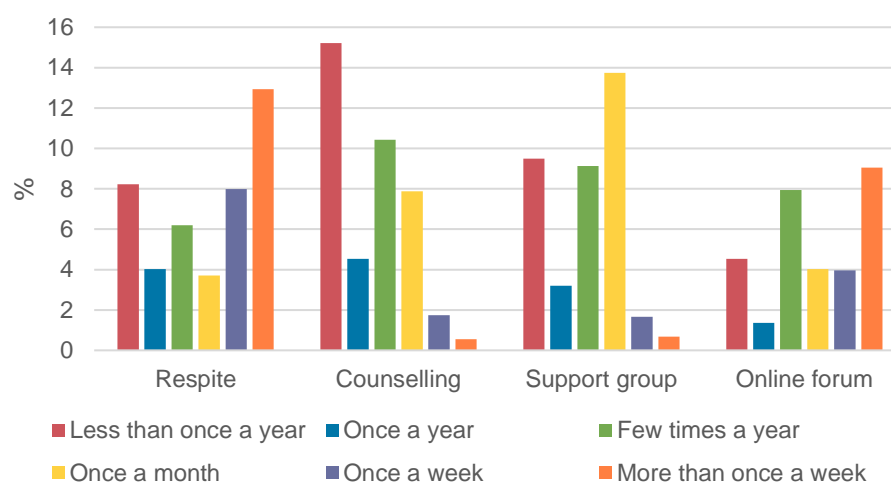


Figure 16. Frequency of use, all identified carer support types



Paid work

Highlights

- The most common career impacts of caring on respondents' paid work were reduced working hours and exiting employment.
- The majority of carers (72%) indicated they were not interested in being a paid care worker.
- The typical working carer worked 27 hours per week in a permanent position in the health care sector, and had been in the job for 12 years.
- Working carers were most likely to report that their caring *often* interfered with their jobs.
- Almost half of all working carers had used carer's leave and flexible start/finish times in their current jobs.
- Carers were five times more likely to agree (75%) than disagree (15%) that they felt comfortable telling people at work about their caring responsibilities.

As outlined in Table 7, 34% of current carers reported being in paid employment, while 66% were not (53% of those not employed were aged 65 years and over, and therefore may have retired). As found in previous Carers NSW Carer Surveys, working carers were more likely to be female. Working carers unsurprisingly have a lower mean age, were more likely to have completed higher levels of formal education, and had lower rates of long-term illnesses or disabilities than those who were not employed.

Table 7. Demographic comparison of working carers and those not working

		Employed (%) (n=621)	Not employed (%) (n=1202)
Gender	Female	84	77
	Male	10	19
	Self-described	0	0.2
Age (Mean)		51 years	63 years
Education	Bachelor or higher	46	27
	Certificate/diploma	33	33
	High school	6	16
	Less than high school	8	19
Disability		29	41

Working carers spent on average 27 hours per week doing paid work. Of the 621 carers with paid jobs, most were in permanent positions (57%, n=351), compared to other employment types, as shown in Figure 17. Carers had been working in this job for an average of 12 years. Working carers were most commonly employed in four main industries: health care, community/non-profit, government/public sector, and education/training. A breakdown of the percentage of carers employed in different industries is shown in Figure 18. Examples of other industries carers worked in included; real estate, publishing, and farming.

Figure 17. Carers' employment types

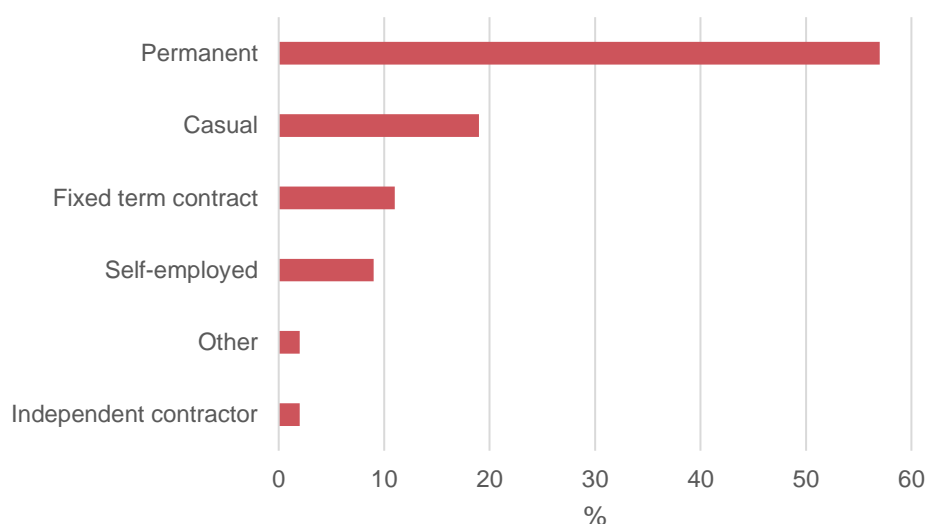
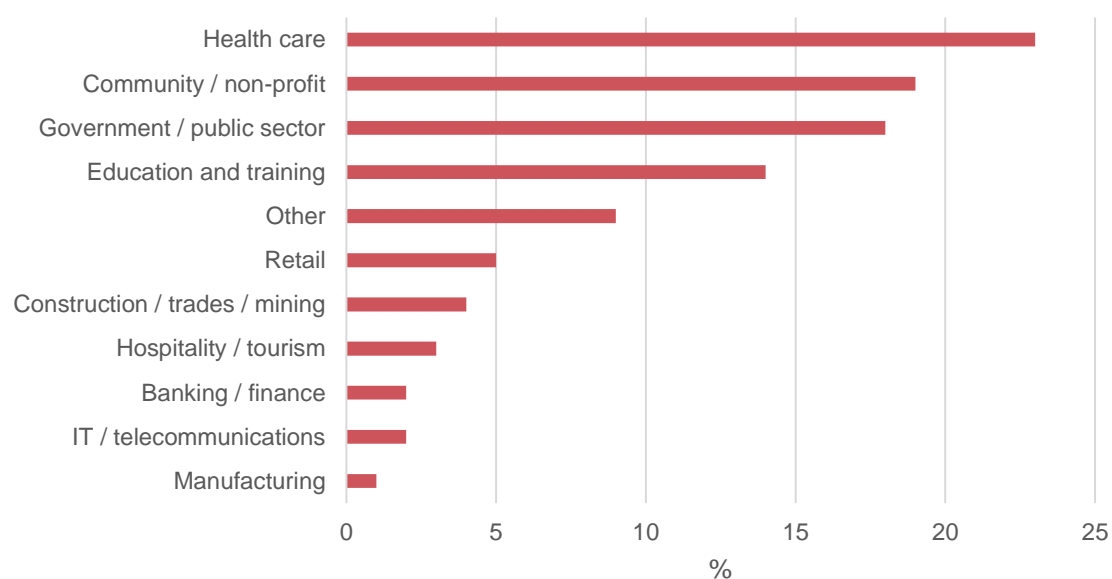


Figure 18. Carers' employment sectors



Carers were also asked about work and care interference over the last six months, drawing on established work-family enrichment and work-care conflict scales (Grzywacz, Frone, Brewer, & Kovner, 2007; Kacmar, Crawford, Carlson, Ferguson, & Whitten, 2014; Matthews, Kath, & Barnes-Farrell, 2010). Most carers reported that their job interfered with their caring *sometimes* (36%). In addition, most said their caring role interfered with their job *often* (34%) (Figure 19). Working carers were twice as likely to agree (57%) than disagree (27%) that they had autonomy in (i.e. the ability to control) their work scheduling (Figure 20).

