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# National survey of carers' respite needs

Final report

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## INTRODUCTION

In August and September 2016, Carers NSW conducted a national online survey of carers on behalf of the National Network of Carers Associations (the Network). The purpose of the survey was to understand carers' respite needs and experiences of using respite. Findings from the survey will help to inform advocacy work across the Network.

## METHODOLOGY

The survey tool was developed using Survey Monkey by the Carers NSW Research and Policy teams. Prior to its development, a draft version of the tool incorporated feedback and approval from Network CEOs, the Carers NSW Executive, and the Carers NSW Research & Evaluation Committee. The survey was piloted by several Carers NSW staff before it was launched on 26 August 2016.

Promotion of the online survey took place across the Network, with each Carers Association distributing information to their contacts via email, e-newsletters and social media. No hard copy of the survey was available, however phone entry with a Carers NSW staff member was offered when requested.

The survey and surrounding promotion included a blurb explaining the context of the project and a Participant Information Statement approved by the Carers NSW Research & Evaluation Committee.

On 23 September 2016 the survey officially closed, following which the data were cleaned and analysed by the Carers NSW Research and Policy teams using Survey Monkey, SPSS and NVivo programs.

## RESULTS

### Sample

A total of 2,145 responses were received, however only 1,803 were included in the final sample. 186 respondents were screened out early in the survey because they indicated that they were not informal carers, and a further 156 responses were later omitted as they were deemed incomplete.

The majority (54.6%) of respondents lived in New South Wales (NSW), with the next largest group (24.2%) living in Queensland. The proportion of carers from each state or territory is shown in Figure 1, including the 5.1% who did not nominate their state or territory.

The vast majority of respondents (84.2%) were female, which is in line with other large scale surveys conducted by Carers NSW (e.g., the Carers NSW 2016 Carer Survey sample included 80.6% females: Carers NSW, 2016). This overrepresentation of females is to be expected, considering that the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC: ABS, 2012) estimates that 69.7% of primary carers are female. Most respondents (75.0%) were of working age, with the largest group being 45-54 year olds (see Figure 2). Again, this reflects Carers NSW 2016 Carer Survey findings, where 48.1% of respondents were aged between 45 and 64 years (Carers NSW, 2016), and SDAC (2012) estimates that 45.0% of primary carers fall within this age range (ABS, 2012).

### Caring situation

Most respondents (70.8%) were caring for a person with disability, followed by relatively large proportions of people caring for someone living with a mental illness (28.5%), those caring for someone with a chronic condition (22.6%), and carers of the frail aged (16.7%). 10.4% were caring for someone with a terminal or serious illness, and only 2.9% of respondents were caring for someone with a drug or alcohol dependency. This question allowed multiple responses to accommodate care recipients with more than one condition and carers caring for more than one person.

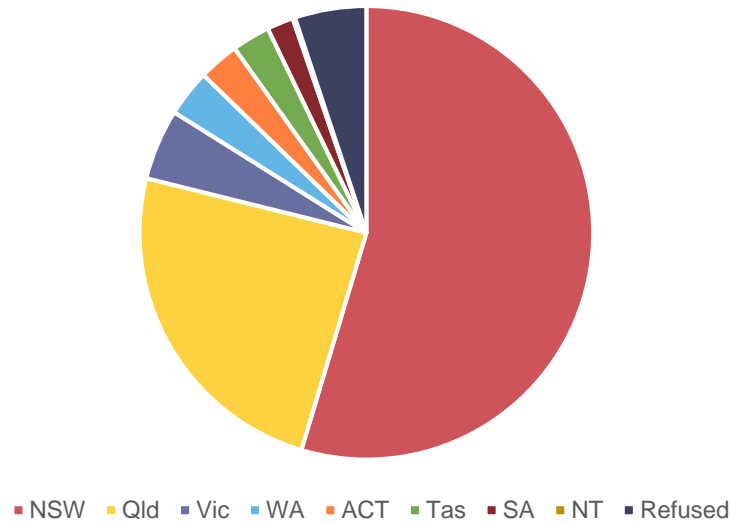


Figure 1. In which state or territory do you live?

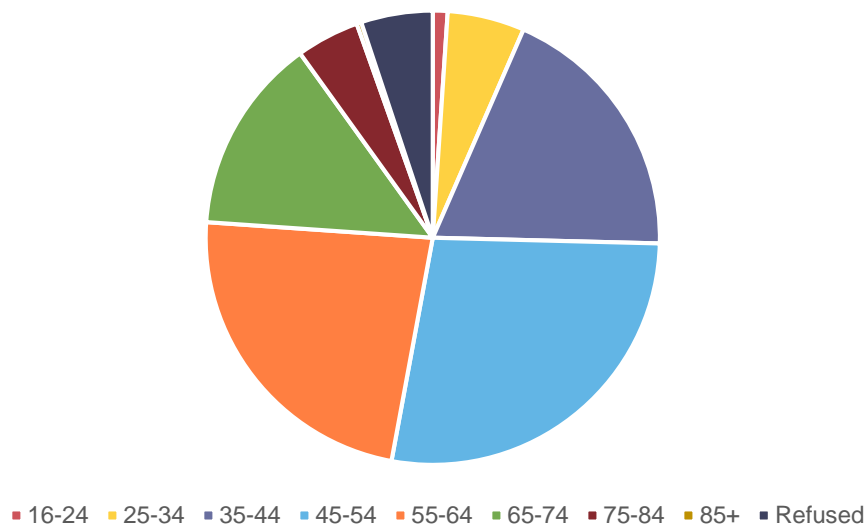


Figure 2. How old are you?

