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**Carers NSW**

**40 Years of Carer Surveys in NSW**

1976-2016

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## Introduction

*“In December, 1974, an application was made to the Australian National Advisory Committee, International Women’s Year, by the NSW Council on the Ageing, asking for a grant for a survey into the problems arising from the care of an aged person at home” (NSW Council on the Ageing, 1976).*

This grant awarded to the NSW Council on the Ageing funded the first survey into the needs of carers in NSW. The resulting report, “Dedication”, was published in 1976 and highlighted the need to provide carers with support, particularly in relation to household tasks, respite, and financial assistance. That same year, a Carers Committee was formed within the Council on the Ageing NSW, marking the beginnings of the organisation now known as Carers NSW.

Over the 40 years since “Dedication” was published, Carers NSW has strived to understand the needs and lived experiences of carers across NSW in order to advocate on their behalf and provide direct supports. An important aspect of this work has included conducting research to inform the organisation’s strategic planning and systemic advocacy. Since 2002, Carers NSW has undertaken periodic surveys of carers across NSW to inform different aspects of the organisation’s work. This report documents the findings of these surveys, from the 1976 “Dedication” report, through to the most recent Carers NSW 2016 Carer Survey. This historical perspective of surveys highlights shifting organisational priorities over this time, while also revealing that several important aspects of carers’ experiences and needs remain somewhat unchanged, even after 40 years.

## Survey Aims

Each survey has had a slightly different focus. While there are certain similarities between them all, there have also been important differences, as each survey has sought to hear from carers on different issues and to direct the work of Carers NSW in a different way.

### **“Dedication”: A report of a survey on caring for the aged at home carried out in NSW, Australia, June - Dec. 1975 (1976)**

This ground-breaking survey was conducted during the International Women’s Year (1975), in response to anecdotal evidence of women having to retire early to care for parents. The survey was advertised as widely as possible with the intention of turning the public’s thoughts towards the issue of caring for an aged person at home, and to encourage as many carers as possible to participate. This resulted in a final sample size of 490 completed surveys. The survey focused on caring situations and relationships, employment, home ownership and other financial issues, church attendance, and community participation.

### **Carers NSW 2002 Membership Survey**

The Carers NSW 2002 Membership Survey was only sent to members of Carers NSW, with 185 returning completed surveys. As the first survey conducted since the 1976 report, the focus of this survey was to find out which issues members believed should be priorities for Carers NSW to focus on.

### **Carers NSW 2004 Membership Survey**

The Carers NSW 2004 Membership Survey was also sent only to Carers NSW members. The response rate was greater than in 2002, with 466 completed surveys received. The purpose of this survey was to determine how carers believed they could be provided with better support and recognition.

### **Carers NSW 2007 Carers News Survey**

The Carers NSW 2007 Carers News Survey again included Carers NSW members only, this time with 570 carers returning completed surveys. This survey had a particular focus on Carers NSW as an organisation, with three main aims: 1) to find out why carers had joined Carers NSW; 2) to determine what benefits they had gained from membership; and 3) how they thought Carers NSW could serve them better.

### **Carers NSW 2008 Survey**

The Carers NSW 2008 Survey was the first to include carers who were not members, therefore aiming to increase the number of responses received. This aim was achieved, with 654 completed surveys being returned. The main aims of this survey were to obtain a more detailed understanding of carers' caring roles and demographic characteristics, and to inform the Carers NSW 2008/2009 Budget Submission.

### **Carers NSW 2010 Survey**

The Carers NSW 2010 Survey followed a very similar format to the 2008 survey. As well as collecting demographic data and information about caring roles, this survey sought to inform the Carers NSW 2011 NSW Election Strategy and the Carers NSW 2011/2012 Budget Submission. The response rate was again improved, with 854 completed surveys being received.

### **Carers NSW 2012 Carer Survey**

The Carers NSW 2012 Carer Survey shifted focus from the previous two surveys, to address the following issues: 1) carer recognition; 2) carers' mental health and wellbeing; 3) knowledge and expectations of person centredness and individualised funding; and 4) former carers. Due to an increased emphasis on promoting the survey as widely as possible, the 2012 survey received more than twice as many responses as the previous survey (1,919).

### **Carers NSW 2014 Carer Survey**

The Carers NSW 2014 Carer Survey aimed to improve the quality of data collected, in order to allow for more in-depth analysis of key issues facing carers in their roles. Planning included a strong focus on enhancing the methodological rigour of the survey. Reflective of previous surveys, and with the intention of developing a framework that could be replicated in future surveys, the following focus areas were included: 1) carer demographics; 2) the person/s cared for; 3) carer employment; 4) service access and social support; 5) health and wellbeing; 6) former carers; and 7) person centred approaches. This survey was significantly longer than any previous survey, yet was still completed by 1,797 participants.

### **Carers NSW 2016 Carer Survey**

The Carers NSW 2016 Carer Survey continued the quality improvement process implemented in 2014, with the methodological rigour of the survey further enhanced. After fine-tuning the structure of the 2014 survey, the following focus areas were addressed: 1) carer demographics; 2) the person/s cared for; 3) health, wellbeing, and carer recognition; 4) carers' employment; 5) service access and social support; and 6) former carers. This survey received the most responses of any survey to date, with 2,081 valid responses received.

