2022 National Carer Survey

Tasmanian Results

December 2023

About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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Contents

1. Background 4
2. Executive Summary 5
3. Snapshot of findings 6
4. About the survey 8
5. Findings about Tasmanian carers 9
About the survey respondents 9
People being cared for 10
The caring experience 11
Service access for the person being cared for 11
Recognition and inclusion at the services level 12
Educational attainment 15
Young carer findings 15
Employment 16
Finances 18
Social connection 19
Time for self 20
Carer wellbeing and psychological distress 21
6. Conclusion 29

1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Australian Government Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Executive Summary

The National Carer Survey is an initiative of Carers NSW in partnership with Carers Tasmania and the other State and Territory Carer Organisations. This survey is conducted every two years and aims to understand the experiences of carers and how the services and support for carers can be improved on both national and state-by basis.[1]

The survey was first conducted in 2020, and then for the second time in 2022, across all Australian states and territories. The second survey was open for completion between June and July 2022. Of the 6,825 carers who responded to this survey, 691, or 10.1% were from Tasmania.

We thank Carers NSW for leading this important initiative, along with the State and Territory members of the National Carer Network who supported the development and promotion of this survey. We recognise and thank all carers and former carers who participated in this survey. We value the contributions, deep insight, and experiences shared by the survey respondents. We also thank those working within the community sector and members of the broader community who assisted in sharing this important survey.

This report summarises the information gathered from Tasmanian respondents to the second survey. We note that these results are only representative of the carers in Tasmania who participated, not carers more broadly. This report follows the release by Carers NSW of the full survey data in October 2023 to mark National Carers Week.

Content warning:

This report contains data regarding the wellbeing of carers. We acknowledge that this may be upsetting for some people and encourage anyone feeling distressed to access support. Please call one of the numbers below if this raises any issues for you.

In an emergency call 000

Lifeline	**13 11 14**	24/7
Access Mental Health	**1800 332 388**	24/7
MensLine	**1300 78 99 78**	24/7
13Yarn	**13 92 76**	24/7
QLife	**1800 184 527**	3pm to midnight every day
Carer Gateway	**1800 422 737**	8am - 5pm weekdays (24/7 for emergency respite)

[1] Carers NSW (2023). 2022 National Carer Survey: Full report. Available online at: http://www.carersnsw.org.au/research/survey

3. Snapshot of findings

2022 National Carer Survey
Tasmania Results

CarersTAS Australia

Highlights from Tasmania

This year's National Carer Survey heard from a total of 691 carers from Tasmania. The Survey results tell us a lot about carers' day to day experiences, support needs and perspectives on caring. Below are some of the key findings so far.

Carers from Tasmania represented a total of 10.1% of respondents to the 2022 National Carer Survey. They mainly responded to the Survey online and 53.3% were connected with Carers Tasmania.

The 2022 National Carer Survey was conducted from June to July 2022 and received a total of 6,825 valid responses from carers across Australia.

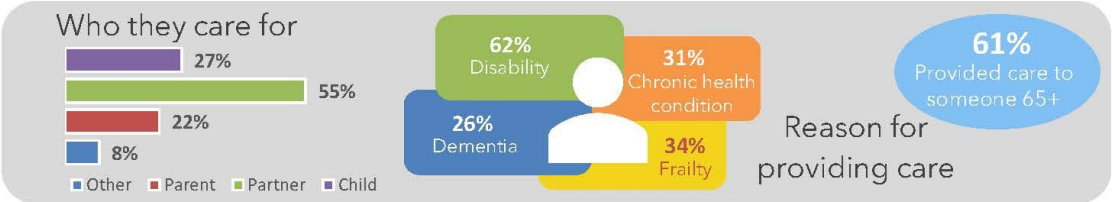
A carer is any individual who provides unpaid care and support to a family member or friend, who has disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence or is frail or aged.

About the carers who responded

Of the 691 carers who responded to the 2022 National Carer Survey from Tasmania, the majority identified as female and were aged 70 to 79. The average age was 65.5 years. They represented a range of locations and cultural backgrounds, but most identified as Australian and lived in regional locations. 21.1% of respondents were working while providing care.

About the people they care for

Most Tasmanian carers who responded to the Survey were caring for a partner, and the most commonly respondents were caring for someone living with a disability. The average age of the people they care for was 63.4 years. However, not everyone who responded to the Survey was still in a caring role; 47 respondents (6.8%) identified as former carers, and a further 150 (23.3%) had previously cared for someone, and were now caring for someone else.



About the caring experience

Most carers who responded from Tasmania cared for one person and most were the sole carer. They were most likely to living with the person they care for. Carers from Tasmania typically spent 108 hours per week caring, and had been caring for 11.3 years.

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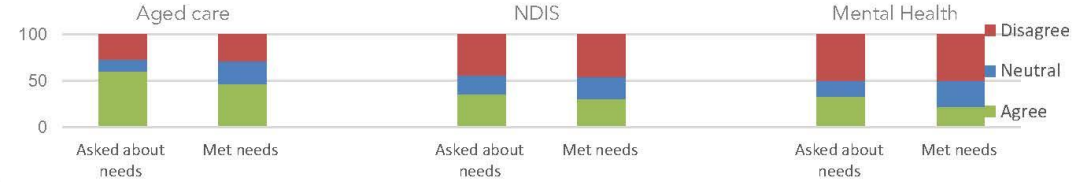
Carers' experiences with services

The 2022 National Carer Survey asked carers about their use of a range of services, and how included and supported they felt. Most carers from Tasmania were accessing the aged care services with or on behalf of the person they care for. Aged care services were more likely to ask carers about their own needs than health services, NDIS and mental health services however, services didn't always meet carers' own needs or enable them to work or take breaks. Many carers also reported long waiting period to access services and reduced or interrupted services due to COVID-19.

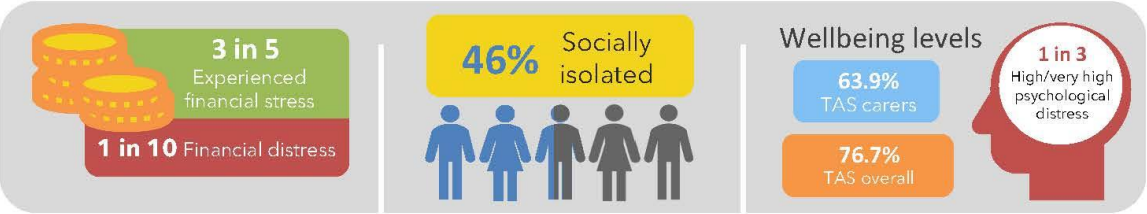
The 'typical' respondent from Tasmania was a woman in her 70s, caring for a partner living with disability, who was not in employment.

Carers' experiences with service systems



Key challenges experienced by carers

In addition to the many challenges carers experienced when accessing formal services, many carers in Tasmania told us they were financially stressed and socially isolated. Compared to other Australians, carers in Tasmania were much more likely to be at risk of mental illness and had much lower wellbeing.



What carers told us

"Currently, I study at high school and my parents are blind. They always need someone to help them. After school I help them a lot."

"I love my son unconditionally even with all his little quirks, I worry every day of what will happen to him when I fall off the perch, who will care for him as I have done over the years without selfishness."

"I like being her carer and appreciate all the help we receive from services and our community. It is, however, the hardest thing I've ever done and requires me to give more than I have sometimes."

Carers in Tasmania provide invaluable support to the people they care for and the community. And yet, recognition and timely support is lacking.

This National Carers Week, Carers Tasmania calls on the Tasmanian and Australian governments, service providers and communities to better support Australia's carers.

The National Carer Survey is an initiative of Carers NSW in partnership with Carers Tasmania and the other State and Territory Carer Organisations. The Survey is proudly funded by the NSW Department of Communities and Justice. More detailed results will be released in the coming months. For more information, visit www.carersnsw.org.au/research/survey or contact research@carersnsw.org.au or (02) 9280 4744.

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4. About the survey

The Survey was designed by the Carers NSW Research team, with input from an Academic Working Group that consisted of researchers, stakeholders, and importantly, carer representatives. An additional working group was also established, comprising of employee representatives from each State and Territory carer organisation.

Ethics approval was obtained by the Macquarie University Faculty of Arts Human Research Ethics Committee. A Participant Information and Consent Form was provided alongside the survey, containing all relevant information for participants, including the intent and purpose of the research, the involved researchers and organisations, data usage, and information in case of participants experiencing distress.

The Survey questions were developed by the Carers NSW Research team, in collaboration with the Academic Working Group and the State and Territory Working Group. The questionnaire was piloted with five carers and five employees of Carers NSW.

The survey consisted of 77 questions across six sections. Not every question was compulsory, and many questions could be skipped depending on prior responses. For consistency, the questions were similar to those asked in the 2020 Survey, but some additional questions were included on paid work, carers' own use of health and community services, the impacts of COVID-19 and recent natural disasters. Carers NSW advised that from the data available, the Survey took approximately 20 minutes to complete. The Survey questionnaire, Participant Information and Consent Form, and additional information can both be found on the Carers NSW website.[2]

The Survey was available for completion online (via Survey Monkey) and also in a hard copy version. It was sent to all carers registered with Carers Tasmania who had an email address, and a hard copy to all who did not have email.

[2] Carers NSW. (n.d). https://www.carersnsw.org.au/about-us/our-research/carer-survey

5. Findings about Tasmanian carers

A total of 691 carers from across Tasmania participated in the Survey. Of these, 61.8% were completed online and 38.2% were paper responses. Despite 47 respondents reporting that they are no longer in a caring role, their insight and experience is incredibly valuable. Interestingly, 150 respondents indicated that they had been previously providing care to someone and were now providing care to someone else.