Figure 19. Work and care interference

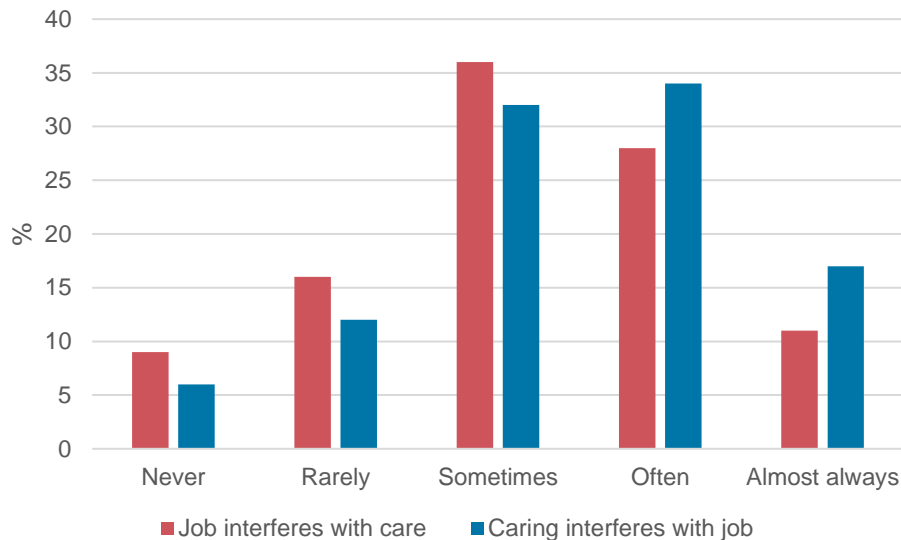
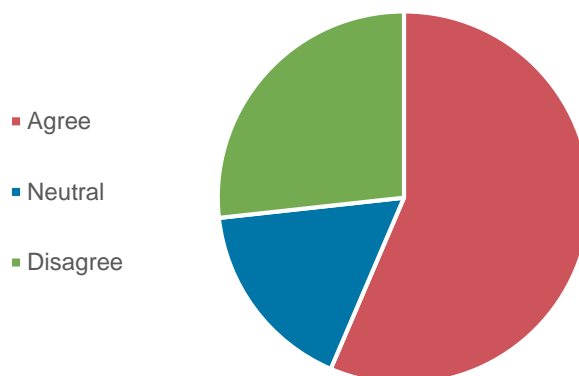


Figure 20. Work scheduling autonomy



Around half of all working carers had used carer's leave and flexible start/finish times in their current jobs, and 18% had not used any of flexible work arrangements. Around one in ten working carers reported using other flexible work arrangements, such as flexible work days. Carers' use of flexible work arrangements is shown in Figure 21.

In their workplaces, working carers were five times more likely to agree that they felt comfortable telling people about their caring responsibilities (75%), than they were to disagree (15%). Similarly, the majority of working carers agreed that people supported them to combine work and care (60%), and only 16% disagreed. These results are shown in Figure 22.

Figure 21. Carers' current use of flexible work arrangements¹⁴

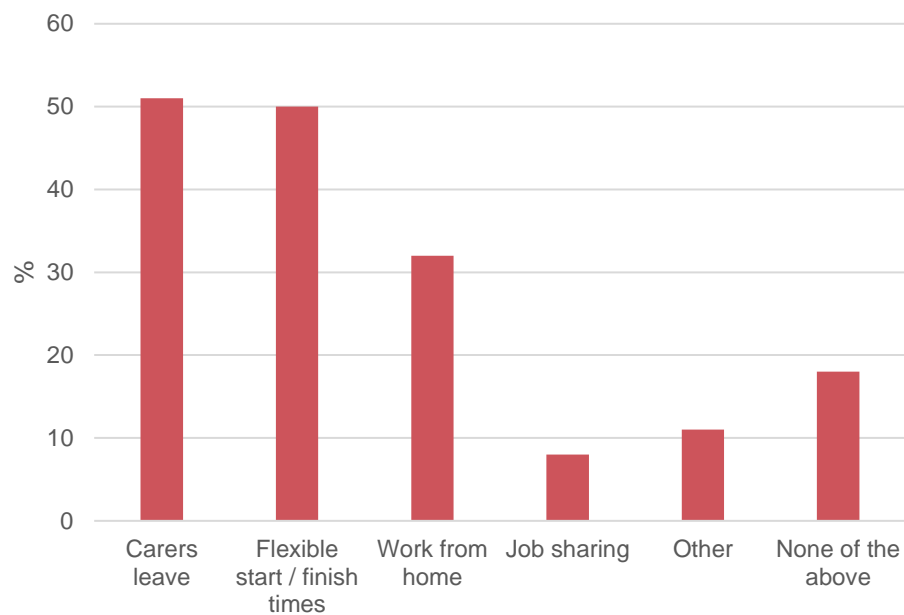
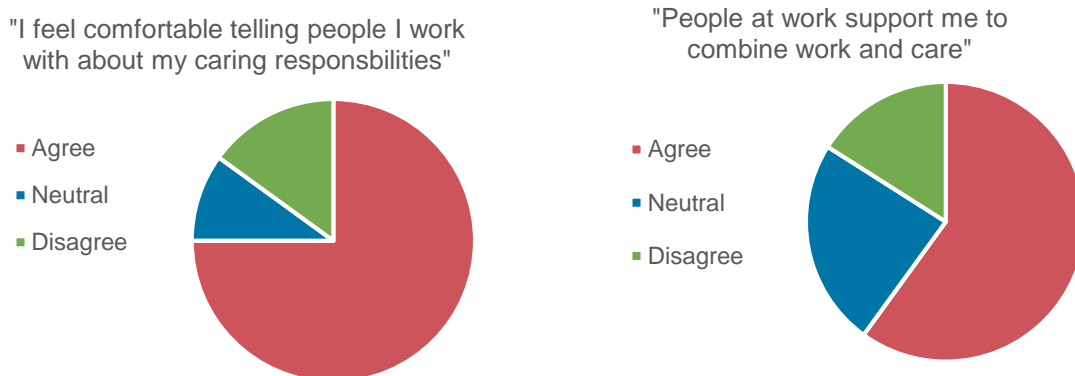


Figure 22. Workplace culture supporting carers



Carers' satisfaction with their paid jobs was assessed using the Job Satisfaction Subscale (JSS) from the Michigan Organizational Assessment Questionnaire (Cammann, Fichman, Jenkins, & Klesh, 1979). The majority (69%) of working carers agreed they were satisfied with their jobs, and very few reported that they didn't like their jobs (11%). However, despite feeling satisfied at work, many carers (41%) had seriously considered quitting their jobs (Figure 23).