Unsurprisingly, the vast majority of respondents were caring for someone who could spend very little, if any, time alone. 40.0% could not spend any time alone, 28.8% could spend a few hours alone, and 14.6% could only spend less than one hour alone.

The largest group of respondents (33.4%) were caring for their son or daughter under the age of 18. Similar proportions were caring for an adult son or daughter, or for a partner/spouse (25.3% and 24.7% respectively – see Figure 3).

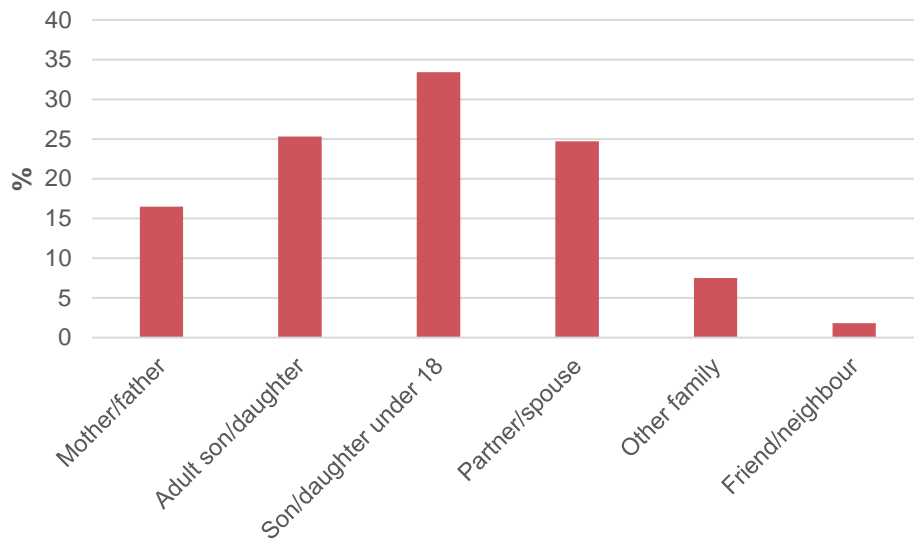


Figure 3. Who do you care for?

Respondents were able to choose one or more cultural backgrounds with which they identified. The vast majority of respondents (81.5%) identified as having an Australian cultural background, however, 58 other cultural backgrounds were listed by respondents, with 13.4% identifying with a culturally and linguistically diverse (CALD) background<sup>1</sup>. The most common diverse cultural backgrounds were: Italian (1.9% of respondents), Korean (1.9%), Dutch (1.3%), Chinese (0.9%), and Greek (0.9%).

In addition, 60 (3.3%) respondents indicated that they were from an Aboriginal and/or Torres Strait Islander background. By comparison, 2011 Census data estimate that 2.6% of the Australian population identify as Aboriginal and/or Torres Strait Islander.

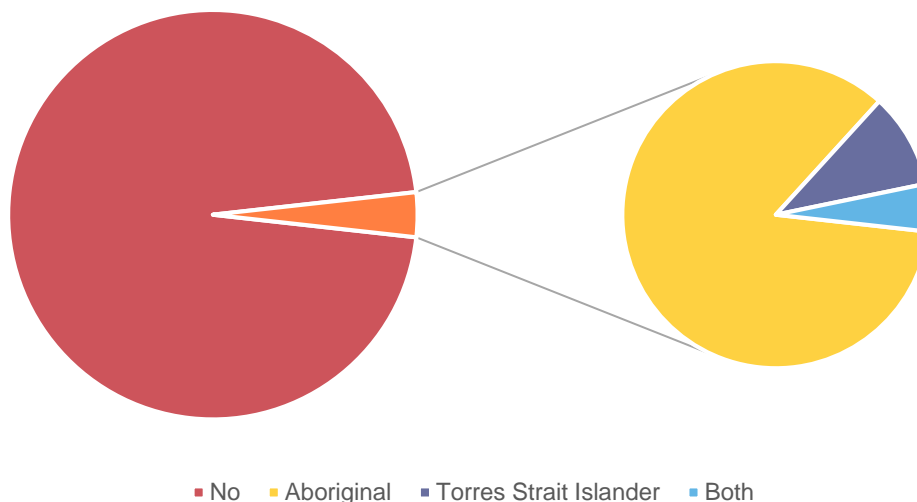


Figure 4. Are you from an Aboriginal or Torres Strait Islander background?

<sup>1</sup> For the purposes of this analysis, CALD is defined as a cultural background that is not on the Australian Bureau of Statistics' list of Main English-speaking countries: Australia, Canada, Republic of Ireland, New Zealand, South Africa, United Kingdom, England, Scotland, Wales, Northern Ireland, United States of America.