About the survey respondents

A diverse range of carers and former carers from across Tasmania participated in the survey.

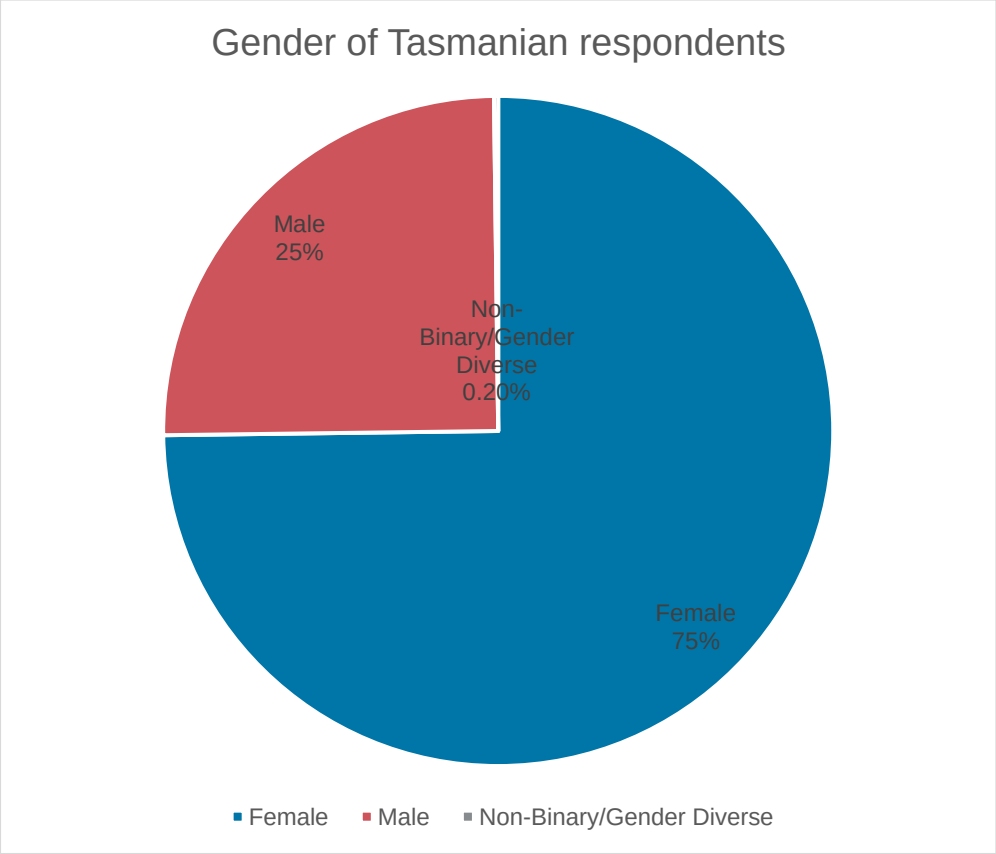

Figure 1: Gender of Tasmanian respondents

Three quarters of Tasmanian respondents identified as female, and most respondents were aged between 70 and 79 years. The average age was 65.5 years, and 58.7% were aged 65 or older. Respondents identified as being from a range of locations and cultural backgrounds, but most identified as Australian and lived in regional locations. Only 3% of respondents identified as Aboriginal or Torres Strait Islander and 6% indicated they also spoke another language aside from English. Around 3.8% reported that they identify as LGBTIQ+. Ten carers, (equating to 1.4% of respondents) identified as young carers under the age of 25 years.

Most respondents were living in the Hobart area, followed by Launceston.

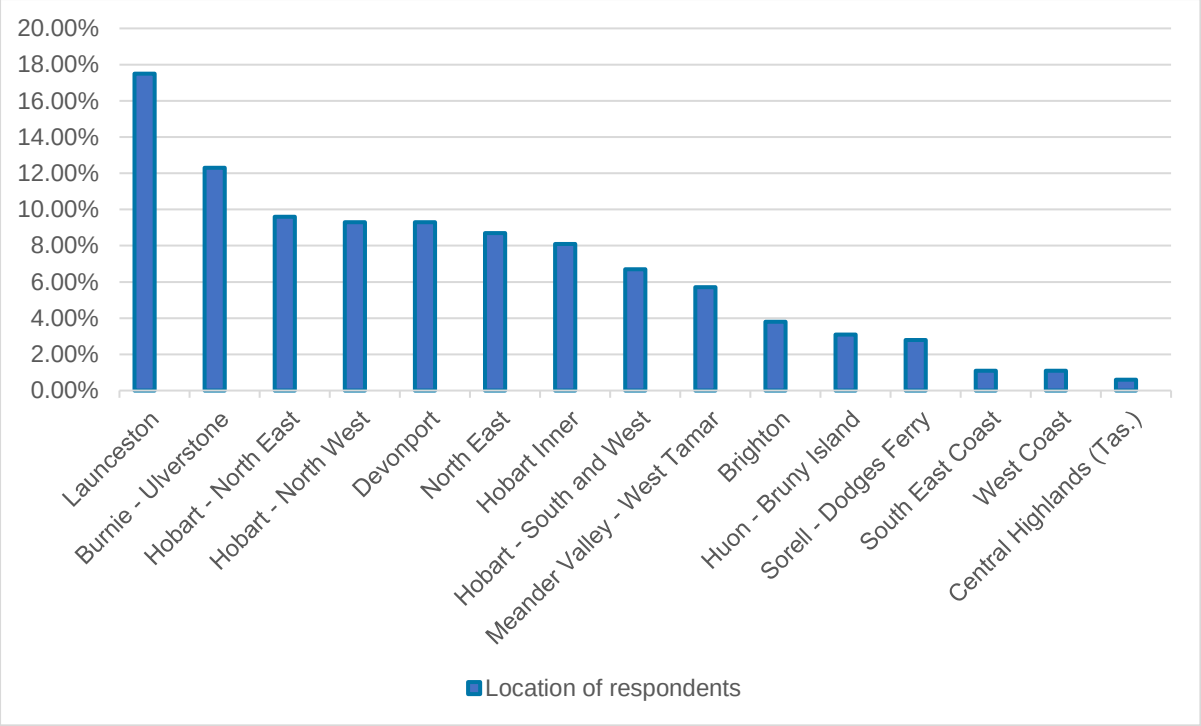

Figure 2: Location of respondents

People being cared for

The survey findings revealed that most Tasmanian carers were providing care for a partner. This was followed by those caring for a child, and subsequently for a parent. The number of individuals caring for a sibling was approximately equivalent to those caring for a friend or neighbour.

Most commonly, survey participants were providing care for people with disability (62%). Notably, just below 20% of respondents were responsible for the care of more than one person. Additionally, some care recipients reported having co-morbid conditions. Of the respondents, 61% reported caring for people aged 65 years or older, 34% were providing support to someone who was frail, 31% were caring for those with a chronic health condition, 26% were tending to someone with Dementia, and 22.5% were assisting an individual with mental ill health. The average age of those receiving care was 63.4 years.

The caring experience

Most Tasmanian respondents were providing care to only one person (80.8%). Most were also the sole carer, however, some people reported caring for multiple people at once.

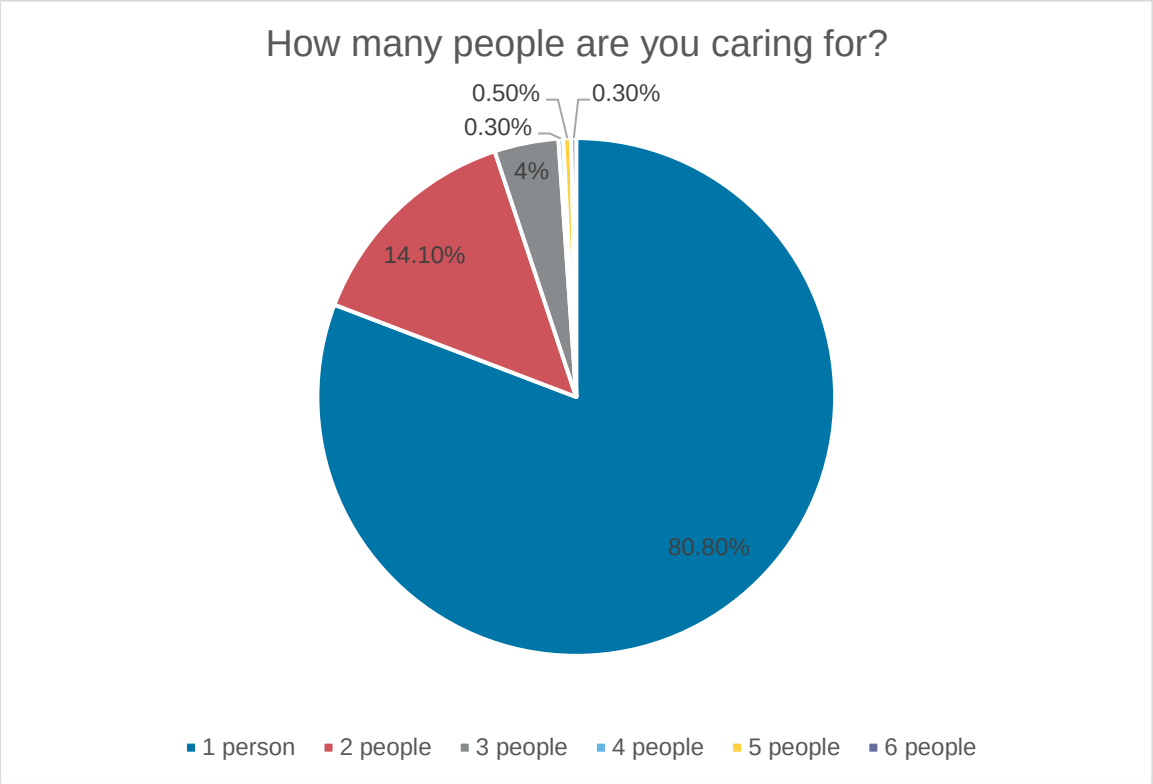

Figure 3: Number of people providing care to

The majority (82%) of respondents indicated they were living with the person they were providing care for. Carers from Tasmania typically spent 108 hours per week caring, and on average, had been providing care for 11.3 years. Carers commonly assisted with personal care, prompting for activities of daily living, dressing, cooking, cleaning, gardening, shopping, communication, companionship, support to regulate emotions, medication, decision making, budgeting, administration duties (forms, paperwork, phone calls, bill paying), transport and interpreting.