Respondents were asked about the impacts their caring role had ever had on their ability to engage in paid work. Around one in three respondents reported that their caring role had led them to reduce their working hours (37%) and quit their jobs (31%), and more than one in four said caring had resulted in their skills and qualifications becoming out of date due to time out of the workforce (29%). This is illustrated in Figure 24. 23% of carers reported they had experienced none of these impacts, and 20% gave other responses, for example, saying they were self-employed or had retired.

¹⁴ This question was a 'select all that apply' question, therefore the percentages exceed 100%.

Figure 23. Carers' job satisfaction

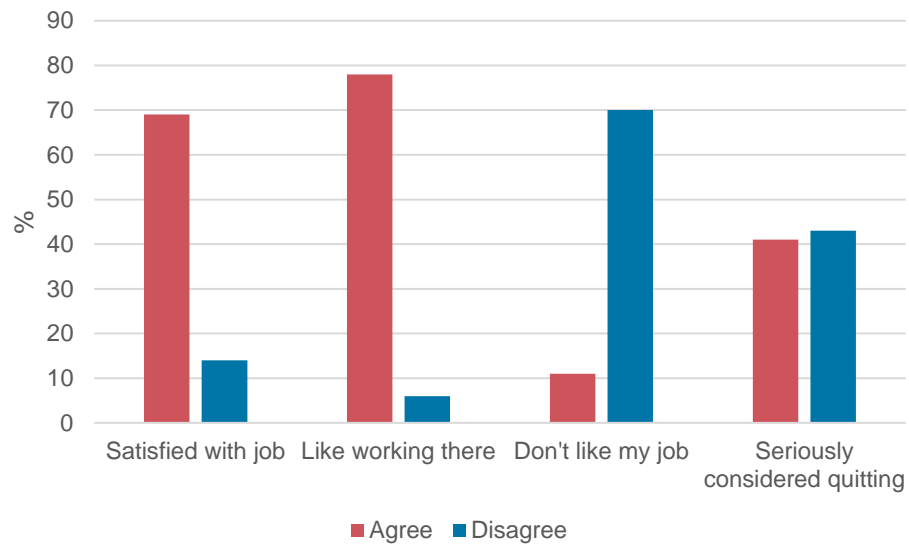
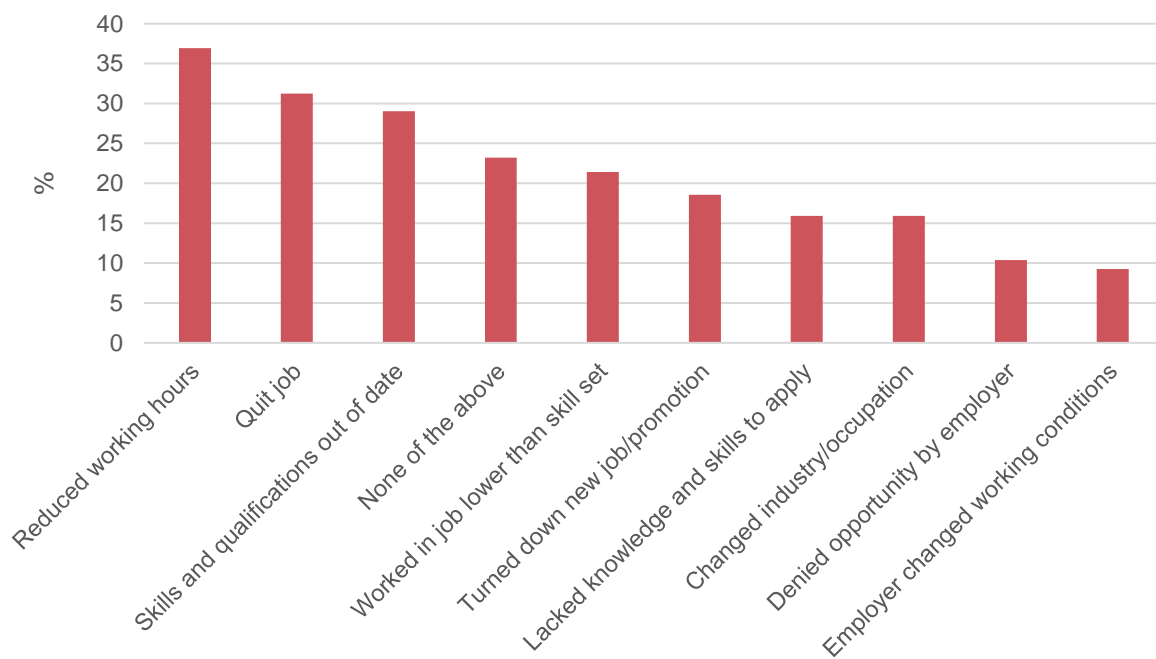


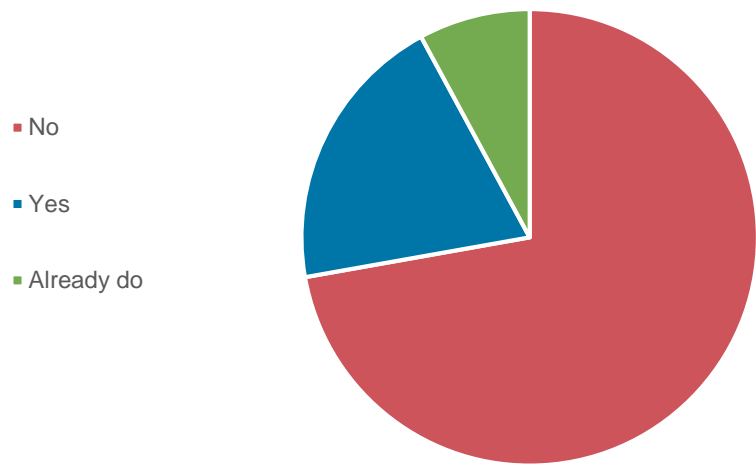
Figure 24. Impacts of caring on paid work¹⁵



¹⁵ This question was a 'select all that apply' question, therefore the percentages exceed 100%.