## Understanding of respite

The survey asked respondents to indicate which of a range of statements reflected their understanding of the main purpose, or purposes, of respite. The most common purpose identified was that respite gives carers a break from their caring responsibilities (83.8%), followed by it giving carers an opportunity to look after their own health and wellbeing (76.0%), and its propensity to help carers sustain their caring role (67.5%). Table 1 details the distribution of all responses to this question.

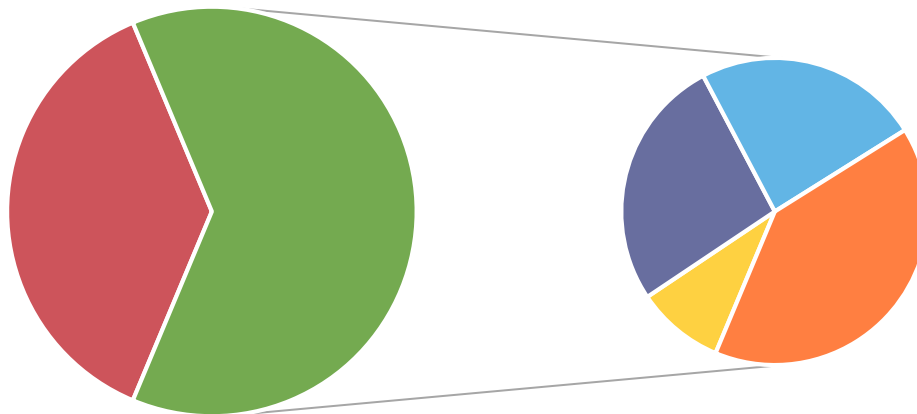
*Table 1. What do you see as the MAIN purpose(s) of respite? (Tick all that apply)*

<b>Purpose</b>	<b>% of respondents</b>
It gives carers a break from their caring responsibilities	83.8%
It gives carers an opportunity to look after their own health and wellbeing	76.0%
It helps carers sustain their caring role	67.5%
It gives carers an opportunity to spend time with other family members and friends	59.0%
It provides replacement care in case of an emergency	54.8%
It gives care recipients a break from their carers	53.5%
It gives care recipients the opportunity to participate in activities they enjoy, or which benefit them	53.4%
It provides replacement care when carers have planned medical appointment and procedures	45.7%
It gives carers an opportunity to do domestic tasks, such as shopping or washing	41.3%
It enables carers to go on holiday	39.4%
It gives carers an opportunity to spend quality time with the person they care for while someone else takes responsibility for the person's practical care	29.9%
It enables carers to remain in paid employment	28.7%
I don't know what respite is	2.0%

## Use of respite

More than one in three respondents (37.4%) had never used respite. However, of those who had, 40.2% had used it regularly (see Figure 5). Unsurprisingly, when care recipients were able to be left alone for longer periods of time, carers were less likely to have used respite (see Figure 6).

There were also some differences in respite use between carers of care recipients with different conditions. In particular, those caring for someone with a chronic condition were most likely to have never used respite, and those caring for someone with a disability were most likely to have regularly used respite (see Figure 7).



■ Never ■ Only in an emergency ■ Rarely ■ Once in a while ■ Regularly

Figure 5. Have you ever used respite?