Service access for the person being cared for

The Survey asked carers about services for those they were caring for and whether they felt included and/or supported by these forms of assistance. Most carers indicated the person they cared for was accessing aged care services. Aged care services are supports designed to be provided to people who need assistance when they are aged over 65 years (or over 50 if they are Aboriginal or Torres Strait Islander).

Others reported the person they were caring for was accessing disability or mental health supports, whilst a proportion (17.4%) of carers indicated the person they were caring for was not accessing any formal services. There are many potential reasons why a person may not wish to utilise formal services. Some of these reasons include cultural or religious reasons, impaired cognitive ability, or lack of insight into care needs. For some people, care needs

are so complex that it is easier to provide constant care themselves, rather than have changing support workers.

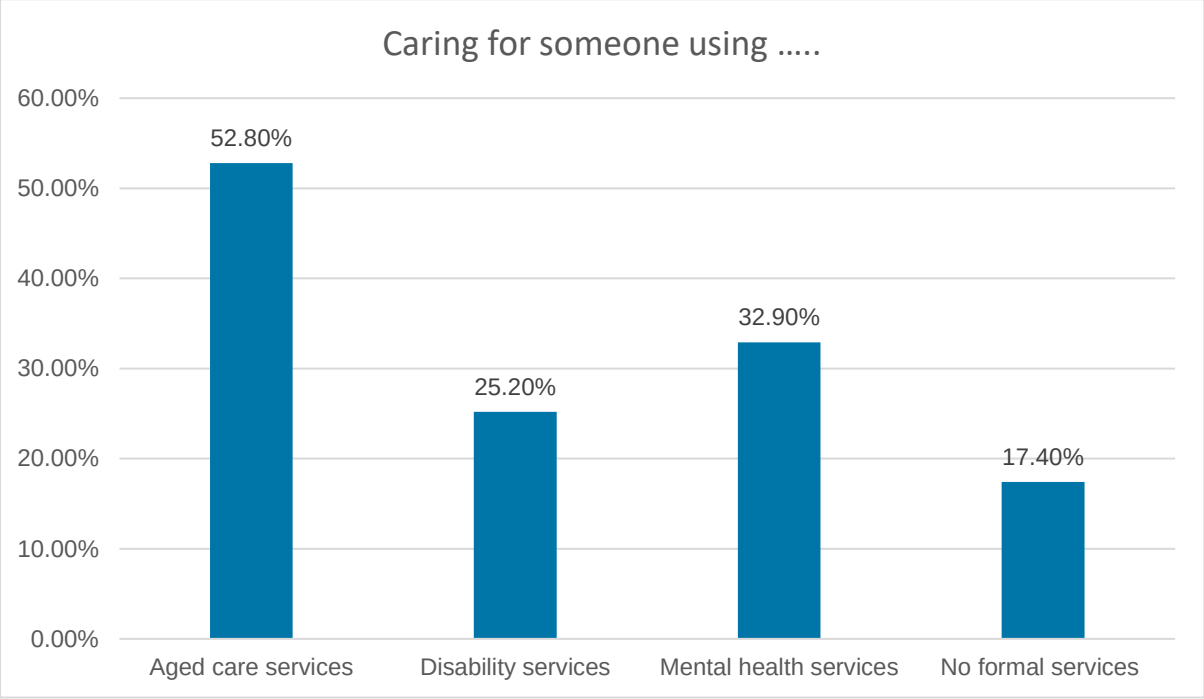

Figure 4: Services used by the person being cared for

Carer recognition and inclusion at the services level

Many carers said that they were rarely asked about their needs and not included in support and treatment planning discussions despite the valuable insights they hold, as well as the regular care and support they provide.

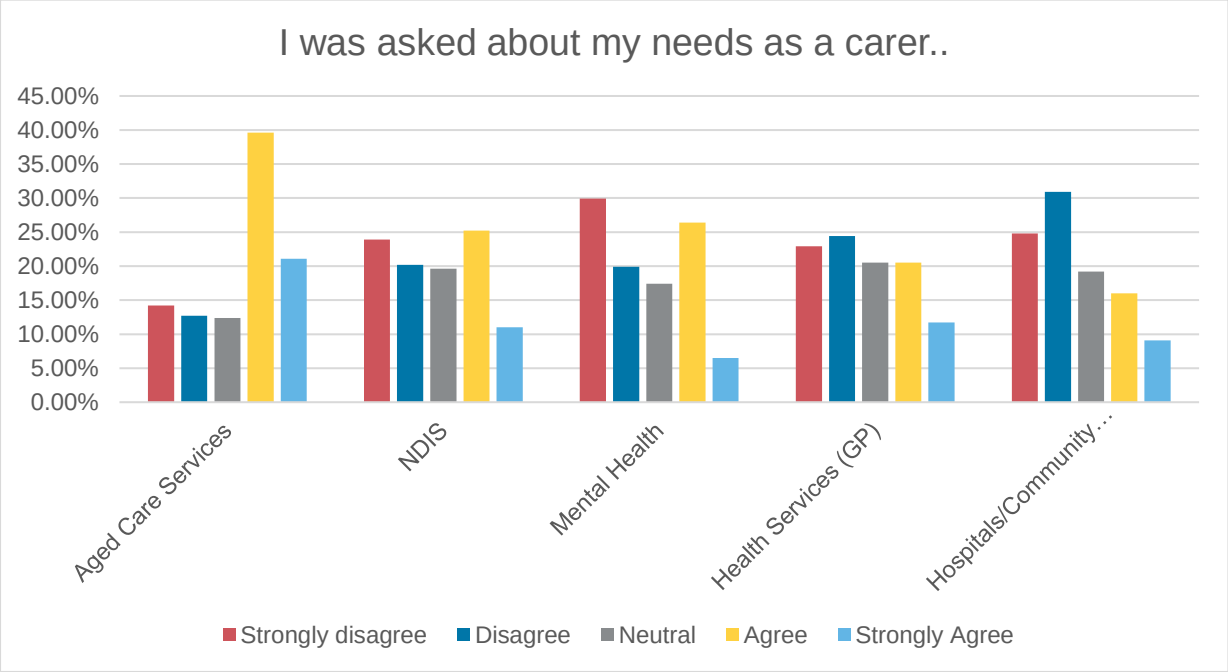

Figure 5: Services asking about carer needs

Aged care services were the most likely to ask about carer needs than any of the other services. Mental health services were the least likely.

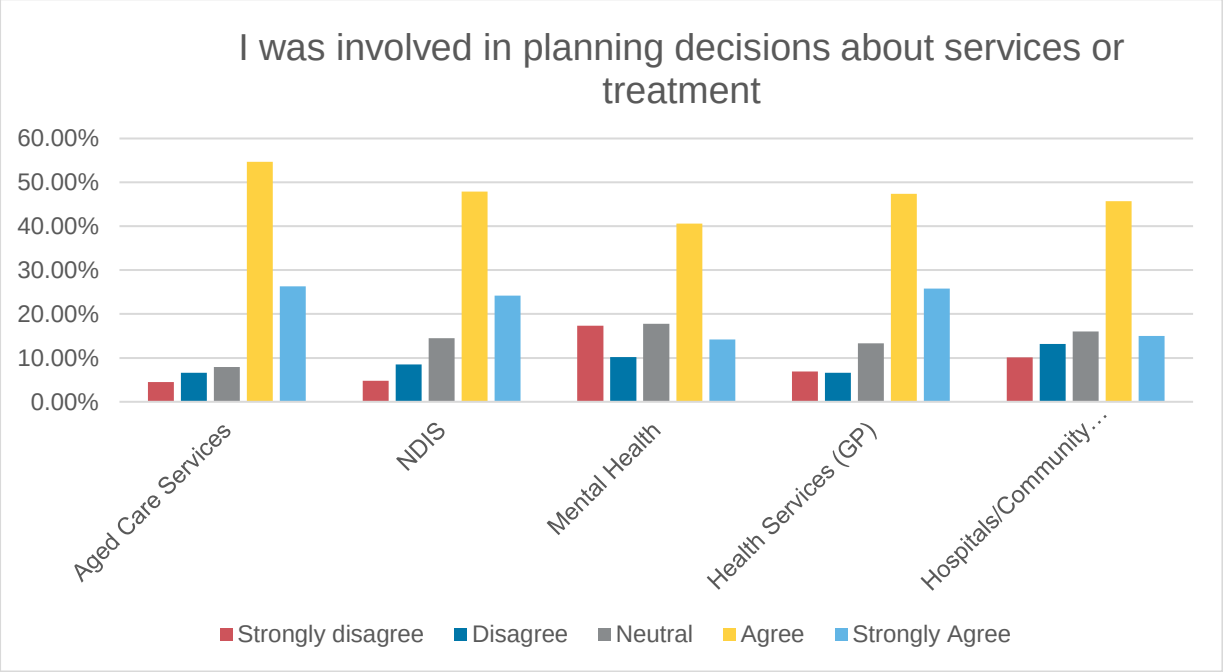

Figure 6: Services involving carers in planning

Aged care services were also more likely to involve carers in planning about services and treatment for the person they cared for, whilst mental health services were the least likely. Data from the national survey results also indicates that overall, carers of people using aged care services reported feeling more recognised than carers of people using disability and mental health services.[3]