All respondents were asked if they would consider working as a paid care worker. The majority (72%) said no, 20% said yes, and 8% reported that they already do (see Figure 25). Respondents explained their responses in an open-text question, which will be analysed and reported elsewhere.

Figure 25. Carers’ willingness to engage in paid care work



Health, wellbeing, and carer recognition

Highlights

- The majority (77%) of carers with a long-term illness or disability reported their caring responsibilities had affected their illness or disability.
- Carers reported lower overall wellbeing than those carers captured in previous Carer Surveys.
- Carers responding to the survey had higher levels of psychological distress than the average carer in NSW (according to the 2015 SDAC).
- Carers perceive the most social support from their significant others, and the least from their families.
- 43% of carers agreed that their caring had positive aspects, compared to the 25% carers who disagreed.
- Carers were less likely to agree that their caring is recognised by their community.

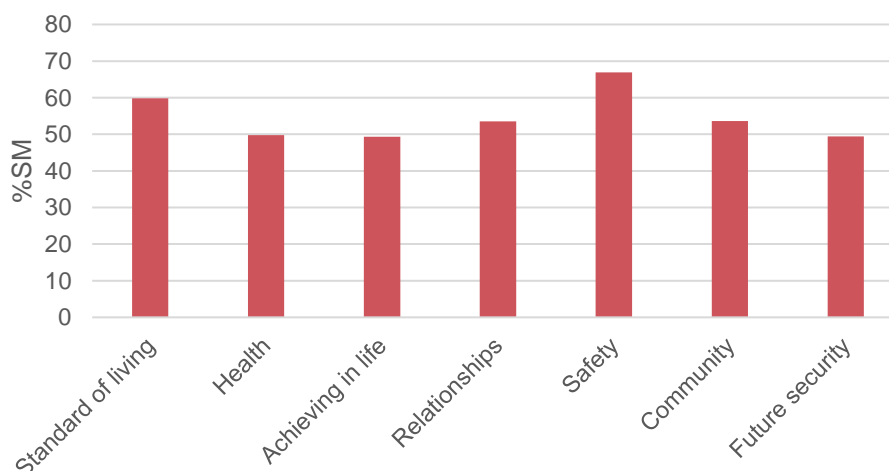
The 670 carers who had a long-term illness or disability (see Table 1), were more than three times as likely to report that their caring responsibilities had affected their long-term illness or disability (77%), compared to those who reported no affect (23%).

Question 48. Have your caring responsibilities affected your long-term illness or disability?

“Worrying about my son's future has increased my anxiety.”

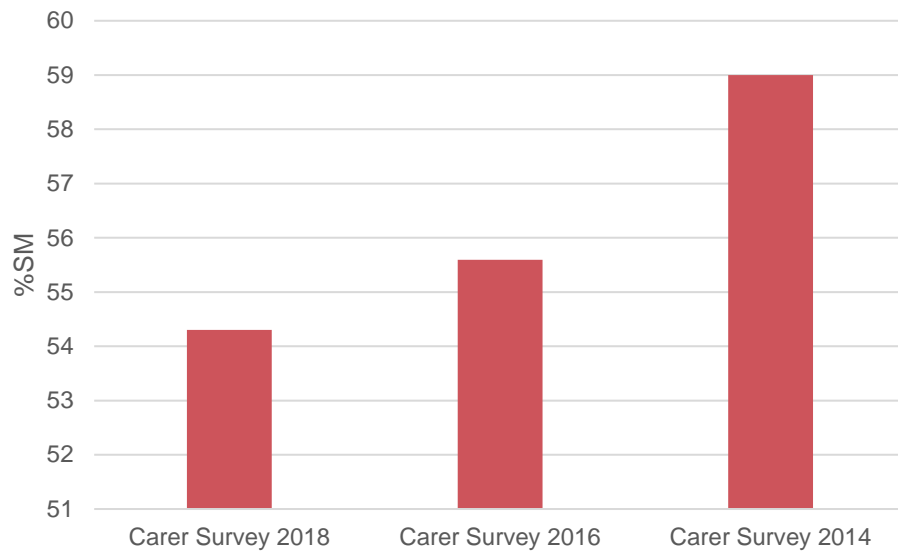
The Personal Wellbeing Index (PWI) measures satisfaction with life across seven domains, which can either be assessed individually, or collectively as an overall indication of personal wellbeing. Figure 26 shows that carers report the lowest scores on measures of future security, achieving in life, and their health.¹⁶ The overall PWI score is presented alongside the mean score of carers in the Carers NSW 2016 and 2014 Carer Surveys in Figure 27, showing carers' overall reported wellbeing is lower than in previous surveys.

Figure 26. Carers PWI scores



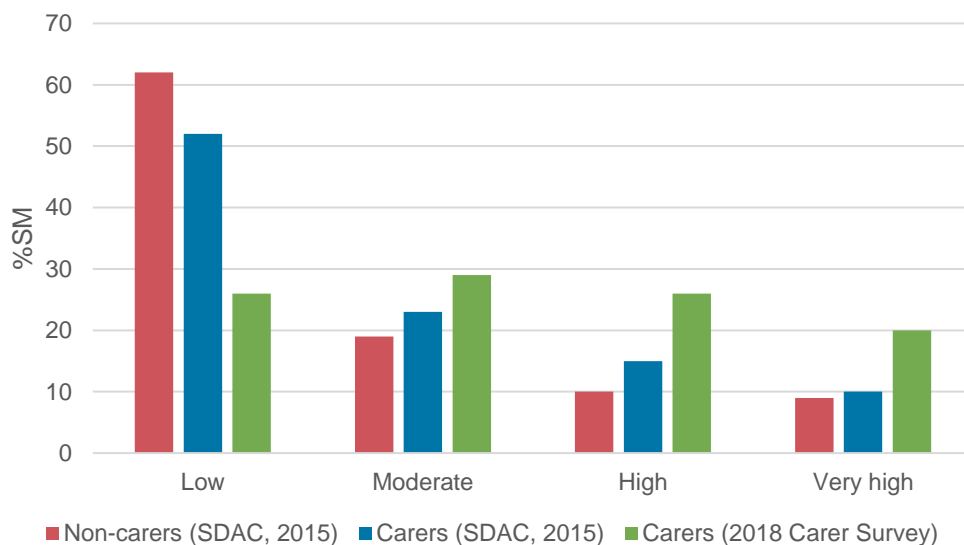
¹⁶ For the purpose of reporting results that can be easily compared, scores on each of these scales have been converted into a score out of 100, referred to as “percentage of scale maximum” (%SM).