## Participants

The focus of each survey, as outlined, showed some differences in target populations of carers. Most notably, the initial cohort comprised carers of the elderly (1976), whereas later surveys targeted only Carers NSW members (2002-2007). Most recently, surveys have aimed to sample as broad and diverse samples of carers as possible (2008-2016), in order to investigate carers' experiences in as many different situations and caring contexts as possible.

As has already been described, these surveys have significantly increased in the number of responses received over time. Despite this, many demographic characteristics of the samples have remained similar, as outlined below.

## Demographics

### Age

The age distribution of respondents to each of the surveys has been remarkably similar. A majority of each sample was aged between 45 and 64 years, with the highest proportion in 1976 (54.9%) and the lowest in 2004 (42.1%). Unsurprisingly, as it focused on caring for the elderly, the 1976 report comprised the lowest representation of carers under the age of 45 years (6.3%).

Since surveys have been opened to carers beyond the Carers NSW membership database, the proportion of carers under 45 years of age has increased, from 13.8% in 2004 to its highest point of 19.9% in 2014, before dropping off slightly in 2016 (17.3%).

### Gender

Across all surveys, male carers have proven far more difficult to engage than female carers. While population statistics have long demonstrated that women are more likely to undertake caring roles than men (e.g., 68.1% of primary carers in Australia are female; ABS, 2016), the gender breakdown in these surveys is still skewed far more towards females.

Possibly reflecting the changing nature of gendered roles within the community over time, the lowest representation of male carers was in the 1976 report (9.2%), though it should also be noted that this survey was framed to target females as it was expected that women would be the ones caring for the elderly. The highest male representation was in 2004 (24.0%). Since the surveys have been opened up beyond Carers NSW members, the proportion of male carers has ranged from 14.9% (2014) to 20.2% (2008).

### Aboriginal and Torres Strait Islander

Identification as Aboriginal and/or Torres Strait Islander was not measured in the 1976 report, and representation was very low within the Carers NSW members' only surveys (e.g., less than 1% in 2004). Since 2008, the proportion of Aboriginal and Torres Strait Islander carers completing these surveys has steadily increased, from 1.8% (2008) to 3.4% in 2016, which is more in line with the proportion of Aboriginal and Torres Strait Islander people within the Australian population.

### Culturally and Linguistically Diverse (CALD)

The cultural diversity of respondents mirrors the trend of Aboriginal and Torres Strait Islanders outlined above – this information was not collected in the 1976 report, and representation was low (below 10%) in members' only surveys. Since broadening the target population to all carers, culturally and linguistically diverse carers have comprised between 12.4% (2004) and 20.3% (2014) of the survey samples.

## Relationship to care recipient

From 2008 onwards (with the exception of 2012), detailed information about the people being cared for has been collected. In each survey, carers have most commonly been parents caring for their own son or daughter, ranging from 42.0% (2008) to 46.6% (2010) of the total samples. This is followed by those caring for a partner or spouse, ranging between 24.0% (2014) and 41.1% (2010). The other notable category has been those caring for a parent, representing between 17.6% (2014) and 19.3% (2010) of total samples. It is also worth noting that 42.2% of the 1976 respondents were daughters caring for their mothers, and 18.3% were wives caring for their husbands.

## Care recipient condition

The 1976 survey was conducted entirely with people caring for an ageing person. Since 2002, however, all surveys have included any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness, or who is frail.

Carers of people with a disability have formed the largest proportion of respondents, ranging from 39.1% in 2004 to 44.0% in 2014. In 2010, 43.9% cared for a person with a physical disability and 31.7% cared for someone with an intellectual disability.

The proportion of those caring for someone with a mental illness has increased over time, from 9.0% in 2004, to 19.3% in 2010, and 27.1% in 2014. In 2016, care recipient conditions were coded according to the ICD-10, with 61.9% of care recipients having a mental or behavioural disorder.

Meanwhile, the proportion of those caring for the aged and frail has steadily decreased, from 30.0% in 2004, to 18.4% in 2010, and 13.8% in 2014.

## Hours of care

Since 2008, carers have been asked to estimate the hours of care they provide on average, either per day or per week. The combined results of these surveys demonstrate the extensive nature of many caring roles, with almost one in two carers reporting more than 10 hours per day (or 70 hours per week) – 47.9% in 2008, 46.2% in 2010, and 46.8% in 2016. The only exception was in 2014, where comparatively fewer carers (27.0%) reported providing more than 70 hours of care per week.

## Length of caring roles

Not only have these surveys highlighted the intense nature of many caring roles, they also demonstrate that many caring roles last for significant periods of time. In the 1976 report, 31.4% of respondents had been caring for more than 9 years. As more recent surveys have targeted a broader cohort of carers, the reported length of caring roles has increased. In 2008, 39.0% of carers had been caring for more than 10 years, including 24.0% who had been caring for more than 20 years. By 2016, 55.5% of survey respondents reported having been caring for more than 10 years, including 27.0% who had been caring for 20 years.

## Education

In the 1976 report, 12.4% of survey respondents indicated that they had completed tertiary level education. Education levels were not reported on again until 2010, when 25.1% of survey respondents indicated that they had completed a bachelor level degree or higher. This proportion has increased over each of the following surveys, with 31.3% reporting bachelor or higher qualifications in 2016.