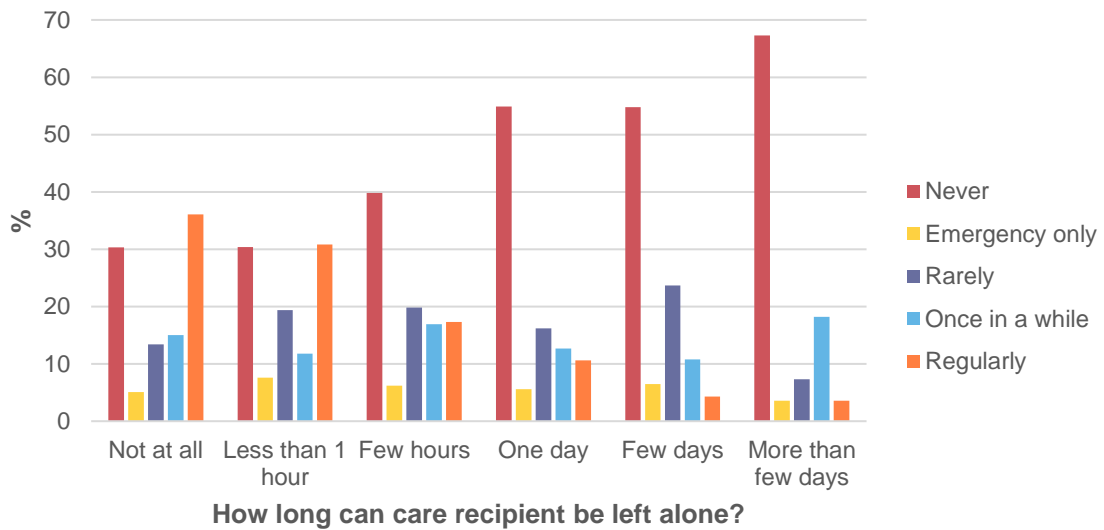


Figure 6. Use of respite by how long care recipient can be left alone

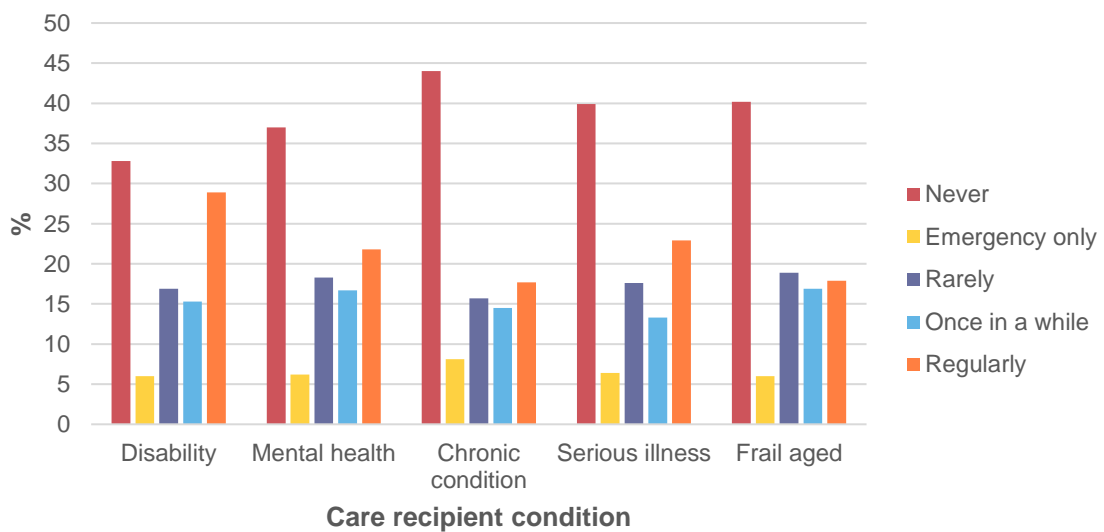


Figure 7. Respite use by care recipient condition

Carers who indicated they had never used respite were asked why, and provided with several options. The most commonly chosen option was 'I don't know where or how to access it' (30.4%), followed by 'I can't find anything that suits the needs of the person I care for' (18.2%). 14.7% of respondents chose 'I can't afford it', and 11.4% selected 'I don't want to use it' (see Table 2). Interestingly, not wanting to use respite rated relatively low, despite the frequency of this response to a similar question in the 2012 Survey of Disability, Ageing and Carers (ABS, 2012).

*Table 2. Why haven't you used respite?*

Reason	% of respondents
I don't know where or how to access it	30.4%
I can't find anything that suits the needs of the person I care for	18.2%
I can't afford it	14.7%
I don't want to use it	11.4%
I'm not eligible for it	9.8%
It's not available in my area or is too far away	7.7%
I can't find anything that suits my needs	6.8%
I don't know what respite is	4.0%
I can't find services that speak the same language as the person I care for	1.0%
I can't find services that are culturally appropriate	0.9%

There were 231 'Other' responses regarding why carers had not used respite. These are summarised below. Many of these overlapped with comments recorded in a subsequent question. The most commonly cited 'Other' reasons were: that respite was not currently required by the carer and/or care recipient; that the care recipient refused respite or was resistant to the idea; that the carer and/or care recipient did not feel comfortable with strangers providing replacement care; and that no respite services or funding was available.

Respondents were invited to comment on their answer to the above question. These open responses are useful in drawing out the barriers identified above. Below they are grouped into categories relating to the statements above selected by more than 5% of respondents. Additional issues are explored under the subheading 'Other'.

### **I don't know where or how to access it**

In addition to the 30.4% of respondents who said they did not know where or how to access respite 16 respondents elaborated on how they did not know enough about what was available or how to access it.

*"Not sure if eligible or if there is a cost involved."*

*"It is the most impossible thing to figure out how to get."*

*"I really do not know a lot about the services available or how to use them and not really clear on when we should utilise respite."*

*"It needs to be clearer how to access these services."*

*"Don't know where to start looking pr [sic] how to access."*

Furthermore, 6 respondents found the process too complex or confusing, 5 had applied but never heard back, 5 said it had never been mentioned or offered to them by service providers, and 4 simply



had not known it existed. Respondents also noted that respite was hard to access, hard to find and associated with long waiting lists.

*"I met with a service provider they said [sic] yes we met the criteria was offered a package. I never heard again. It's [sic] hard for me to ask for help."*

*"I applied once & nothing happened."*

*"Despite services such as speech, physio, OT, behavioural therapies being offered or recommended respite never has."*

*"I have never known that I [sic] could use it although our family is in desperate need of this."*

*"I would love to access respite but it's just too hard to access, I'm tired and simply soldier on with no support at all."*

*"We were on a wait list for over 2 years, which has caused me to lose faith in the system."*

### **I can't find anything that suits the needs of the person I care for**

In addition to the 18.2% of respondents who said they could not find anything that suits the person they care for, 11 respondents identified that the level of need of the care recipient was a barrier in finding suitable respite, 8 cited age appropriateness as a barrier, and 6 believed appropriate respite for the care recipient's condition was not available. 6 respondents felt that respite could not adequately cater for the individual needs and interests of the care recipient, and 4 noted that respite would be disruptive for care recipients to whom routine and consistency were particularly important.