Figure 27. Comparison of PWI scores from Carers NSW 2018, 2016, and 2014 Carer Surveys



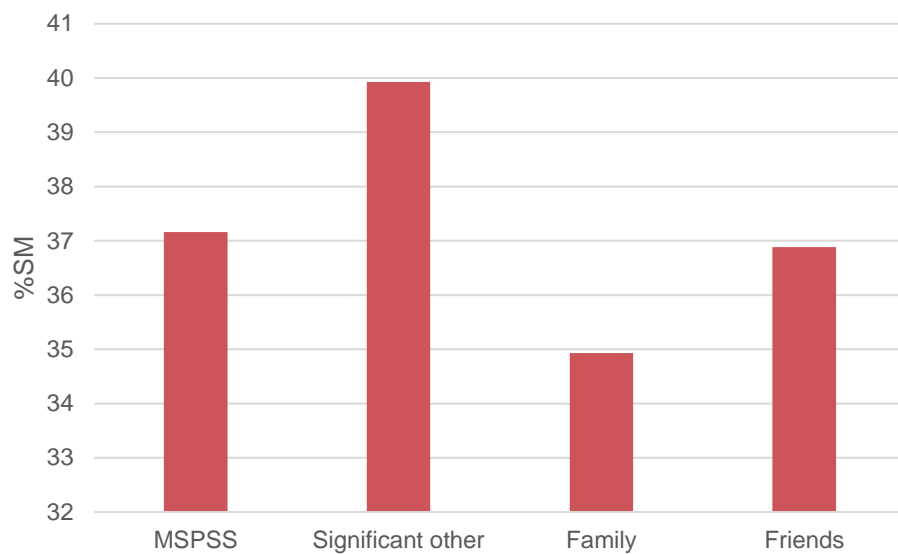
Psychological distress was measured using the K10, which is categorised to indicate low, moderate, high, or very high levels of psychological distress. Carers' responses from this survey are compared to responses from both carers and non-carers from the 2015 SDAC (ABS, 2015) in Figure 28, showing that non-carers have the lowest distress, and respondents to the 2018 survey reported significantly higher levels of psychological distress than the carers responding to the SDAC.

Figure 28. Comparison of K10 categories from Carers NSW 2018 Carer Survey and SDAC (2015)



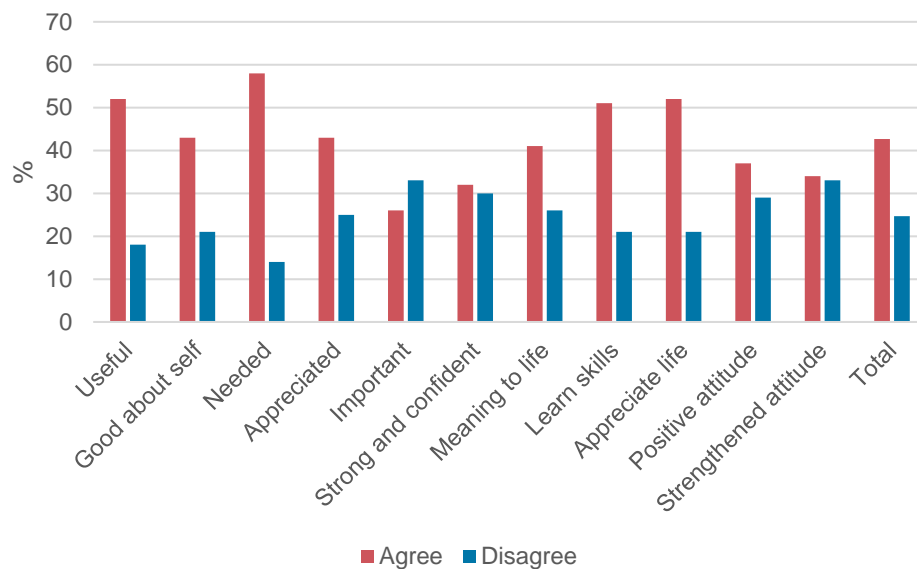
The social support experienced by carers was measured using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988). This scale provides a measure of overall social support, as well as measuring perceived support from three separate sources: significant others, family, and friends. Carers perceived the most support from significant others, while the family was comparatively least supportive (Figure 29).

Figure 29. Mean MSPSS and subscale scores



The Positive Aspects of Caregiving scale (PAC) measures the extent to which respondents agree with a range of statements regarding potential positive aspects of their caring roles. Overall, 43% of carers indicated agreement with these statements, compared to 25% indicating disagreement. Carers were more likely to agree that caring made them feel needed (58%), useful (52%), and appreciated (52%), but were less likely to agree that their caring made them feel strong and confident (32%), or important (26%). (Figure 30).

Figure 30. Carers PAC scores



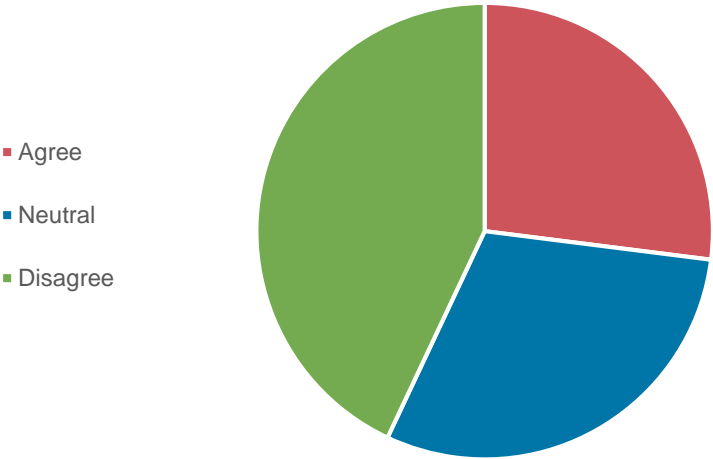
Carers were asked the extent to which they agreed that their caring role was recognised and valued by their community, outlined in Figure 31. More carers disagreed that their caring role was recognised (43%), than those who agreed (27%), or felt neutral (30%).

Question 46. Do you feel that your caring role is recognised and valued by your community?

“We have wonderful emotional and tangible support from our community.”

“[It is] very hard to get other people to truly understand the effort required and the impact on us in caring”

Figure 31. Carers' agreement with being recognised and valued by the community



Conclusion

This summary report has provided an initial overview of results from the Carers NSW 2018 Carer Survey. A valid sample of 1,830 current and former carers of diverse circumstances and backgrounds responded to the survey, resulting in important insights into the impacts on carers of ongoing sector reforms, and providing an overall snapshot of the demographic and socio-economic characteristics of carers in NSW.