## Employment

The 14.5% of carers who reported being in paid employment in the 1976 report was the lowest representation of working carers across all surveys. The question of employment status was reintroduced in 2008, with 30.5% indicated they were in some form of paid work. The highest representation of working carers was in 2014 (42.8%).

## Comments on demographics

It is noteworthy that so many demographic characteristics of these survey samples have remained similar over time. While proportions may have shifted, trends have remained stable, with female carers and those aged 45-64 years comprising the majority of all respondents. Similarly, carers of people with disability have been particularly prominent (aside from the 1976 survey report, which focused only on carers of the elderly). The high levels of care provided on a daily/weekly basis has also remained consistent over time, highlighted by the large proportions of carers reporting more than 10 hours of care per day (or 70 hours per week).

Alongside these similarities, some general trends have also emerged, such as increasing prevalence of Aboriginal and Torres Strait Islander carers, CALD carers, higher levels of formal education, increased workforce participation, and increased length of caring roles. It may be the case that these trends represent a changing demographic profile of carers in NSW (e.g., education and employment), though it is likely also a result of improved promotion and sampling techniques (particularly regarding cultural diversity).

The demographic profiles over time also demonstrate certain groups of carers that are more likely to be engaged with Carers NSW (and other stakeholder organisations), namely: female carers, those aged 45-64 years, those caring for a person with a disability, and those providing high levels of care. While there has been a sizeable representation across other demographic groups in recent surveys (particularly in 2014 and 2016), the comparative underrepresentation of groups such as male carers, young carers, CALD carers, and those with shorter and/or less intense caring roles suggests that these are groups that are at most risk of remaining hidden, and may therefore warrant the greatest attention in advocating for increased support and recognition.

## Main Issues and Findings

As mentioned earlier, the surveys have focused on somewhat different issues and had slightly different aims. Nevertheless, some similar themes have emerged from the results of each. The most notable findings and recommendations from the surveys over 40 years are summarised below.

### Finances

Financial issues were a major focus of the 1976 survey report, with various forms of financial support being recommended as a result. A particularly notable finding from this survey was that approximately 80% of respondents received the Domiciliary Nursing Care Benefit. It was also noted that the rate of this benefit had not increased in line with average weekly earnings, nor was it increased along with other payments such as the Age Pension or Supporting Mothers Benefits. The Domiciliary Nursing Care Benefit was clearly of great importance in financially supporting carers in 1976, leading to the recommendation that it be increased in line with other payments, and also for the eligibility to be broadened to include particular groups of carers who were not previously eligible, but were in no less financial need.

The 1976 report also found that carers could claim tax deductions on certain items (e.g., medications, nursing and medical equipment), which provided greater savings for those on higher incomes than for those with lower incomes. The survey highlighted the need to provide greater financial equity, particularly since carers were at heightened risk of being on a low income due to their caring roles. Financial concerns were so prevalent in this survey that additional financial support for carers was recommended in the form of a “Carers Benefit” to provide financial assistance to those carers who were otherwise ineligible for other forms of government financial support. To place this recommendation in context, the Spouse Carer Pension (which has since been renamed “Carer Payment”) was first introduced in 1983, though the Carer Allowance (which combined the Child Disability Allowance and Domiciliary Nursing Care Benefit) was not introduced until 1999.

Carers’ concerns regarding finances have also been evident throughout later surveys. In 2002, increasing the Carer Allowance and Carer Payment were high priorities for 82.1% and 80.5% of respondents respectively. Carers in this survey provided further feedback on the importance of financial issues, particularly pointing out the perceived inadequacy of the Carer Allowance and Carer Payment, the comparatively high cost of services, and other expenses (e.g., utilities, travel, and other caring related expenses).

While financial assistance was an apparent need in the 2004 survey, it was less of a priority for carers than practical support and services. More than one in four respondents (28.4%) directly reported needing improved financial assistance, and 14.3% indicated that financial assistance was the most important support they could receive. While practical support was more highly valued, financial barriers were also identified as restricting access to services, indicating a mutually influential relationship between these issues. In addition to being a barrier to greater service access, financial concerns were also identified as important issues in their own right, most notably: high costs associated with disability; high costs of medication; insufficiency of Carer Allowance; and the difficulty of surviving on income support.

In 2007, Carers NSW members who responded to the survey indicated a desire for Carers NSW to advocate for increased payments and allowances for carers. Many reported experiencing financial hardship, and others expressed a feeling of injustice in that they were not adequately compensated for their efforts.

The 2008 survey began to provide a clearer indication of carers’ financial status, with 37.0% relying on government allowances (namely Carer Payment and/or Carer Allowance) as their main source of income. An additional 29.1% received their income from the Age Pension or superannuation, while 20.9% indicated that their salary was their main income source. The practical implications of these financial situations were demonstrated by 13.0% of the sample, who indicated that better financial support would

make their caring role easier. In line with 2004 survey results, financial needs were significant, but were less important to carers than the need for services (especially respite). Nevertheless, respondents identified a need for improved financial support, suggesting options such as discounts on utilities and assistance with covering the costs of medical appointments and treatments.