*"My Dad would have been able to stay in the home longer if Day centre respite was available however because he was high level care including incontinence, in pads, and in a wheel chair we were told there was no service for him."*

*"My husband has a physical disability and is 60 years old. He does not fit into a disability service or an aged care program."*

*"The person I care for does [sic] not want to go & there are no respite centers [sic] that cater for young adult high functioning mental health."*

*"Staff not allowed to give injection to clients. My son is a diabetic, insulin dependent and needs at least 3 injections per day."*

*"My husband is still very fit and physical. 2 Years ago we had a few different carers. Most did NOT fit into his physical needs. We needed a carer who could go on walks, take him to the golf course and be generally physically [sic] well and active."*

*"My child doesn't cope well with changes in routine and I would be concerned that the negative impact of using respite would outweigh the positive."*

### **I can't afford it**

In addition to the 14.7% of respondents who indicated that they could not afford respite, 8 specifically referred to not being personally able to afford out-of-pocket respite costs, while 6 said they did not think that enough respite funding was available.

*"Its not cheap [sic] not sure how I will afford it when the time comes but I will have to find a way."*

*"cant [sic] afford it on a pension."*

*"It is impossible to access due to lack of funding and availability."*

*"When I have looked into in the past there was never funding available."*

### **I don't want to use it**

While 11.4% of carers who reported that they did not want to use respite, of the respondents who elaborated on this in the open question, more (12) framed their response in a way that suggested they might or would definitely need respite in future. Only 5 said categorically that they didn't need it. 10 respondents said they simply would not be comfortable with strangers providing care. 6 carers referred to a sense of guilt or obligation being a barrier to their using respite, 6 expressed that they did not 'deserve' respite or that others needed it more, and 3 noted that they were hesitant to use respite due judgement or stigma from others.

*"Respite care not required at this time, mostly likely will be required in the future."*

*"So far, have been able to manage without it. May need in future if person cared for deteriorates."*

*"Because I would never trust anyone but family with my disabled child."*

*"I just don't feel like I can approach anyone to ask again for respite because my son isn't making me stressed. My need for respite is to be a better carer, and from what I understand that isn't good enough for respite."*

*"The idea of respite invokes lots of feelings for me. While I would really appreciate a break from my caring responsibilities I worry a lot about about [sic] how the person I care for (my partner) would interpret this...I also worry about how friends and family would view my taking respite."*

*"I feel to [sic] guilty to try and source it. I feel bad when anyone else has to step in and help mum when I have clashing appointments. I feel like it's wrong to prioritise myself. I know it isn't. But I still feel what I feel."*

*"I am carer for my son. I don't feel I can complain about how tired I feel because that is my job as his mum."*

*"I always felt like there were people worse off than us who deserved it more being that funding and availability was so scarce. So we just plodded along and coped."*

### **I'm not eligible for it**

In addition to the 9.8% of respondents who indicated that they had not used respite because they were not eligible for it, 7 elaborated on this.

*"To be honest i asked for help and was told that i [sic] was not eligible so just gave up even though i [sic] know of other parents getting help and their [sic] child is just autistic."*

*"The disabled child's main carer has it. We don't get any help."*

*"Funding is means tested and so we don't qualify. However, it is difficult to know what's available if the information is not provided because we're not eligible. It's a vicious circle."*

### **It's not available in my area or is too far away**

7.7% of respondents had reported that respite was not available in their area or was too far away. 10 respondents provided further information. In most, but not all, cases these respondents were living in regional or rural areas.

*"For a few years I have been looking for long respite day care but there is nothing in the inner western suburbs...no one operates long day care for the full time worker unless it is further west. Also you have to be in their catchment area. Nothing in Burwood, Strathfield or Auburn for the elderly."*

*"Nothing up where we live has anything like that to Get [sic] someone from Brisbane would cost dearly."*

*"respite is something I have looked into but unfortunately all available respite is either too far away not suitable."*

### **I can't find anything that suits my needs**

Only 6.8% of respondents indicated that they had not used respite because what was available did not suit their own needs. Most of the 12 respondents who wrote further about this pointed to respite not being available when they needed it, including incompatibility with their hours of work and rigid time periods being offered that were too long for their needs.