The survey found that across aged care, disability and health services, carers tended to be included in decision making and support planning, but were considerably less likely to be asked about their own needs in these service settings. This is not surprising in the aged care and disability contexts, given their increasing consumer focus, but has potentially concerning implications for the identification of hidden carers and of carer support needs overall.

In the disability services context, one third of carers supporting someone under the age of 65 years reported that the support they accessed as a carer had decreased since the full rollout of the NDIS commenced in NSW, even though support for the care recipient was more likely to have increased during the same period. In spite of this, the majority of carers were spending more time organising support for the person they care for. These findings suggest that under the NDIS, carers are being expected to undertake more of a support coordination role than previously, which may have implications for their health and wellbeing and socio-economic participation.

Perhaps unsurprising given the ongoing changes to carer support, survey respondents reported lower wellbeing than in previous Carers NSW Carer Surveys, and higher levels of psychological distress than the average carer in NSW. Further, more than three quarters of carers reporting a long-term illness or disability referred to the impact of their caring responsibilities on their condition. Potential relationships between these variables will be explored in future publications.

Carer recognition in the broader community has been tracked in Carers NSW Carer Surveys since 2012, following the introduction of the NSW *Carers (Recognition) Act 2010*. In 2018, carer recognition remains low, with only one in four respondents feeling their caring role was recognised by their community. Although the respondent sample cannot be considered representative of the broader carer population, this result indicates that considerable work remains to be done in order to improve carer recognition in NSW.

A more positive finding with regard to carer recognition was that working carers tended to report comfort in disclosing their caring role at work, and many took advantage of flexible working arrangements. However, care often interfered with paid work, and had often led respondents to reduce their working hours or quit their job. Given that respondents also reported high levels of financial hardship, the implications of changes in carer employment on carers' financial stability will continue to be explored in future analysis.

Internet usage was relatively high among survey respondents, even those who completed the paper questionnaire, and a large number of carers reported using online groups and forums as a form of carer support. These findings are significant given the ongoing digitisation of many carer supports and service gateways. However, demand for face to face carer support services remained high, confirming that ongoing provision of face to face carer support needs to remain a priority moving forward.

The findings from the Carers NSW 2018 Carer Survey will continue to be analysed and disseminated as part of Carers NSW ongoing work in advocating for and supporting carers. Learnings from the 2018 survey will inform the development of future Carers NSW Carer Surveys which will allow Carers NSW to continue to understand the needs and experiences of carers across NSW.

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Appendix A



CARERS NSW 2018 CARER SURVEY

Thank you for taking the time to complete this survey. By sharing your opinions and experiences, you will help Carers NSW advocate for greater recognition and support of carers.

The survey closes on **30 June 2018** and can be completed online via the Carers NSW website (www.carersnsw.org.au/research/survey), or by completing this form and returning it in the reply paid envelope provided.

The survey should take you **approximately 20 minutes** depending on your responses. You can leave any question blank if it does not apply to you, or if you would prefer not to answer. Your responses will remain anonymous.

By completing and returning this survey you indicate that:

- you have read the enclosed Participant Information Sheet
- you voluntarily agree to participate
- you are at least 16 years of age

If you have any questions about this survey, please contact the Carers NSW Research Team on (02) 9280 4744 or research@carersnsw.org.au.

SCREENING QUESTIONS

1. Do you live in New South Wales?

- ☐ Yes (**go to Question 2**)
- ☐ No (*unfortunately you do not fit our respondent profile. Thank you for your interest.*)

2. Do you care for someone who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing?

- ☐ Yes (**go to Question 3**)
- ☐ Not currently, but I have in the past (**go to Question 3**)
- ☐ No (*unfortunately you do not fit our respondent profile. Thank you for your interest.*)

3. Is/was the person you care(d) for a family member, friend or neighbour?

- ☐ Yes (**if you currently provide care go to Question 4, if you no longer provide care go to Section 3: Paid work**)
- ☐ No, I care / cared for this person as paid work (i.e. nurse, support worker) (*unfortunately you do not fit our respondent profile. Thank you for your interest.*)
- ☐ No, I care / cared for this person as a formal volunteer (*unfortunately you do not fit our respondent profile. Thank you for your interest.*)

SUPPORTS ALL CARERS • AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS • AN AUSTRALIA 1

SECTION 1: THE CARING RELATIONSHIP

4. How many people do you care for? _____

The following questions are about the person(s) you care for. If you care for more than one person, please complete both columns, thinking about the TWO people you provide the MOST care for.

PERSON 1

5. What is this person's gender?

- ☐ Female
☐ Male
☐ Self-described _____
☐ Prefer not to disclose

6. How old is this person?

_____ years

7. What is this person's relationship to you?

They are my:

- ☐ Parent / parent in law
☐ Spouse / partner
☐ Son / daughter
☐ Brother / sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other (please specify):

8. What is this person's cultural background? (e.g. Italian, Chinese, Australian)

9. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ Yes, they speak

☐ No, English only

10. Is this person of Aboriginal or Torres Strait Islander origin? For people of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.

- ☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander

PERSON 2

5. What is this person's gender?

- ☐ Female
☐ Male
☐ Self-described _____
☐ Prefer not to disclose

6. How old is this person?

_____ years

7. What is this person's relationship to you?

They are my:

- ☐ Parent / parent in law
☐ Spouse / partner
☐ Son / daughter
☐ Brother / sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other (please specify):

8. What is this person's cultural background? (e.g. Italian, Chinese, Australian)

9. Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)

☐ Yes, they speak

☐ No, English only

10. Is this person of Aboriginal or Torres Strait Islander origin? For people of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.

- ☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander

PERSON 1 (continued)

- 11. For what conditions / disabilities / illnesses does this person need your care? Tick all that apply.**

- ☐ Physical disability
 - ☐ Frailty due to ageing
 - ☐ Intellectual disability
 - ☐ Autism Spectrum Disorder
 - ☐ Mental illness
 - ☐ Drug or alcohol dependency
 - ☐ Dementia
 - ☐ Chronic health condition
 - ☐ Terminal or serious illness
 - ☐ Other (please specify):
-

- 12. Please describe the types of support needed by the person you care for. Tick all that apply.**

- ☐ Personal care (e.g. eating, showering, dressing)
 - ☐ Mobility (e.g. walking, getting out of bed)
 - ☐ Communication
 - ☐ Cognitive or emotional assistance (e.g. decision making, managing finances)
 - ☐ Health care (e.g. taking medication)
 - ☐ Reading or writing tasks
 - ☐ Transport
 - ☐ Household chores
 - ☐ Property maintenance
 - ☐ Meal preparation
 - ☐ Other (please specify):
-

- 13. Does this person live with you?**

- ☐ Yes
 - ☐ No, they live independently
 - ☐ No, they live with another family member or friend who cares for them
 - ☐ No, they live in a care facility (e.g. nursing home)
 - ☐ No, they live in supported accommodation / a group home
 - ☐ Other (please specify):
-