Approximately 40% of respondents to the 2010 survey indicated that caring caused them financial difficulties on a regular basis. Caring roles were almost unanimously reported as having created additional financial costs, most commonly in relation to medication and travel costs. Significantly, 58.3% of respondents reported having to borrow money to cover the costs of caring. Better financial support was believed to be a major way in which caring would be made easier. Carers in the 2012 survey likewise widely reported that financial support would help improve their mental health and wellbeing.

Over one-third (33.8%) of working carers in the 2014 survey indicated that they would like to work less but could not afford to, and this proportion increased to 50.3% in 2016. Financial concerns were also a barrier for 37.1% of carers in accessing supportive services for themselves (2014 survey).

Carers have reported different specific issues related to finances throughout these surveys, but there is a common message. Carers have widely reported low incomes (often due to forced reductions in employment) and simultaneous high costs associated with caring (e.g., accessing services, medication, equipment, etc.). With low income and high expenses comes significant concern, worry, and stress for carers. Financial issues associated with caring are as real in the present day as they were in 1976, and while there have been changes in government financial assistance policies, it is clear that a large percentage of carers are still not being adequately supported in a financial sense.

## Respite

When asked which issues were of greatest importance to them, respondents to the 2002 survey indicated that increasing emergency and short-term respite was the most important issue of all, with 85.8% rating it as high priority. Improving the quality of respite services was also a high priority for 74.4% of respondents. Responses highlighted the significance of respite, as many carers identified a lack of accessible respite care, a lack of flexibility in respite provision, and its cost. Cost was seen to be particularly prohibitive for carers wanting to access respite. Others raised issues which included; the need for more respite for carers of people with a mental illness; the need for more short-term, day care, and residential respite; inadequate allotments of respite hours; and insufficient rural respite services.

In 2004, carers again reported the need for respite as their highest priority, with their need to have a break from caring being the most significant issue raised. Respite was identified by 63.7% of participants as a type of assistance they would like to access, with 33.3% identifying it as the most important type of assistance they could receive. While several did not use the term “respite”, many comments clearly referred to allowing them to take a break and therefore experience a respite effect. Carers identified a range of issues related to respite, from simply needing to access more of it, to describing preferred models of respite service, and additional comments about the quality of respite they had encountered. Survey respondents in 2007 also identified respite as an area for more advocacy on the part of Carers NSW, particularly in relation to increasing access to more respite services.

Respite was the most popular service in 2008 when carers were asked to identify the types of services that they would most like to receive in order to assist them in their caring role, nominated by 24.0% of respondents. Further qualitative comments highlighted the need for more, and better organised respite services.

Funding for respite was also the single most important issue that carers wanted the NSW Government to focus on in 2010, and taking a break from caring was the most popular response as to what would most improve carers’ mental health and wellbeing in 2012. Usage of many services was low amongst respondents to the 2014 survey, but amongst those, respite stood out as being the one service that carers

would like to access more of. In 2016, respite was used by more carers than counselling or carer support groups, though 63.9% of those using respite indicated that they would like to use more.

Respite, or more specifically, the need to take a break from caring is clearly an ongoing issue for carers. Whether identified by the specific term “respite”, or whether the expressed desire is to have a holiday or take some time off, carers very clearly identified this need. Data from these surveys have also demonstrated the potentially time-consuming and extensive nature of caring responsibilities, so it is understandable that carers would prioritise respite and breaks from caring so strongly. For as long as family members and friends are providing unpaid care and support, they will continue to remain in these time-consuming and often exhausting situations. The issue that remains is that there are significant gaps in providing them with the opportunity to take a break from their role when needed. This is exemplified amongst the large proportions of carers who reported accessing respite services, but still wanted more. Whether provided through formal services and informal support networks, the need to provide carers with respite from their role is abundantly clear, as is the insufficiency of current options.

## Wellbeing

In 2008, many carers expressed feelings of loneliness in their roles and subsequently described the personal burdens experienced through social isolation. This isolation and emotional burden was the most commonly identified negative impact of caring and also had significant impact on carers’ personal relationships. The 2010 survey found that carers reported negative personal outcomes as a result of their caring roles, with half identifying negative effects on their emotional health and almost as many identifying negative physical outcomes.

Results from the 2012 survey indicated that while almost two-thirds of respondents rated their own health and/or mental health as “good”, “very good”, or “excellent”, up to half of survey respondents believed that their mental health had been negatively affected by caring, and 40.0% reported that they had needed mental health support.

Wellbeing was investigated in more detail in the 2014 survey, including several different measures. Across these measures, carers were found to report lower wellbeing than the general Australian population. Despite reporting low wellbeing on average, the positive value of caring was consistently greater than the negative impacts. The 2014 survey also identified groups of carers who were at risk of reporting the lowest wellbeing, including: carers with a long-term illness or disability; those who had been caring for longer; those providing more hours of care per week; female carers; and younger carers.

Results from the 2016 survey validated those from 2014, with reported wellbeing of carers being lower than the Australian population. Again, widespread agreement was found with positive aspects of caring, despite low wellbeing. Better health, higher wellbeing, and lower psychological distress were all closely related. Certain groups were again identified as being at higher risk of poor wellbeing, including: female carers; those receiving government financial assistance; Aboriginal and Torres Strait Islander carers; those living outside Greater Sydney; and those experiencing their own long-term illness or disability. In addition, carers from CALD backgrounds reported particularly low wellbeing, but simultaneously reported more positive aspects of caring than their non-carer peers.