*"Both Primary Carers are shift workers, starting between 05:00 and 07:00, unable to find any organization to provide respite/care early in the morning so both can go to work and also put client on the bus to School at 08:15."*

*"Am in need of it now, but if any places are available they aren't available when we need it. So surgeries are deferred, or any idea of a short holiday (even a weekend) is quashed."*

*"Respite is for a minimum of 14 days. I only want respite for 1 night & 2 days. My wife needs assistance at night as well as by day. I don't want to leave her for 14 days."*

*"The times that I have tried to access respite options they cannot provide the support as it is either on the weekend or in the evenings."*

### **Other barriers**

Other major themes regarding barriers to respite use included resistance from the care recipient, concerns about quality and adequate existing informal arrangements. 13 said the care recipient was not, or would not be, comfortable with strangers and 12 respondents mentioned prior, or expected, negative emotional reactions from the care recipient. 8 respondents reported that the care recipient lacked insight into their condition and need for care, and 8 that the care recipient simply did not want

to access respite. 5 indicated that the topic had been, or would likely be, the cause of family tension or conflict.

*"The person I care for does not want anyone else to be in the house. Does not trust strangers. Will not allow anyone but me to care for them."*

*"Those who are being cared for refuse to have respite carers...they say they would rather cope alone if I am not there....I know they cannot cope alone. Puts me in an awkward position!"*

*"The person I care for would be very upset if I said I needed to get away for a bit. Abandonment is a huge mental health issue for her."*

*"If I were to consider, let alone, use it the person I care for would react in a very negative way and the impact of this for me personally, emotionally, and psychologically would be significant."*

*"The person I care for has dementia and wouldn't understand why I am organising for someone else to stay with them and may be quite angry about it."*

*"She will not participate in or permit any home services or stay at other premises to receive care."*

7 respondents were concerned about the quality of respite services, with 7 being particularly concerned about safety and/or risk of abuse. 4 referred to previous bad experiences they themselves or others had reported as a reason for resisting respite.

*"I also worry that he would not have sympathetic care. I also worry that his belongings might go missing."*

*"I don't use it because I don't think it is up to standard nor do I think the staff are properly qualified or supervised."*

*"Concerned about physical and sexual abuse."*

*"I had to put him in respite a few times when I went away for treatment one home he came back with the skin off his bottom and a very bad urine infection which puts a bad taste to things."*

21 respondents said they did not use respite because they had adequate informal arrangements, with family and friends providing them with the breaks they needed.

*"So far family has always been available to give me respite."*

*"I have been very fortunate to have some friends who support us."*

*"I have someone who can stay to take care of pets and be there for my parent."*

*"I don't feel the need to use respite at this time as my son stays with his Dad for a short period of time each month giving me time for myself and also space for my son away from me, his Mum."*

For those respondents who had used respite, the vast majority (70.8%) had planned respite rather than using it for an emergency.

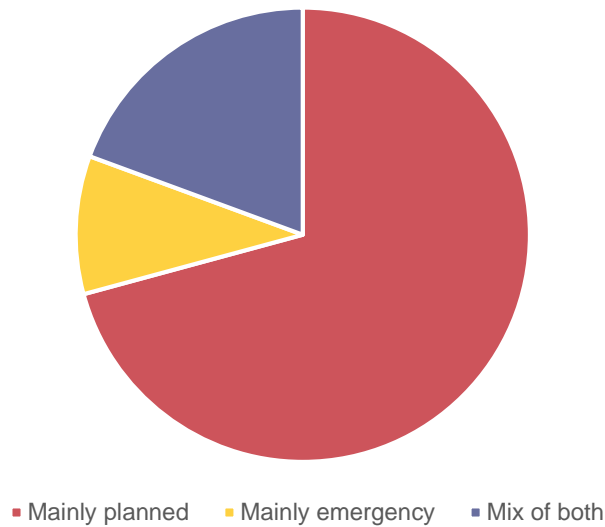


Figure 8. Has your use of respite mainly been planned or emergency?

While the largest proportion of respondents who had used respite referred to a support worker looking after the person they were caring for in their own home (38.8%), this was closely followed by those getting respite from family members or friends (32.2%), and therefore not a formalised respite service. Responses to this question are summarised in Table 3.

Table 3. Who provides you with respite?

Source	% of respondents
A support worker who looks after the person I care for in my/their own home	38.8%
Family members or friends	32.2%
A support worker who takes the person I care for out individually or in a group	26.1%
A day program or day care facility	21.9%
An overnight facility	19.8%
An aged care facility	10.2%
Volunteers in my community	2.7%
A long term facility	2.6%

### Satisfaction with respite

Respondents were asked about their level of satisfaction with the amount, type and quality of the respite they accessed (see Figure 9).