[3] Carers NSW (2023). 2022 National Carer Survey: Full report. Available online at: http://www.carersnsw.org.au/research/survey

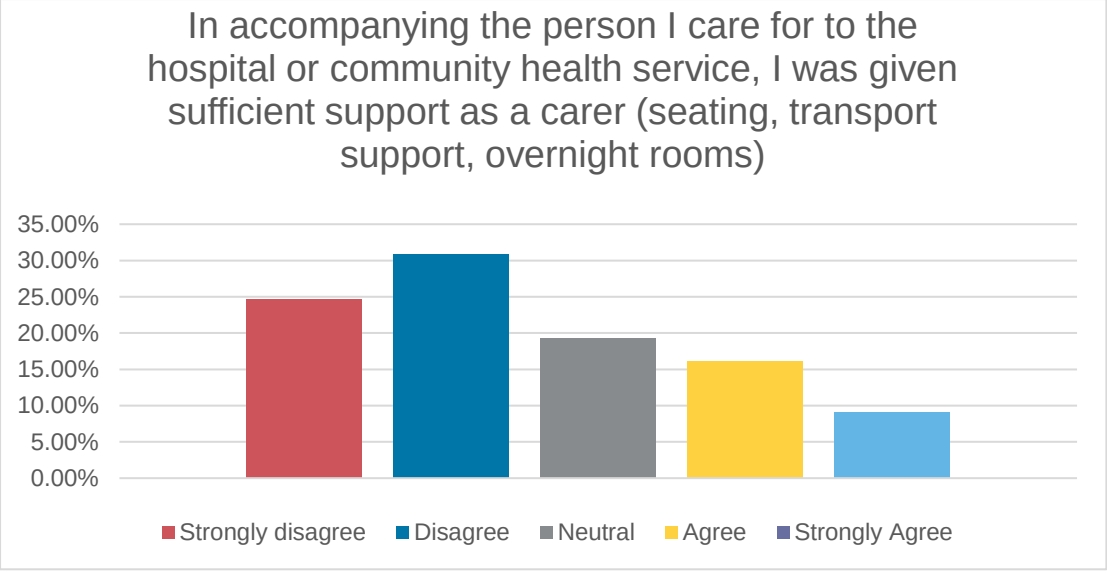

Figure 7: Provision of support for carers as well as patient

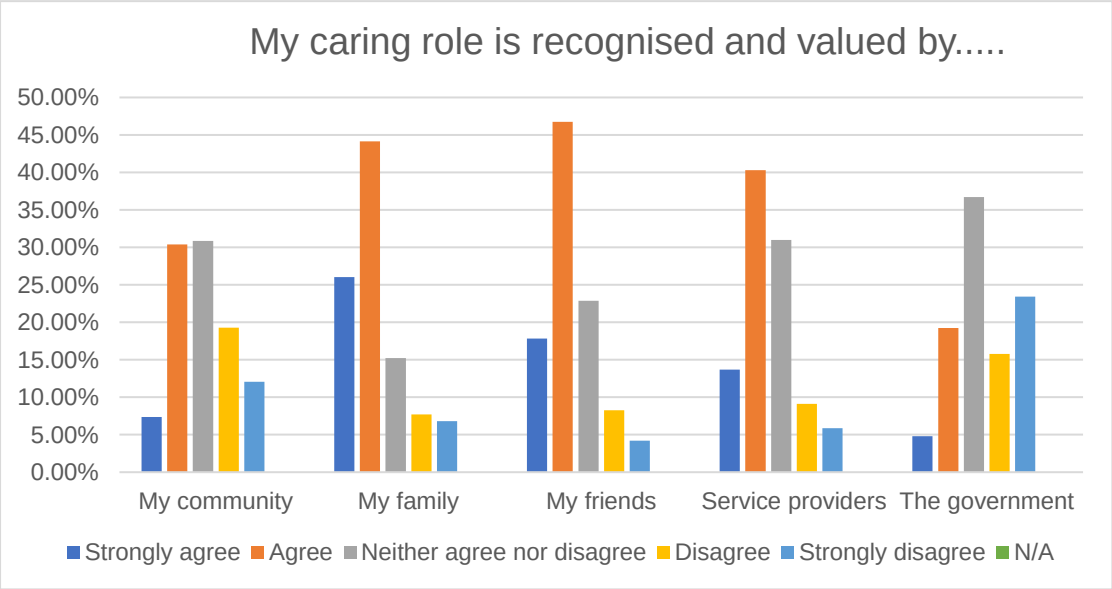

Figure 8: Carer recognition

Data from the Survey suggests there are varying levels of carers feeling recognised or valued. Family and friends generally provided more recognition of the caring role, compared to service providers and the government.

Educational attainment

The survey asked carers to share their highest level of educational attainment. Across the four areas to choose from, the results were fairly even, with slightly more carers reporting they had achieved a certificate/diploma level.

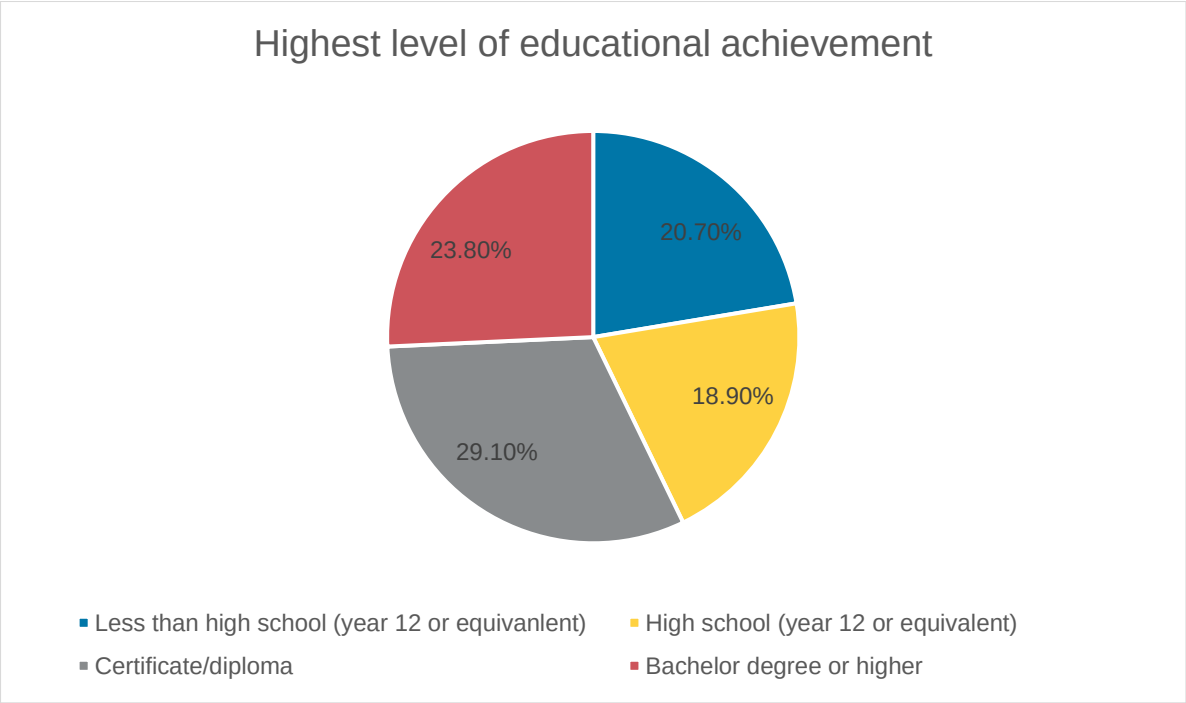

Figure 9: Educational achievement

Only a small proportion of respondents indicated they were currently studying (4.3%).

Young carer findings

Noting that people often care for people with co-morbid conditions, or sometimes provide care to more than one person:

- 8 out of 10 young carers reported providing care to a parent
- 5 out of 10 were caring for a sibling
- 9 out of 10 were caring for someone with disability
- 4out of 10 young carers reported experiencing high levels of social isolation.