- 14. Do any other family members / friends help care for this person?**

- ☐ Yes
- ☐ No

PERSON 2 (continued)

- 11. For what conditions / disabilities / illnesses does this person need your care? Tick all that apply.**

- ☐ Physical disability
 - ☐ Frailty due to ageing
 - ☐ Intellectual disability
 - ☐ Autism Spectrum Disorder
 - ☐ Mental illness
 - ☐ Drug or alcohol dependency
 - ☐ Dementia
 - ☐ Chronic health condition
 - ☐ Terminal or serious illness
 - ☐ Other (please specify):
-

- 12. Please describe the types of support needed by the person you care for. Tick all that apply.**

- ☐ Personal care (e.g. eating, showering, dressing)
 - ☐ Mobility (e.g. walking, getting out of bed)
 - ☐ Communication
 - ☐ Cognitive or emotional assistance (e.g. decision making, managing finances)
 - ☐ Health care (e.g. taking medication)
 - ☐ Reading or writing tasks
 - ☐ Transport
 - ☐ Household chores
 - ☐ Property maintenance
 - ☐ Meal preparation
 - ☐ Other (please specify):
-

- 13. Does this person live with you?**

- ☐ Yes
 - ☐ No, they live independently
 - ☐ No, they live with another family member or friend who cares for them
 - ☐ No, they live in a care facility (e.g. nursing home)
 - ☐ No, they live in supported accommodation / a group home
 - ☐ Other (please specify):
-

- 14. Do any other family members / friends help care for this person?**

- ☐ Yes
- ☐ No

PERSON 1 (continued)

15. Are you the person who provides the most care for this person?

- ☐ Yes
☐ No

16. How long can this person be left alone?

- ☐ Not at all
☐ Less than an hour
☐ A few hours
☐ One day
☐ A few days
☐ More than a few days

17. On average, how many hours per week do you spend caring for this person? _____ hours

18. How long have you been caring for this person?

- ☐ Less than 1 year
☐ _____ years

PERSON 2 (continued)

15. Are you the person who provides the most care for this person?

- ☐ Yes
☐ No

16. How long can this person be left alone?

- ☐ Not at all
☐ Less than an hour
☐ A few hours
☐ One day
☐ A few days
☐ More than a few days

17. On average, how many hours per week do you spend caring for this person? _____ hours

18. How long have you been caring for this person?

- ☐ Less than 1 year
☐ _____ years

SECTION 2: SERVICES AND SUPPORT

Questions 19 to 21 are about services for people **aged 65 years and over**. If you care for more than one person in this age group, try to answer the questions with all people in mind.

If the person(s) you care for are **under the age of 65 years**, please **go to Question 22**.

19. Does the person you care for currently access any of the following aged care services in their home or the community? Tick all that apply.

- ☐ Services provided by a Commonwealth Home Care Package (Level 1, 2, 3 or 4)
☐ Services provided by the Commonwealth Home Support Programme (CHSP)
☐ Services provided by Veterans' Home Care (VHC)
☐ They pay for services privately
☐ They receive aged care services but I don't know what type
☐ They are over the age of 65 years but do not access any of the above services (**go to Question 21**)
☐ Other (please specify): _____

- 20. Please indicate how much you agree with the following statements:** If the person you care for uses more than one type of aged care service, please answer with the service(s) they use most often in mind.

Aged care services currently used by the person I care for have:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
Included me in decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to take a break from my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Given me time to look after my own health needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to stay in, or go back to, paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 21. Have you had any difficulty accessing aged care services for the person you care for? If so, please describe your experience.**

Questions 22 to 25 are about disability services for people **under the age of 65 years**. If you care for more than one person in this age group, try to answer the questions with all people in mind.

If you **do not** care for anyone **under the age of 65 years** who has a disability, please go to Question 26.

- 22. Does the person you care for access disability supports through the National Disability Insurance Scheme (NDIS)?**

- ☐ Yes
- ☐ No (go to Question 24)
- ☐ I don't know (go to Question 24)

- 23. Please indicate how much you agree with the following statements:**

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
<i>The Local Area Coordinator (LAC) / NDIS planner who helped the person I care for create their NDIS plan:</i>						
Included me in the planning process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
<i>The supports included in the NDIS plan (for the person I care for) have:</i>						
Enabled me to take a break from my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Given me time to look after my own health needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to stay in, or go back to, paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. Have any of the following increased or decreased in the PAST TWO YEARS?

	This has increased	This has decreased	This has stayed the same	Don't know
The amount of support the person I care for has access to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of support I have access to as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of time I spend per week organising support for the person I care for (e.g. paperwork, phone calls, emails)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. Have you had any difficulty accessing the NDIS? If so, please describe your experience.

26. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
<i>When the person I care for visits the family doctor or GP, I am generally:</i>						
Included in decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>When the person I care for is in hospital, I am generally:</i>						
Included in decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asked about my needs as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27. Do you have any suggestions for how health services can improve how they work with carers?

28. How often do you currently use the following carer supports?

	More than once a week	Once a week	Once a month	A few times a year	Once a year	Less than once a year	I have never used this
Respite (e.g. day centres, in-home services, cottage respite, or residential respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support group (face-to-face)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online forum or group (e.g. website, Facebook)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. How satisfied are you with how often you use the following carer supports?

	I use this as often as I need	I would like to use this more	Not applicable
Respite (e.g. day centres, in-home services, cottage respite, or residential respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer support group (face-to-face)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online forum or group (e.g. website, Facebook)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. Please tell us more about your experience accessing the above carer supports.

SECTION 3: PAID WORK

31. Which of the following have ever applied to you as a direct result of your caring role? Tick all that have ever applied.

- ☐ I have lacked the knowledge and confidence to apply for jobs effectively
- ☐ My skills and qualifications have become out of date due to time out of the workforce
- ☐ I have worked in a job that is lower than my skill set
- ☐ I have reduced my working hours
- ☐ I have changed industry / occupation
- ☐ I have turned down a new job / promotion
- ☐ I have quit my job
- ☐ I have been denied an opportunity by an employer
- ☐ An employer has changed my working conditions
- ☐ None of the above
- ☐ Other (please specify): _____

32. Would you ever consider working as a paid care worker? (i.e. being paid to work one-on-one with someone who needs care)

- ☐ I already do
- ☐ Yes, I would
- ☐ No, I would not

Please explain your answer:

33. Do you currently have a paid job?

- ☐ Yes
- ☐ No (go to Section 4: Your health and wellbeing)

34. How many hours per week do you usually spend doing paid work? _____ hours

If you have more than one paid job, please refer to your MAIN job (i.e. where you spend the most hours) in answering the following questions.