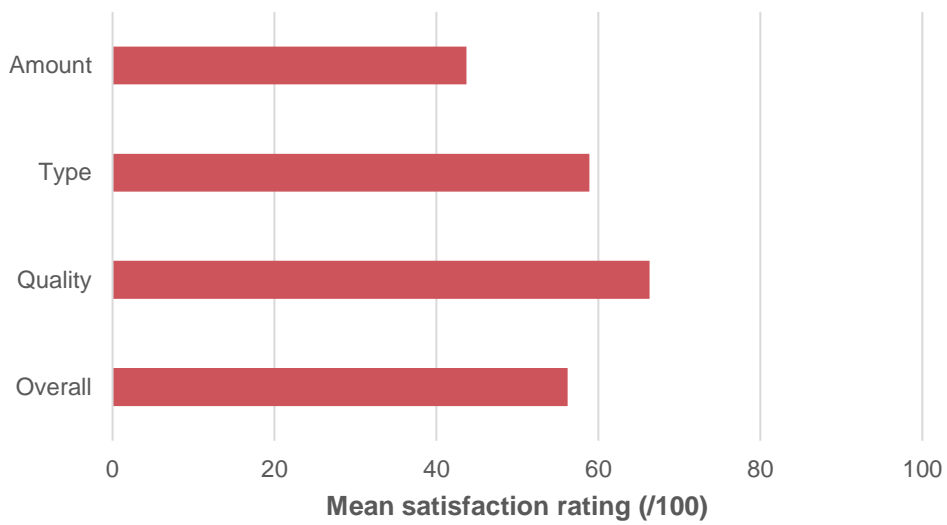


Figure 9. How satisfied are you with the respite you access?

Overall satisfaction with respite was higher amongst older carers, as shown by Figure 10.

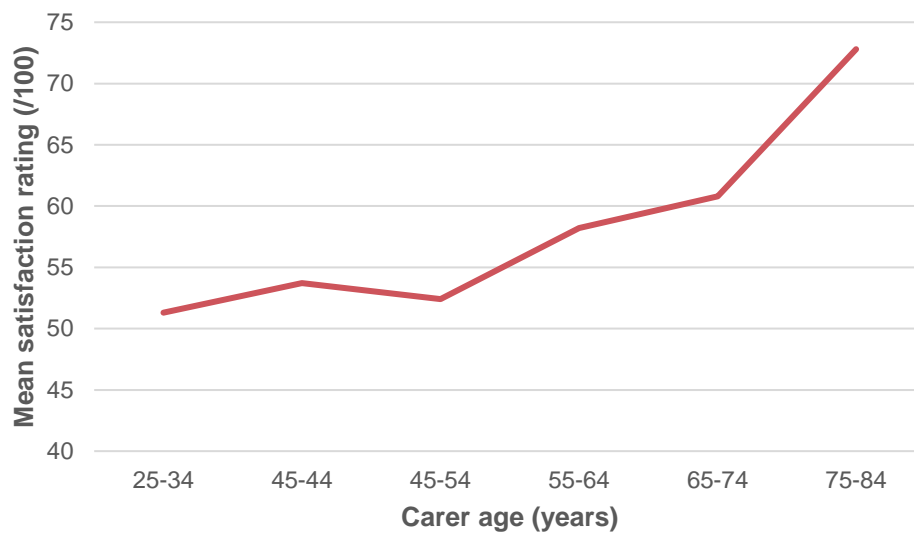


Figure 10. Overall satisfaction with respite by carer age groups

Satisfaction was also rated more highly amongst those carers who reported using respite more regularly (see Figure 11).

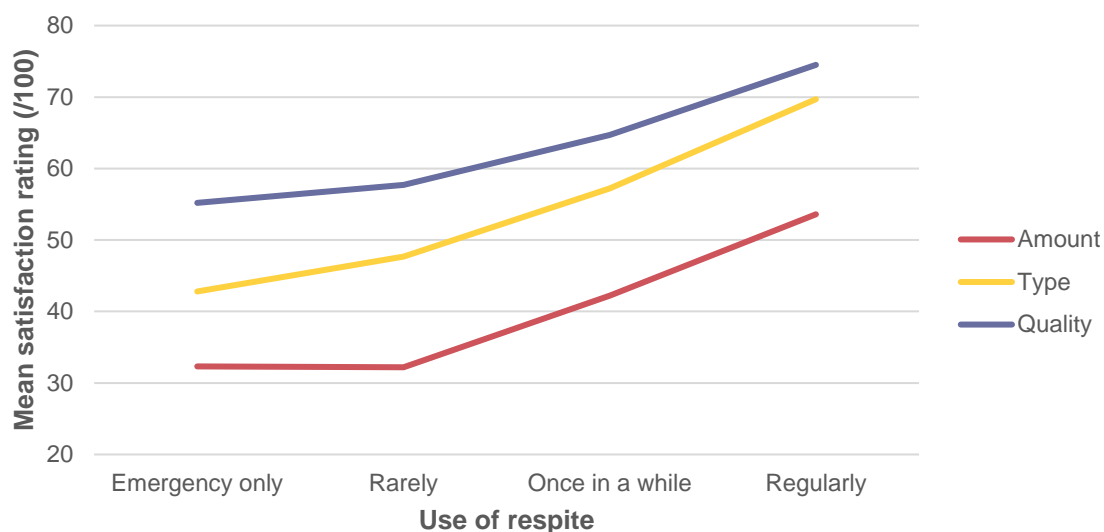


Figure 11. Mean satisfaction ratings by regularity of using respite

### Importance of respite

Respondents were asked how important respite had been for them with regard to a range of personal outcomes, outlined in Figure 12.



Figure 12. How important has respite been for you in terms of the following?

Female carers (M=78.4) rated the importance of respite significantly higher than male carers (M=69.8).

Those who used respite regularly rated its importance higher across all outcomes than those who used it less regularly. The notable exception to this was 'sustaining employment', which was rated significantly less important by carers across all situations (see Figure 13).