Overall, survey results indicate negative wellbeing outcomes for carers. However, the surveys have also demonstrated that positive aspects do exist. The poor wellbeing outcomes experienced by carers should never be underestimated, but neither should the positive aspects of their caring experiences be ignored. The results of the surveys described here indicate that there are multiple aspects to carers’ wellbeing, suggesting that they must receive adequate support to mitigate against poor wellbeing outcomes, but also encouraged to exercise their strengths and celebrate their positive caring experiences. More recent surveys have started to provide more in-depth understanding of groups of carers who are greatest at risk of poor wellbeing, and future work will continue to investigate the separate and interrelated factors that contribute to this.

## Services and support

Practical support was a major area of recommendation in the 1976 survey report. In addition to making recommendations regarding the terms used to name certain types of in-home support (e.g., “Home Help”, “Sitter”, “Emergency Housekeeper”), the need to explicitly recognise the role and authority of carers in coordinating and supervising in-home support was identified. Similarly, fair and equitable rates to charge carers and service recipients were raised as an important issue, to ensure that low-income families could afford to access the support they needed.

The investigation of carers’ priorities in 2002 found that service and support issues rated very highly. For example, 76.7% of respondents felt that encouraging the health system to be more responsive to carers should be a high priority for Carers NSW. Other issues that were widely considered to be high priority included: improving access to services for rural and remote carers (78.1%); improving access to cheaper medicines and aids (72.0%); making services more responsive to carers (71.2%); and assisting doctors to understand carer issues (68.5%). Many carers complained about poor service coordination and an inadequate supply of services to support carers. They also identified a need for better access to information about any available services for carers.

The need for services and support in general was widespread throughout responses to the 2004 survey, with 57.9% indicating that they would have liked to access more services and support, and 21.6% considering community services to be the most important form of assistance for them. This included many different types of support, both for carers and those they cared for (e.g., in-home assistance, domestic assistance, home maintenance, gardening, supported accommodation, help with shopping). Several concerns regarding services were raised, including: increasing waiting lists; high costs of services; lack of information; poor access to services in rural areas; and services are only available in times of crisis.

Support services provided through Carers NSW (especially counselling) were highly appreciated by respondents to the 2007 survey. Nevertheless, the need for additional support was clear, with many carers expressing feelings of isolation and others identifying needs for information and training.

More than one-third of respondents to the 2008 survey indicated that they received no services (33.9%), and 13.0% indicated that receiving community care services would assist them in their caring role. Qualitative responses indicated a perceived need for more responsive and better quality services. Similarly, 38.1% of respondents indicated that better services would make their caring role easier. Had the quality of available services been viewed more positively, it is possible that more than 13.0% of respondents would have wanted to access more community care services. Carers generally appeared to be aware of available services and programs, but felt that they were not adequately supported by what was available. Survey respondents recommended that services should become more appropriate, more accessible, more flexible, more affordable, and should prioritise safety for service users.

In line with 2008 findings, 28.7% of 2010 respondents did not access any formal services. The main reason for this was that they did not know where to find them. Even when carers did receive formal services, perceived support was relatively low, with between 25% and 30% rarely or never feeling supported by service providers. Receiving more support was suggested to be one way to make caring an easier task. Common reasons for carers in the 2012 survey not being able to access the services or support they need included caring responsibilities taking priority and the restrictive costs associated with services.

Respondents to the 2014 survey identified that doctors and family members and/or friends were by far their main sources of support (accessed by 87.5% and 86.1% respectively). While other sources of support (e.g., carer support groups, non-government organisations, counsellors, etc.) were accessed less frequently, the usefulness of all sources was rated quite highly, with 78.7% of all accessed sources of support rated as useful. The main barriers to carers accessing more services were: cost (37.1%); not knowing what was available (36.3%); and caring responsibilities taking priority (31.5%). It was also noteworthy to find that large proportions of carers did not access services, and nor did they want to.

Importantly, providing more hours of care per week was an indicator of increased need for supportive services, but was also a significant barrier to accessing them.

Surveying carers about services often tends to focus on the negative. For researchers and carers alike, it can be easy to focus on what is wrong with service systems under the guise of trying to identify ways in which carers might be more appropriately and effectively supported. This appears to be the case across the surveys described in this report, as many carers highlighted issues of poor access and the inappropriateness of services. Some issues regarding the quality of accessed services were also described, though interestingly, any question regarding satisfaction with services tended to score quite positively.

Similarly, there has been a sense in later surveys that although many carers do not access a lot of services themselves, they do not necessarily want to. The findings regarding accessibility, appropriateness, and quality of services cannot be ignored, as there continue to be certain shortcomings within many services. However, recent survey results equally suggest that many carers are satisfied with the services they (and the person/s they care for) receive, and moreover, that a majority do not want to access services (though direct reasons for this have not been thoroughly investigated in these surveys). It is also worth noting that individual choice and control is intended to be a major outcome of the person-centred approaches that are being implemented across the disability and aged care sectors. The ultimate aim of such approaches includes carers and care recipients having the freedom and autonomy to find and engage services that they feel will be most suitable to their own needs.