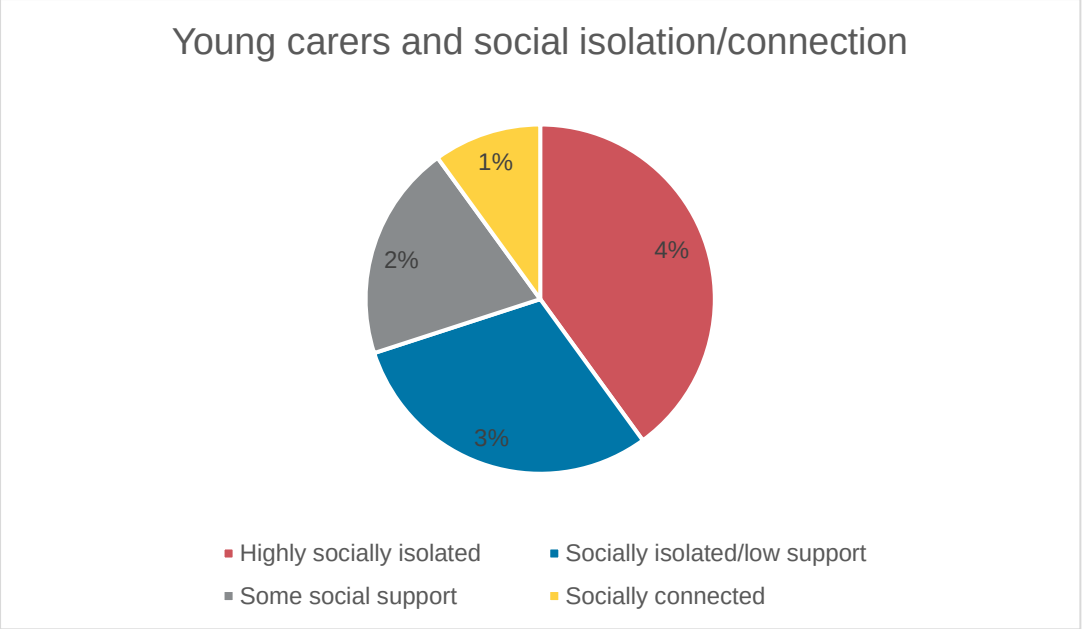

Figure 10: Young carers and their levels of social isolation or connection

Young carer quote:

"Currently, I study at high school and my parents are blind. They always need someone to help them. After school I help them a lot."

Employment

Around 21.7% of respondents indicated they were working in paid employment while providing care. Of the carers who were balancing paid employment, the mean number of hours worked per week was 25. A reduced number of hours worked per week may make juggling a caring role and employment more manageable. In addition, one of the eligibility requirements in order to access the Carer Payment is that a carer cannot work (or study) for more than 25 hours per week. The 25 hours includes time worked and travel to and from work.

Carer quotes about employment:

"I've had to take frequent leave, including unexpectedly, which has impacted my work significantly."

"I haven't felt able to put any consistent focus on a career because of my caring responsibilities."

"I feel less motivated at work as my family and life outside work have the most meaning to me."

"It is backbreaking, and mentally exhausting. It leaves you an emotional and physical wreck, and the government don't want to support you - they just want to make you work fulltime, and the second your loved one passes away, they want you to carry on with your life like it never happened."

"A large part of why I stay in my current job is my carer's responsibilities."

"I am grateful to have a job which has been very understanding about my caring role. I gave up a career/ job I enjoyed to move back to extended family for better support; I took a job below my skill set to enter into the workforce after moving; I have kept the job, which I don't enjoy and doesn't play to my strengths, due to the flexible working arrangements currently available; I have felt supported in my caring role previously, but the organisation has changed and I have a new manager, so I feel uncertain about the future in this role; I lack confidence to apply for other roles since I have been operating at such a low level for so long; I regularly feel like a bad employee due to my caring responsibilities."

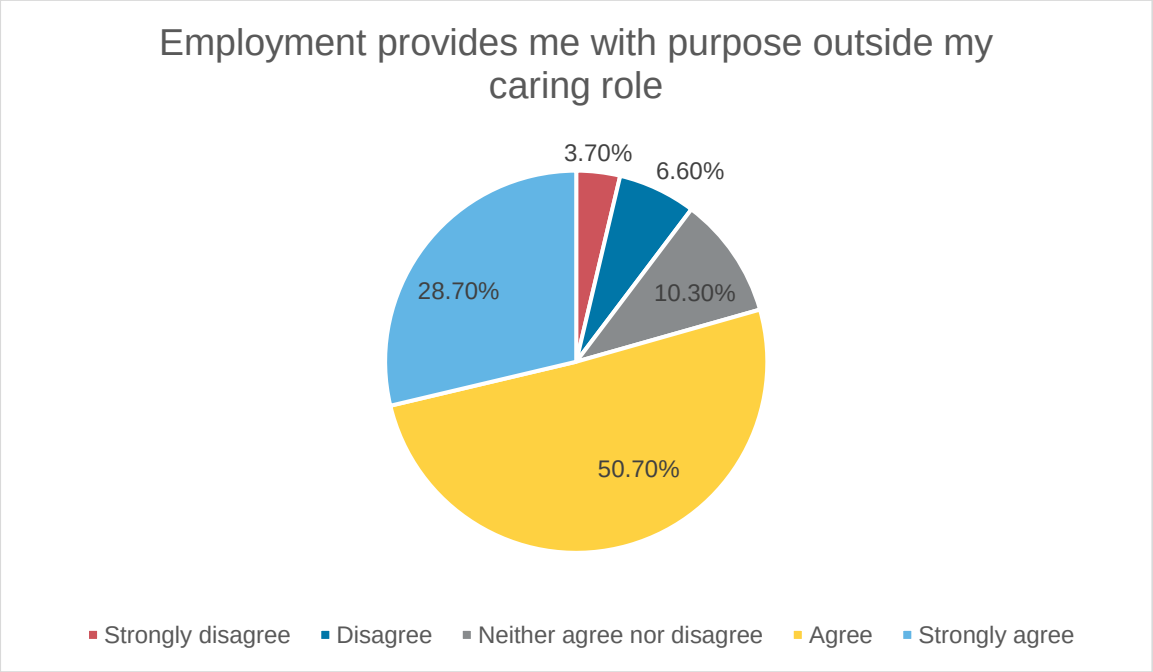

Figure 11: Employment and purpose

Most carers said they agree (50.7%) or strongly agree (28.7%) that their employment provides them with an important sense of purpose outside of their caring role.

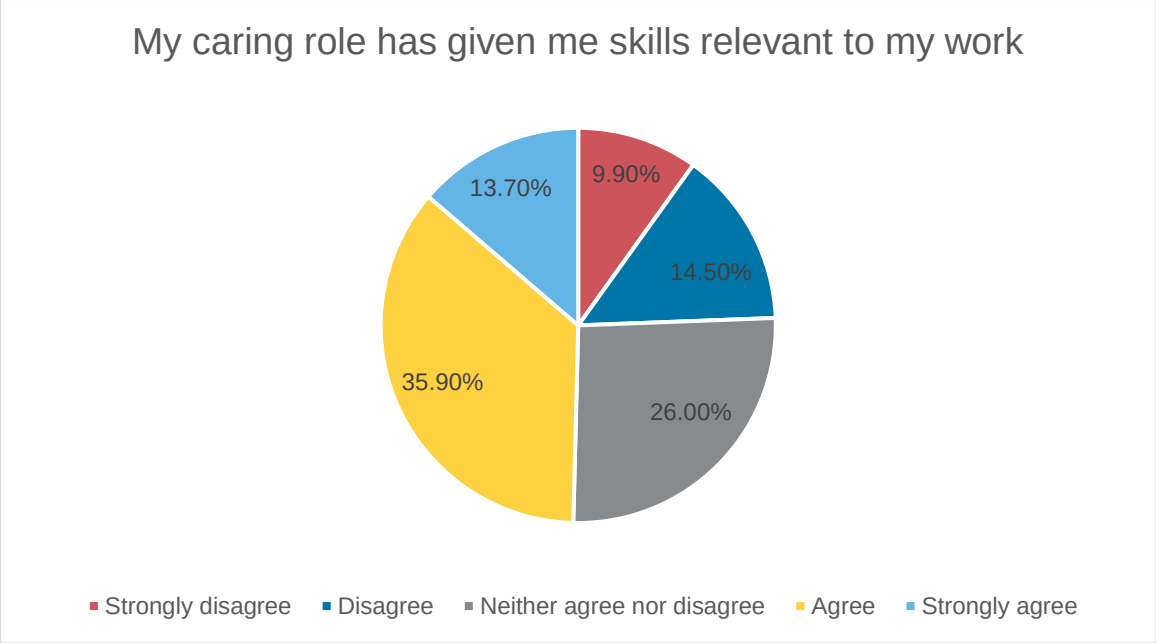

Figure 12: Skills from the caring role transferrable to employment

In addition, most carers also agree (35.9%) or strongly agree (13.7%) that their caring role has provided them with skills that are relevant to their work.

Finances

Many people in Tasmania, and across Australia, have been facing significant cost-of-living pressures. Carers often experience additional financial challenges due to their caring roles.

