

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+¹ 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).

¹ Lesbian, gay, bisexual, transgender, intersex and other sexuality, sex and gender diverse