## Employment

Issues related to employment have been regularly raised since the 2008 survey. In 2008, the major point raised was the low levels of employment amongst carers, with just 12.7% of respondents working full-time and 17.8% working part-time. The 2012 survey investigated carers' employment in more depth, with 37.2% of respondents indicating they were in paid employment. Of those working carers, 87.0% reported that their employer knew about their caring responsibilities, and 75.0% felt supported by their workplace to balance work and care. The most commonly reported helpful practices provided by workplaces were flexible working hours (utilised by 54.0% of working carers) and carers' leave (44.9%). Reducing hours or working in casual or part time roles were other steps taken by carers to ensure that they could maintain both roles.

The 2014 survey had the largest cohort of working carers, with 42.8% of respondents indicating that they were in paid employment. Of those who were not working, only 9.2% were looking for work. However, it was notable to find that 52.0% of carers who were not employed had stopped working as a direct result of the caring responsibilities (56.5% in 2016). Working carers were more likely to be in part-time roles (41.0% of working carers) than full-time (38.8%). In line with 2012 survey findings, 84.7% of working carers reported that their employers knew about their caring responsibilities, and 76.4% felt that their workplace supported them to combine work and care. The most commonly available and used workplace practices were: being able to leave at short notice for emergencies; carers' leave; and flexible start/finish times. The impacts of care on work were also investigated, with 47.8% of working carers indicating that they had reduced working hours because of caring responsibilities. In addition, 32.3% had refused a new job or promotion that may have posed difficulties in balancing both roles, while 25.1% had changed jobs to better fit in with caring responsibilities. Working in lower level jobs or interrupted career progression were also common, experienced by 34.6% of working carers.

In 2016, stopping work, being prevented from working more, and reducing hours were the most common career impacts of caring. Less than one in five (18.1%) working carers reported having previously stopped work because of care, highlighting the difficulty faced in returning to the workforce after a period of not working to focus on caring. Again, carers were slightly more likely to be in part-time employment (40.3%) than full-time (39.0%). While 85.4% of working carers indicated that their employers knew about their caring responsibilities, only 52.7% felt that their workplace supported them to combine work and care

(significantly fewer than previous surveys). It is likely that this difference is due to methodological differences between the surveys, namely using a 5-point rating scale in 2016, as opposed to a yes/no response in 2012 and 2014. Working carers in the 2016 survey also reported high levels of work-to-life interference, though 40.9% had rarely or never considered leaving their jobs. As with the 2014 survey, the most commonly used workplace practices were: leaving at short notice for emergencies; carers' leave; and flexible start and finish times. Working from home was utilised by just 22.2% of working carers, though 34.2% indicated they would work from home if that option was available to them.

The issue of balancing work and caring responsibilities is becoming progressively more important. Increasingly, carers find themselves in a position whereby they either want or need to remain employed, while also upholding their caring responsibilities at home. Results from recent Carers NSW Carer Surveys suggest that many carers derive a great deal of pleasure and satisfaction from their work, while many also view work as an opportunity for respite from the demands of caring for a family member or friend. Conversely, the time pressures involved in maintaining both working and caring roles has been associated with high work-to-life conflict and the challenges associated with balancing conflicting time demands can negatively impact carers' wellbeing and work performance.

Recent surveys have identified different ways in which carers can be effectively supported in the workplace, thereby reducing the likelihood that they will withdraw from the labour force. It is becoming increasingly apparent that the provision of flexibility and supportive workplace practices and policy is helpful to a degree, but workplace culture and working carers' perceptions of a supportive employer are particularly important. While many carers in these surveys reported having supportive supervisors and workplaces, there is clear evidence that this is most certainly not a unanimous situation. Rather, there continues to be a significant need to advocate on behalf of working carers and enable employers to understand the benefits of supporting working carers, both for the carers themselves and for the good of the workplace.

## Recognition

While the recognition of carers was not directly investigated in the 1976 survey report, suggested clarifications of terminology regarding in-home support allude to this concept. By arguing that those who were paid or volunteered to support the elderly and their carers should be referred to as "Home Help", "Sitters", or "Emergency Housekeepers", the term "carer" was solely used to refer to carers as they are currently defined. In doing so, their important and unique roles were recognised and valued for what they were.

In the 2002 survey, questions directly asked about recognition, with 84.3% of respondents indicating that advocating for greater recognition of carers by government and politicians should be a high priority for Carers NSW. The 2004 survey took this concept further and explored what the idea of "carer recognition" meant to carers. Recognition was widely considered to mean that governments, the community, and wider family networks understood the impacts of being a carer and their needs in that role. Carers reported wanting recognition for the fact that caring can be a full-time job, that carers save the government money, that they have skills and knowledge, and that carers have made significant sacrifices in their own lives. At a practical level, carers felt that recognition could be demonstrated through the availability and responsiveness of services, inclusion by health professionals, financial assistance, and emotional support. It was widely felt that people do not understand what it is like to be a carer until they become a carer themselves. Only 8.1% indicated that recognition was not important to them, though for some this was due to a perception that it was idealistic and unattainable, rather than unimportant.