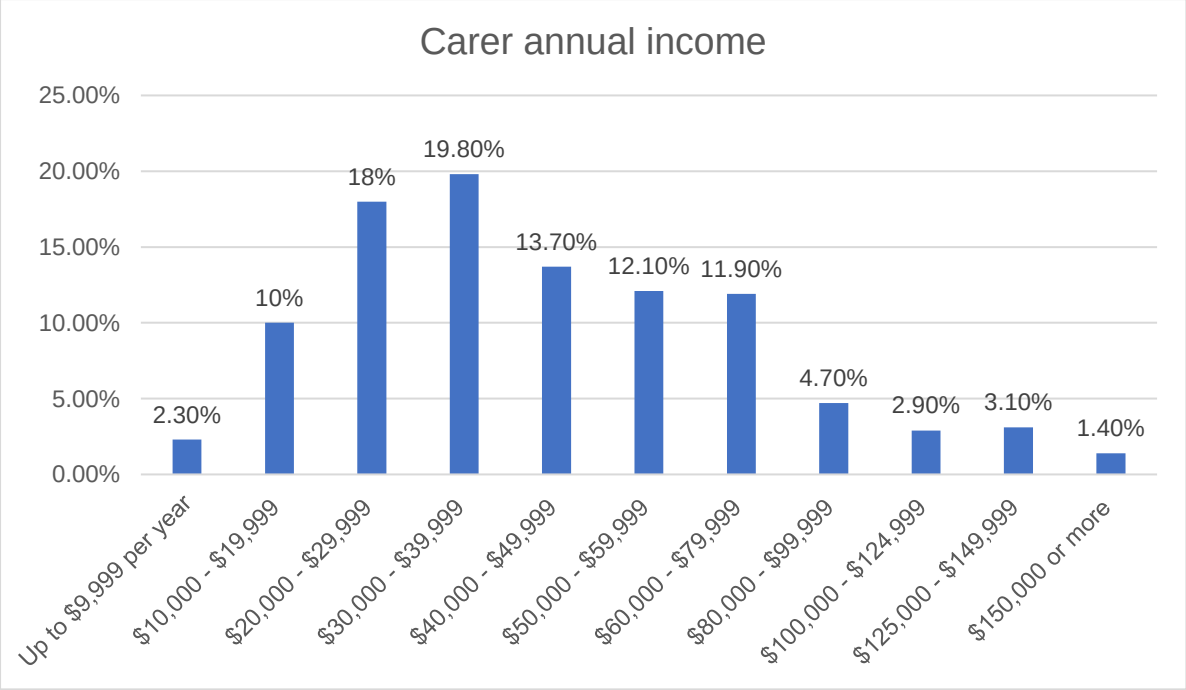

Figure 13: Reported annual income

Carers generally had low incomes, with most carers (19.8%) reporting that their annual income was between $30,000 and $ 39,999. This equates to $576 to $769 per week. When considering the significant increases to costs of living, such as fuel, groceries, rent/mortgage and electricity, this income may make it challenging, and for some almost impossible, to live without having to go without or make significant changes to their lifestyle.

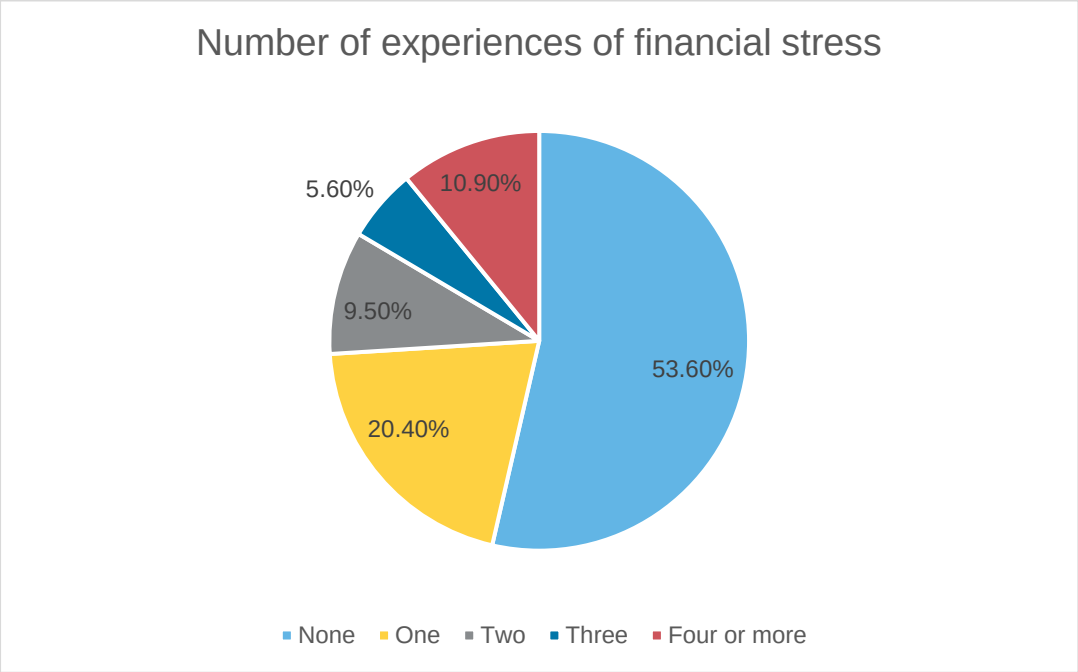

Figure 14: Number of experiences of financial stress within the last 12 months

Three out of five carers reported experiencing financial stress, and one in ten reported more significant financial distress.

Around 76.8% of carers reported that they had extra expenses for the person they care for.

Carer quotes:

"It is one of the most underappreciated and recognised 'occupations' there are. The emotional and financial drains are huge. My financial future is ruined as is my partner's. Before his injury we had three properties. Now we struggle to pay our tiny mortgage and make ends meet. He didn't ask to be injured at work."

"Carers allowance - laughable - when you care for someone 24/7."

Social connection

Around 46% of carers indicated they were socially isolated, with 23.9% of this proportion reporting high levels of social isolation. A small proportion (16.7%) of carers indicated they were highly socially connected. Of carers who were also participating in paid employment, 49.6% agree, and 23.4% strongly agree that their employment provides them with important social connections outside of their caring role. Additional analysis conducted by Sage Design and Advisory found that increased levels of social isolation had significant negative impacts

on carer wellbeing and that social isolation was the most significant contributing factor to poor carer wellbeing.[4]

Carer quotes:

"The only people that help my family have clipboards. The loneliness of not being able to have support from extended family or even friends; is crippling. Only our 70+ mothers really check on us."

"Lack of friendly support, emotional support and care from 'friends'. Feeling isolated has been the biggest upset for me. Unable to ask them to help me. One family member has made a big effort to support by phone and visit from interstate when able. My sister hasn't."

Time for self

The survey sought to understand which services enabled carers to have the most time for themselves.

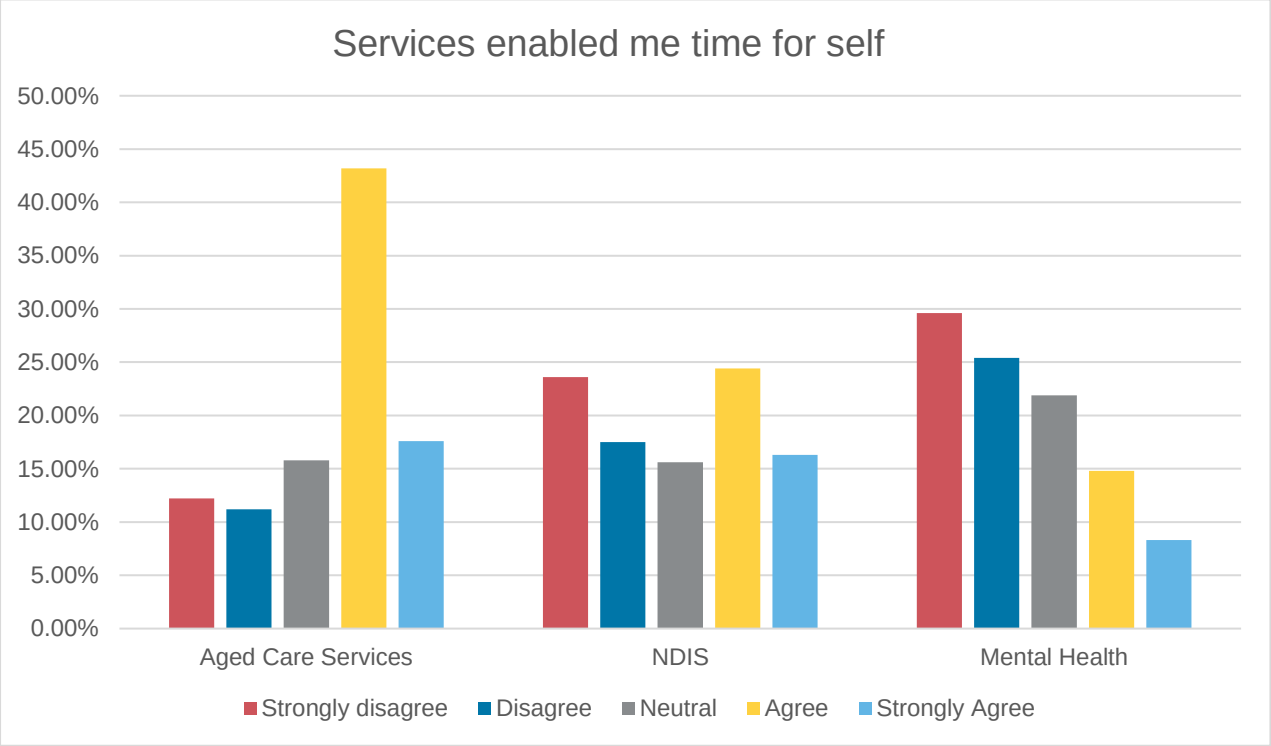

Figure 15: Services enabling carer time for self for activities unrelated to caring duties, work, household and other chores.

According to the results, aged care services were the best enablers of time to self for carers, whilst mental health services were the least effective. Carers must be supported to access time for themselves. Analysis of the National dataset found that as the number of hours per week carers spent in their roles decreased, their wellbeing levels increased.[5]

[4] Sage Design and Advisory. (2022). National Carer Survey Tasmanian Analysis. https://carerstas.org/wp-content/uploads/2024/01/SAGE-Design-and-Advisory-National-Carer-Survey-Tasmanian-Analysis.pdf
[5] Carers NSW (2023). 2022 National Carer Survey: Full report. Available online at: http://www.carersnsw.org.au/research/survey

Carer quotes:

"It is stressful physically, emotionally, and mentally. No breaks, no holidays, just days, weeks, months, and years all the same. Mind you the one being cared appreciates the care."