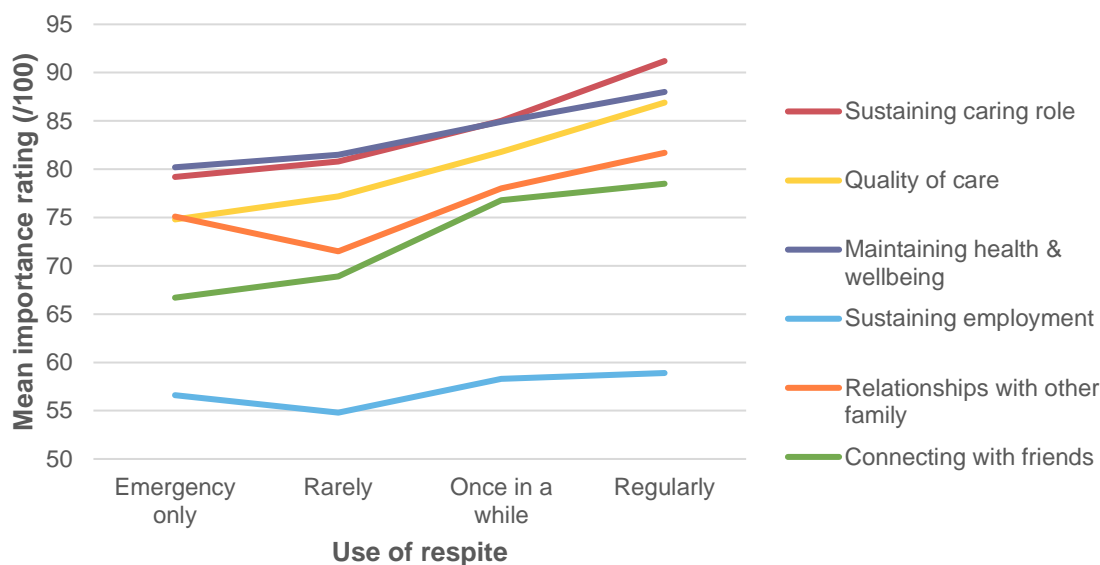


Figure 13. Mean importance ratings by regularity of using respite

## DISCUSSION

While the survey was completed by a diverse range of respondents, the typical respondent was a female carer aged 45-54 years, caring for her son or daughter with disability who cannot be left alone for long, if at all. Carers of people with disability and carers of those unable to be left alone were most likely to have used respite. Interestingly, more than one third of respondents reported that they had not used respite before. Overall, a minority of carers said they had used respite regularly.

However, the large proportion of respondents who had not used respite before, or very often, did not simply reflect a lack of need. Respondents indicated that the main reasons for not accessing respite had to do with factors such as difficulty finding out about and successfully accessing respite options, and a shortage of options appropriate to the individual needs of the carer and care recipient.

Respondents who had used a formal respite service had most often received in home support. Group respite, either in the community or a facility, had been less frequently used. Informal respite provided by family members and friends were also frequently identified by respondents, suggesting that informal options fill many existing supply gaps. However, the Carers NSW 2014 Carer Survey found that many carers do not have family members or friends they can call upon for replacement care (Carers NSW, 2014).

Regardless of whether or not they had used respite before, respondents overwhelmingly understood respite to be primarily a service benefiting the carer, providing them with a break and supporting their health and wellbeing. The benefits of respite for the care recipient, including sustaining the caring role, were less central to respondents. This is interesting given the focus in the National Disability Insurance Scheme (NDIS) as the limit of carer support that will be funded as part of a plan. The emphasis on carers returning to work as a natural outcome of disability supports was also not supported by the survey data, which registered engagement with employment as a comparatively unimportant issue in relation to using respite.

Respondents who had used respite rated it as highly important, however, their overall satisfaction was relatively low. Satisfaction was lowest with the amount of respite they had accessed. In combination with the evident correlation between frequency of respite use and overall satisfaction with respite, this suggests that adequate supply of respite is of prime importance.



## CONCLUSION

The findings from this survey clearly indicate that respite is a highly valued service, especially for parent carers of children and adults with disability who need a high level of support. They also reflect that, in carers' minds, the break respite provides in itself and the health and wellbeing impacts of respite are its most important elements. A lack of information and referral about respite options and pathways was clearly identified, as well as a shortage of flexible respite options that can be tailored to the needs of individual carers and care recipients.

As disability and carer supports across Australia transition to the NDIS, the clearly articulated assumption is that providing individualised support to people with disability will in itself have a respite effect, sustaining the caring role and enabling carers to work. The data from this survey contradicts this assumption, highlighting the importance of a focus on carers' own health and wellbeing and need for a break, and suggesting that workforce participation is not automatically increased when carers have more time to themselves.

An ongoing supply of flexible respite services specifically geared towards improving carers' health and wellbeing and facilitating, where appropriate, their engagement with employment are clearly still required. We recommend that, in addition to NDIS supports providing a respite effect with the aim of sustaining the caring role, planned and emergency respite options remain available to carers in their own right.

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