The recognition of carers and their contribution to society was a recommendation arising from the 2008 survey, with the development of a Carers Recognition Act emerging as the top priority recommendation. This finding was in line with the NSW Carers Action Plan 2007-2012, which outlined a government policy approach to recognising and supporting carers. Strategies revolved around increasing the respect and recognition of carers' roles, improving services, encouraging service providers to view carers as partners

in care, reaching out to family members who do not identify as a carer, and supporting carers to engage with the workforce. Survey responses related to carer recognition supported the importance of such initiatives.

In 2010, approximately one-third of respondents (32.0%) reported that they rarely or never felt appreciated as a carer. However, it was believed that receiving recognition from government would help make caring roles easier. That same year, the *NSW Carers (Recognition) Act 2010* was passed, signifying a legislative commitment from the NSW Government to formally recognise carers. Despite this, respondents to the 2012 survey expressed a great deal of uncertainty about what carer recognition was, with many highlighting the need for more and better services. Carers were asked if they had seen any evidence of the Act being put in practice, with only 4.0% indicated that they had. Overall, results from the 2012 survey indicated a need to address carer recognition through increased awareness and understanding of the *NSW Carers (Recognition) Act 2010* (including education for carers around their rights under the Act). Furthermore, carers clearly identified a need for service providers to improve in terms of their quality and support provided to carers.

The perceived recognition and acknowledgment of carers in the 2014 survey was again low, as it was in 2016, when only 24.9% of respondents agreed that their caring role was recognised and valued in the community.

From 2002, when recognition was identified as a major priority for carers, to 2016, when only one in four believed their role was recognised, carers have widely indicated feeling undervalued and underappreciated. It is encouraging to note that the NSW Government has introduced the *NSW Carers (Recognition) Act 2010*, though a majority of survey respondents still do not feel recognised or valued. As outlined previously, carers responding to these surveys identified a range of practical ways in which their lives could be made better as carers. It appears that for carers to more widely feel that the community and government values and recognises the vital role that carers play in the community, more practical and personally useful supports need to be made available (e.g., in the form of formal services, financial support, collaborative service providers, etc.). Positive signs exist in the establishment of government policies, procedures and legislation to speak to the recognition of carers, however, greater attention must be paid as to how this policy level recognition can be more appropriately translated into practical initiatives that make carers feel valued and recognised, as opposed to overlooked and ignored.

## Legislation and policy reforms

The 2012 survey was noticeably different from other surveys, in that it had a major focus on carer recognition legislation and significant policy reforms (i.e., the introduction of person centred approaches and individualised funding). Results very clearly indicated that most carers had little or no knowledge of the *NSW Carers (Recognition) Act 2010*, but would like to know more. Carers NSW members were more than twice as likely to have heard of the Act than were non-members. Carers also commonly demonstrated cynicism about the benefits of this legislation.

When investigated again in 2014, awareness of this legislation had increased slightly. Carers NSW members were again far more likely to have heard of the *NSW Carers (Recognition) Act 2010* (42.9%) than non-members (18.6%), suggesting that organisational communication was useful in informing members about such policy developments.

Similarly, carers' knowledge and understanding of person centred approaches and individualised funding was limited in 2012, with 39.5% and 51.9% of respondents being familiar with these reforms respectively. Despite this, carers tended to display positive attitudes towards the changes, with more than half indicating that they would manage their own funding if the option was available. Amongst those who did want to manage their own funding, the most commonly cited reasons were that it sounded too complicated and that they did not have enough time. There was some apparent reservation amongst some participants, who raised concerns about potentially negative impacts of these changes, but it was more common for respondents to express hope for a better life for themselves and those they cared for.

Two years later, awareness of person centred approaches and individualised funding had increased (55.5% and 59.3% respectively). Expectations surrounding both were far more positive than negative, though 44.0% of responses were neutral, reflecting expectations of no real change or uncertainty of what to expect. The 2014 survey also found that those who had practical experience of individualised funding packages were more positive about outcomes than those who had not yet received a package.

Legislation and policy reforms have not comprised a large part of the surveys outlined in this report. However, when addressed, it was clear that carers (as a whole) were uninformed about legislative and policy changes that were intended to directly impact them. On one hand, it may be argued that carers' awareness levels of reforms in legislation and policy is not a major concern, but rather, the important issue is that carers are supported in the manner intended by such reforms. On the other hand, it is important that carers understand their rights and obligations under new legislation, and that they are also aware of how service providers must behave in relation to carers. Survey results suggest that many carers hold an interest in policy and legislation that directly affects them. There is therefore a responsibility that falls to government, service providers, and support and advocacy organisations to ensure that carers are informed of their rights, that they understand what they (and those they care for) are entitled to, and that they are empowered to act in accordance with those rights.