"I have no time to myself to just be me."

The survey results showed that the mean number of hours carers reported as having for themselves was 14.5 per week. The survey explained time for self as *"where you can pursue activities of your choice, that are not related to caring responsibilities, work, or to household and other chores."*

Carer wellbeing and psychological distress

Levels of psychological distress were measured using the Kessler 5-item Scale of Psychological Distress (K5). Scores of 5-11 fall into the low to moderate category, whilst scores from 12-25 indicate high to very high psychological distress. The K5 scale is adapted from the full Kessler 10-item Scale[6] and it was also used in the previous 2020 National Carer Survey.[7] One in three Tasmanian carers reported high or very high levels of psychological distress. The mean score was 10.38, compared to the 2020 mean of 10.3, indicating a slight increase in levels of psychological distress over the two years.

Overall, 64.8% of Tasmanian respondents indicated low to moderate levels of distress, meaning that 35.2% indicated high to very high levels of distress.

The charts below (figures 16 to 22) show further analysis of the K5 categories by specific carer cohorts.

[6] Kessler, R. C. et al. 2002: Short Screening Scales to Monitor Population Prevalences and Trends in Non Specific Psychological Distress. Psychological Medicine 32
[7] Carers NSW (2023). 2022 National Carer Survey: Full report. Available online at: http://www.carersnsw.org.au/research/survey