35. Which of the following best describes your main job?

- ☐ I am a permanent employee
- ☐ I have a fixed-term contract
- ☐ I have a casual job
- ☐ I am self-employed
- ☐ I am an independent contractor
- ☐ Other (please specify): _____

36. How many years have you had this job?

- ☐ Less than a year
- ☐ _____ years

37. In which industry do you work?

- ☐ Health care
☐ Government / public sector
☐ Community / non-profit
☐ Education and training
☐ Retail
☐ Banking / finance
☐ Hospitality / tourism
☐ Construction / trades / mining
☐ Manufacturing
☐ Information technology / telecommunications
☐ Other (please specify): _____

38. Please respond to the questions in the table below:

	Almost always	Often	Sometimes	Rarely	Never	Not applicable
<i>In the last 6 months how often did your job:</i>						
Interfere with your responsibilities as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keep you from spending the amount of time that you would like to spend with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interfere with your life as a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>In the last 6 months how often did your caring role:</i>						
Interfere with your responsibilities at work, such as getting to work on time, accomplishing daily tasks, or working overtime?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keep you from spending the amount of time you would like to spend on job or career related activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interfere with your job or career?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
My job allows me to make my own decisions about how to schedule my work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My job allows me to decide on the order in which things are done on the job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Not applicable
My job allows me to plan how I do my work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All in all, I am satisfied with my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In general, I don't like my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In general, I like working there	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have seriously considered quitting my current job over the past 6 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I feel comfortable telling the people that I work with that I have caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The people I work with support me to combine work and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41. Which of the following flexible working arrangements have you used in your current job? Tick all that apply.

- ☐ Carer's leave
- ☐ Flexible start / finish times
- ☐ Working from home
- ☐ Job sharing
- ☐ None of the above
- ☐ Other (please specify): _____

SECTION 4: YOUR HEALTH AND WELLBEING

42. Please indicate how satisfied you are with each of the following:

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your standard of living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What you are achieving in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your personal relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How safe you feel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling part of your community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your future security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43. In the past 4 weeks, about how often did you feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Tired out for no good reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So nervous that nothing could calm you down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless or fidgety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So restless you could not sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That everything was an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
So sad that nothing could cheer you up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worthless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

44. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
There is a special person who is around when I am in need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a special person with whom I can share my joys and sorrows	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family really tries to help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get the emotional help and support I need from my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I have a special person who is a real source of comfort to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My friends really try to help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can count on my friends when things go wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my problems with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have friends with whom I can share my joys and sorrows	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a special person in my life who cares about my feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family is willing to help me make decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my problems with my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

45. Please indicate how much you agree with each of the following statements:

Providing help to the person(s) I care for has:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Made me feel more useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel appreciated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Made me feel strong and confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Given more meaning to my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to learn new skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to appreciate life more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enabled me to develop a more positive attitude toward life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strengthened my relationship with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

46. Please indicate how much you agree with the following statement:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I feel that my caring role is recognised and valued by my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please explain your answer:

47. During the last 12 months, have you had any long-term illness or disability that has lasted, or is likely to last, at least 6 months?

- ☐ Yes
- ☐ No (go to Section 5: About you)

48. Have your caring responsibilities affected your long-term illness or disability?

- ☐ No
- ☐ Yes, please explain how:

SECTION 5: ABOUT YOU

The following questions will help us make sure we have feedback from a wide range of community groups. Please leave any questions blank that you would prefer not to answer.

49. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Self-described _____
- ☐ Prefer not to disclose

50. How old are you?

_____ years

51. What cultural background(s) do you identify with? (e.g. Italian, Chinese, Australian)

52. Do you speak a language other than English at home? (e.g. Vietnamese, Auslan)

- ☐ Yes, I speak _____
- ☐ No, English only

53. Are you of Aboriginal or Torres Strait Islander origin? If you are of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander

54. Do you consider yourself to be:

- ☐ Lesbian, gay, or homosexual
- ☐ Straight or heterosexual
- ☐ Bisexual
- ☐ Queer
- ☐ Different identity (please state) _____

55. What is the postcode where you live? _____

56. What is the highest level of education you have completed?

- ☐ Less than high school (year 12 or equivalent)
- ☐ High school (year 12 or equivalent)
- ☐ Certificate / diploma
- ☐ Bachelor degree or higher

57. Are you currently enrolled in any formal education?

- ☐ No
- ☐ Yes – high school
- ☐ Yes – TAFE / apprenticeship
- ☐ Yes – university
- ☐ Other (please specify): _____

58. In the last 3 months, did you use the internet on any of the following devices? Tick all that apply.

- ☐ Computer
- ☐ Mobile phone
- ☐ Tablet (e.g. iPad)
- ☐ Other device _____
- ☐ I have not accessed the internet in the past 3 months

59. What is your household's annual income (before tax)? Please include your partner's and / or family members' income (e.g. pension, disability support pension). Please tick your best estimate.

- ☐ Less than \$49,999 / year
- ☐ \$50,000 – \$99,999 / year
- ☐ \$100,000 – \$149,999 / year
- ☐ \$150,000 – \$199,999 / year
- ☐ \$200,000 – \$249,999 / year
- ☐ \$250,000 or more / year
- ☐ I'd prefer not to answer

60. Do you receive any payments from Centrelink? Tick all that apply.

- ☐ Carer Allowance (currently \$127.10 per fortnight)
- ☐ Carer Payment (currently up to \$907.60 per fortnight for singles and \$1,368.20 for couples)
- ☐ Other Centrelink payment (please specify): _____
- ☐ I don't know
- ☐ None of the above

61. Please respond to the question in the table below:

	Very easy	Easy	Neither difficult or easy	Difficult	Very difficult	Don't know
In the last 12 months, how easy was it for you to meet your necessary cost of living expenses like housing, electricity, water, health care, food, clothing or transport?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

62. How will you / do you fund your retirement? Tick all that apply.

- ☐ Government pension
- ☐ Occupational / workplace pension plan
- ☐ Superannuation
- ☐ Selling financial assets (stocks, bonds)
- ☐ Selling non-financial assets (car, property)
- ☐ Income generated from financial or non-financial assets
- ☐ Relying on spouse / partner to support you
- ☐ Relying on children or other family members to support you
- ☐ Other (please specify): _____
- ☐ Don't know / I haven't thought about it

63. Are you a member of Carers NSW?

- ☐ Yes
- ☐ No
- ☐ I am a member of the Young Carer Program
- ☐ Don't know

You have finished the survey - thank you for participating!

Your input will help us better support and advocate for carers in NSW.

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carers NSW Carer Line (1800 242 636, open Monday to Friday, 9am to 5pm), Lifeline (13 11 14, open 24 hours, 7 days), or your local GP.