### Former carers

Since 2012, the surveys have included specific questions related to former carers (who had previously been excluded from survey participation). For most former carers, the reason their caring roles had ended was due to care recipient death (62.7% in 2012; 56.2% in 2014; 68.3% in 2016). A significantly less common reason was that they could no longer cope (12.7% in 2012; 11.0% in 2014; 5.3%). Importantly, large proportions of former carers reported not receiving adequate support when their caring roles ended (25.4% in 2012). The end of caring roles has been identified as a particularly challenging time, when coping was the most difficult. Support from services and emotional support have been identified as the main ways in which the end of caring roles could have been made easier. Former carers' support needs continued beyond the end of their caring roles, though appeared to reduce somewhat over time. On average, former carers rated their health slightly better than current carers. Results from the 2016 survey suggest that health and wellbeing improved across all measures as the time since the end of caring roles increased.

Although limited data have been collected thus far regarding former carers, these surveys are contributing to the evidence base in an important way. Previously, very little attention was paid to former carers, with many avenues of support cut off from them once they were no longer caring and therefore did not fit within most service providers' jurisdictions. However, survey results have indicated important support needs for carers when caring roles cease, and in the time following this. Despite the need for support at the time that caring roles end, former carers reported better wellbeing than current carers, suggesting that there may be significant complexities that arise at this time – most likely due to carers feeling some relief from the removal of caring responsibilities, but simultaneous grief, guilt, and/or sadness (depending on reasons for the end of the caring roles). Ongoing research will aim to investigate carers' support needs after the end of their caring roles, as both positive and negative experiences clearly abound amongst former carers.

## Conclusions

Although society has changed in many significant ways over the past 40 years, it is clear that many aspects of informal care have not. From the 1976 report on carers of the elderly right through to the most recent Carers NSW 2016 Carer Survey report, these surveys have demonstrated that informal care is a vital component of the social fabric that makes up Australian communities. In the present day, just as was the case four decades ago, Australian society relies heavily on family and friend carers to provide necessary support to individuals living with disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness, or who are frail.

Just as the importance of carers has remained significant over the past 40 years, it is both interesting and concerning to note that many of the issues and challenges faced by these individuals also remain. Financial disadvantage continues to impact carers in very meaningful ways, as the costs incurred through providing care, along with reduced earning capacity culminate in situations of financial stress. Though several changes in government financial assistance have occurred over this time, carers continue to perceive these measures as insufficient and inadequate. In a society where carers save governments an estimated \$60.3 billion annually in replacement costs (Deloitte Access Economics, 2015), there is a clear need for meaningful financial investment in supporting carers to overcome the financial barriers they experience as personal and household levels.

Carers have appeared more noticeably on the social agenda in recent years than they did in 1976, for example, through the establishment of the *NSW Carers (Recognition) Act 2010* and other state government commitments to supporting carers (such as the NSW Carers Strategy 2014-2019). While recognition of carers' roles and contributions to society has improved at a political level, carers themselves continue to report feeling undervalued and unappreciated by their communities. The often hidden nature of care is likely to play a role in this.

Carers are most likely to experience the recognition they deserve and receive the support they need through direct contact with supportive services and through proactive support from wider community networks. The support carers and those they care for receive through various community and health sector sources are generally viewed positively, and have been throughout the surveys discussed in this report. However, a significant gap exists in service providers' active recognition and support of carers, particularly when their mandate is to support care recipients. There is clearly a need for continued advocacy, as service providers need to realise that carers are often equally invested in any treatment regimens undertaken by those they care for.

If carers are to be recognised and valued for their contributions in the community, meaningful value needs to be placed on their roles by service providers, governments, employers, and carers' own family and social networks. While survey respondents over time have suggested that family and social networks speak positively of the role they undertake and often provide verbal encouragement, they equally suggest that no person can ever know what it is like to be a carer until they take on the role for themselves. Such lack of understanding can prevent individuals (and even large groups or companies of people) from proactively searching for and implementing strategies that may assist in alleviating inequalities between carers and their non-caring peers (e.g., directly addressing financial disadvantage, promoting equity in the workplace, providing social support to assist with lower levels of wellbeing).

The results of the surveys over the past forty years have highlighted many issues faced by carers – many time limited and heavily contextualised, and others universal and ongoing. These surveys have provided valuable insights and continue to be a vital mechanism through which carers' voices can be heard, their concerns raised, and evidence gathered to inform supportive practices and policy maker decisions. As Carers NSW moves beyond its 40<sup>th</sup> Anniversary, this evidence base continues to direct the organisation's direction in a meaningful and well-informed way. Just as importantly, as the landscape of the service sectors change (especially in relation to major reforms to the disability and aged care sectors), ongoing consultation and feedback from carers will be vital to ensure that support and systemic advocacy work

addresses the real-life issues that carers face in their daily lives. Carer Surveys will play a major role in contributing to this, and equally will continue to play a major role in arguing for the necessity of ensuring carers are appropriately and effectively supported.

In 1975, Clare Stevenson wrote “Dedication” as a result of several decisions to investigate problems arising from the care of an aged person at home, and professed that the report should not be the end product. Forty years later, Carers NSW exists to continue the work of raising awareness of carers, supporting them in their roles, and systemically advocating for greater recognition and value of carers throughout the community. The legacy of “Dedication” is that the final report on a survey conducted in 1976 was not the end product, but that enough attention was drawn to the importance of carers that there continue to be people and organisations committed to advocating for and supporting carers to this day.

If you want to find out more or to stay engaged and up to date on the latest developments for carers please visit [www.carersnsw.org.au](http://www.carersnsw.org.au)

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