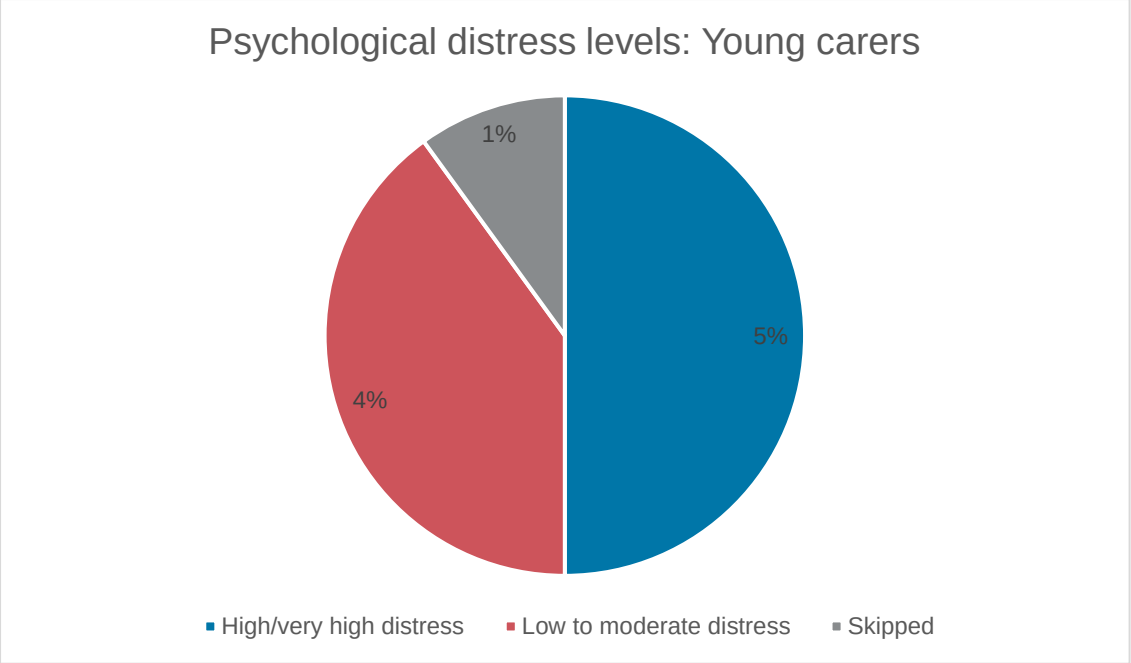

Figure 16: K-5 for young carers

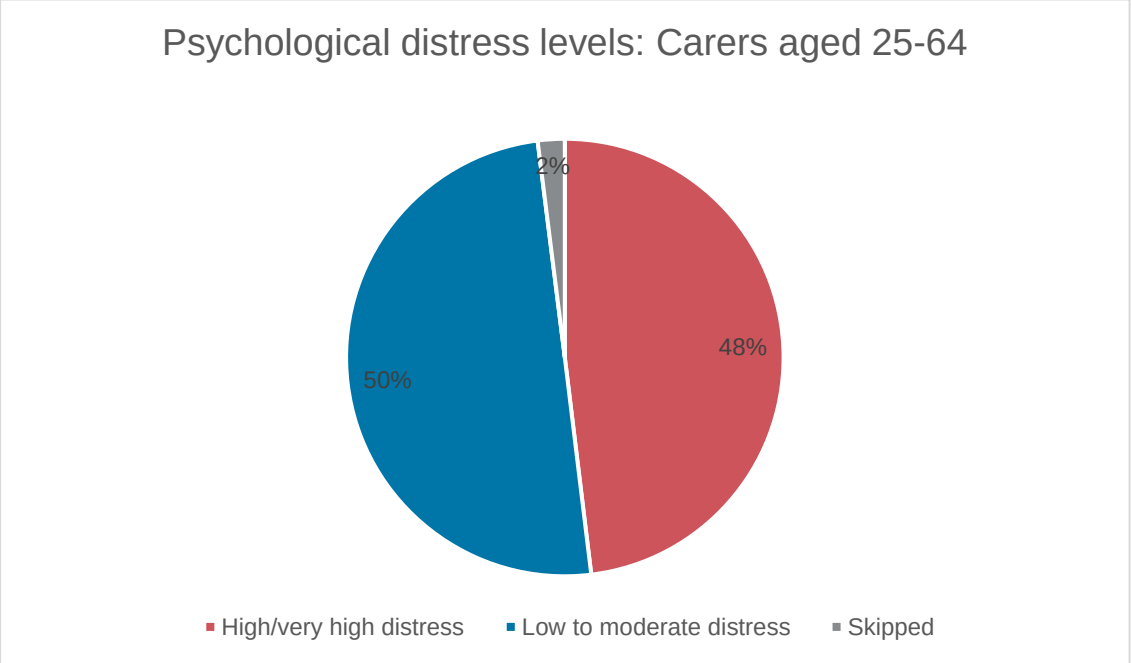

Figure 17: K-5 for carers aged 25-64

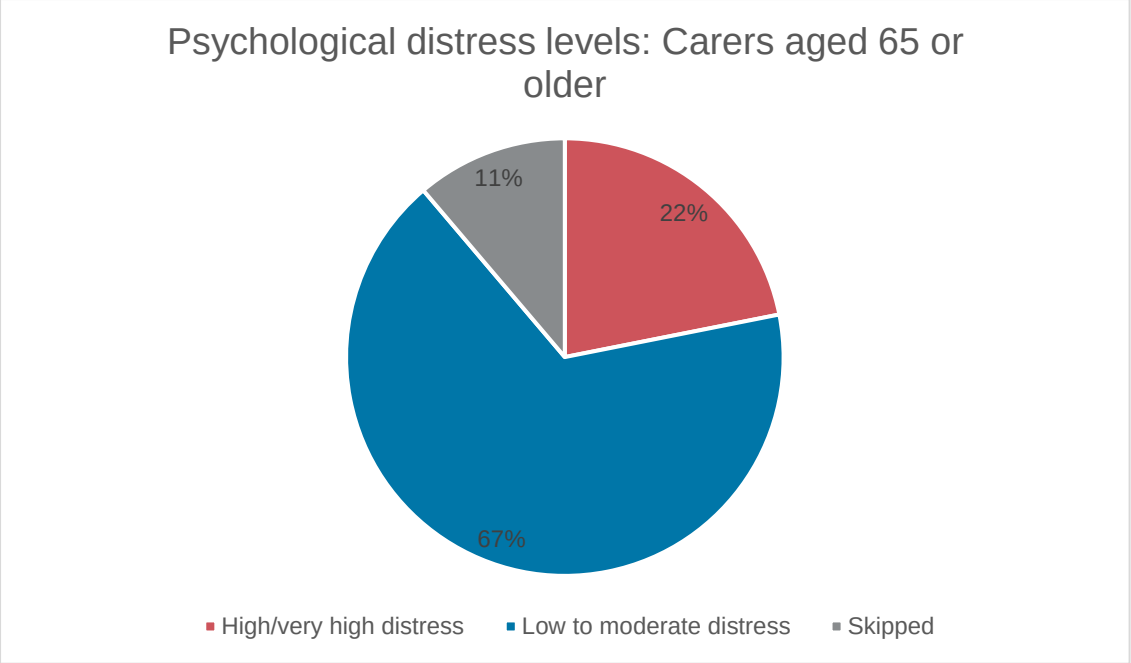

Figure 18: K-5 for carers aged 65 years or older

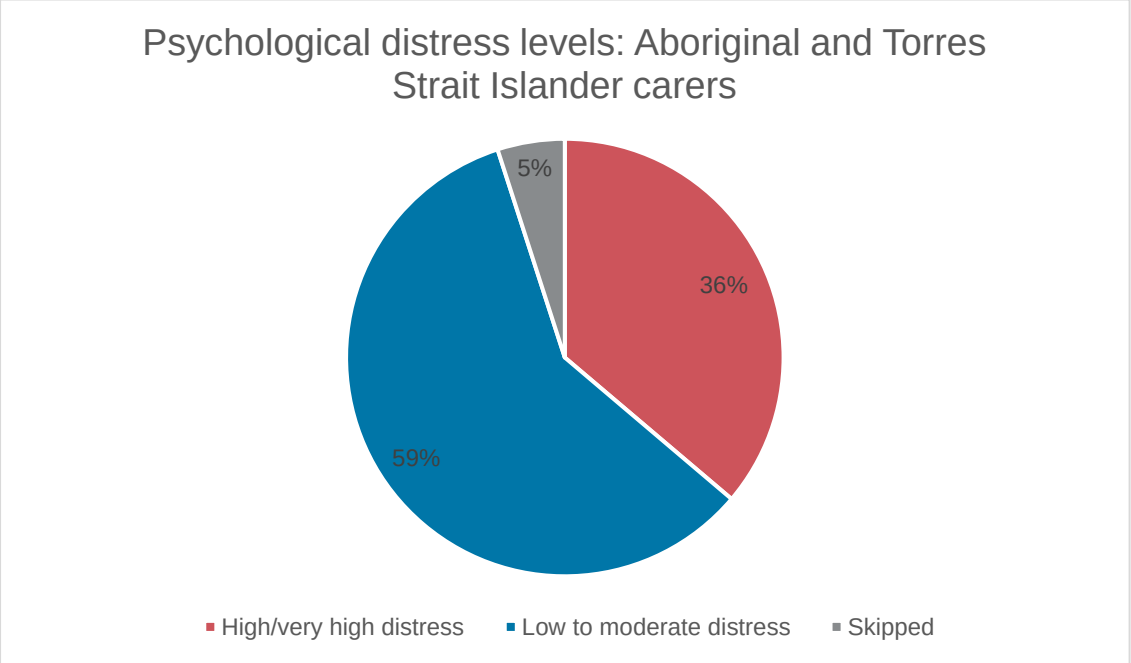

Figure 19: K-5 for Aboriginal and Torres Strait Islander carers

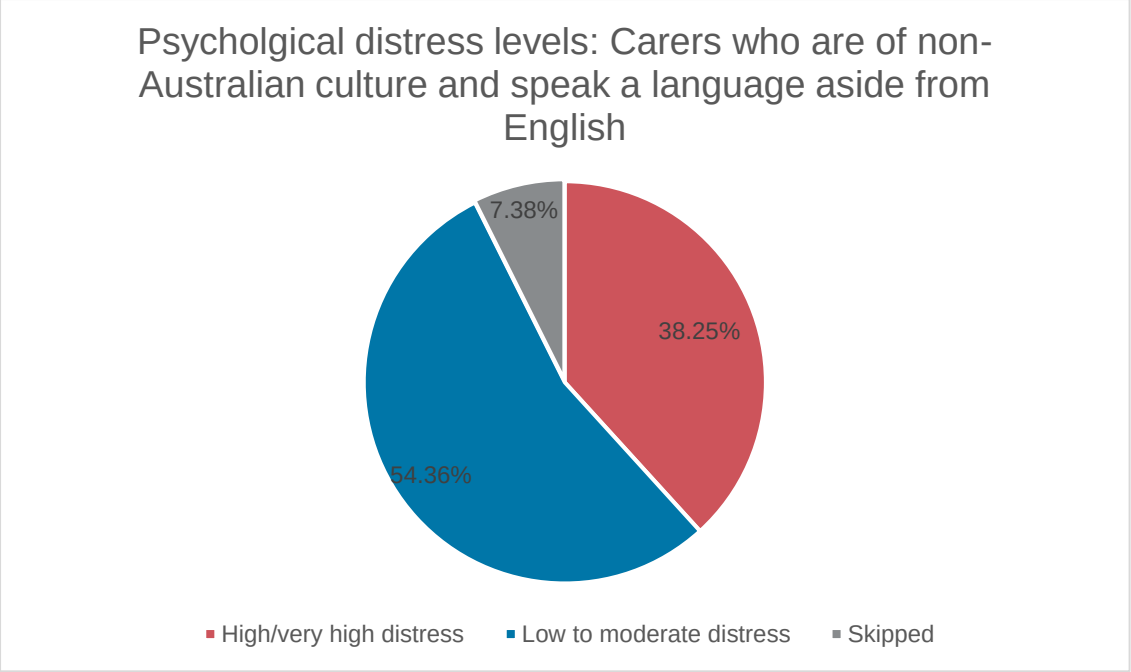

Figure 20: K-5 for carers of a non-Australian culture and who spoke a language other than English

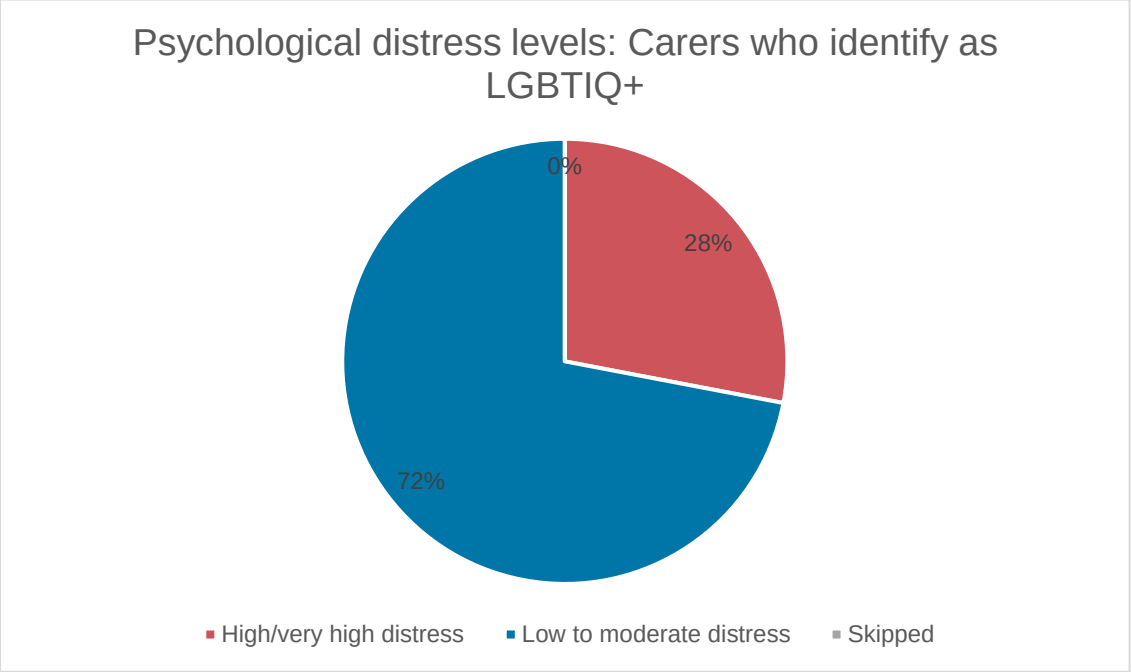

Figure 21: K-5 for carers who identify as LGBTIQ+

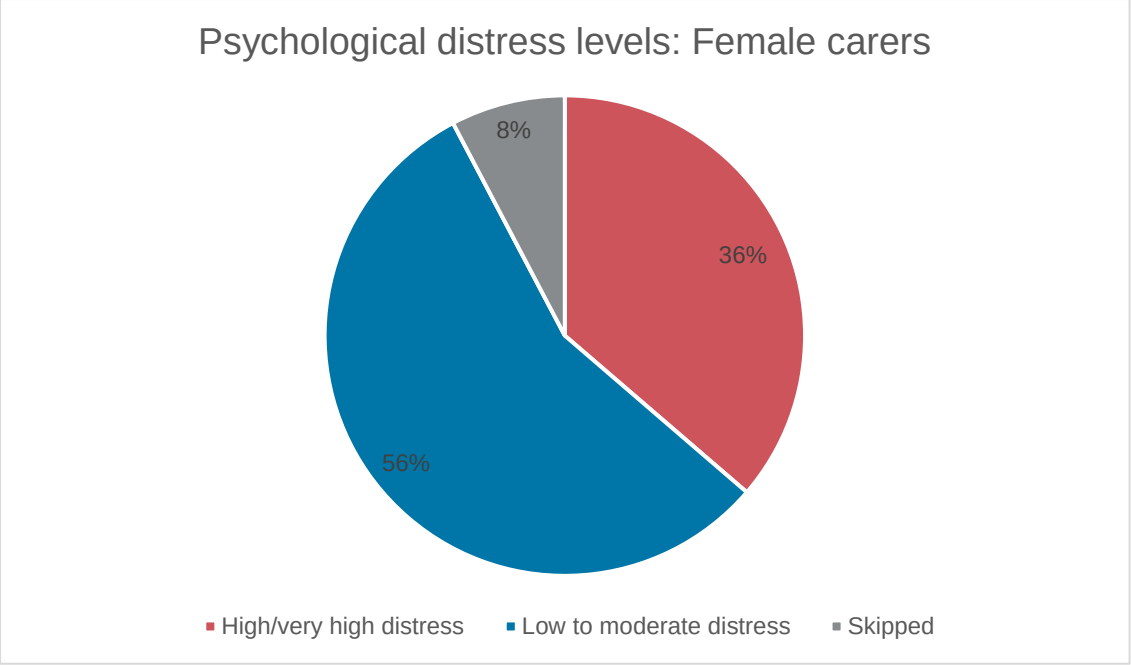

Figure 22: K-5 for female carers

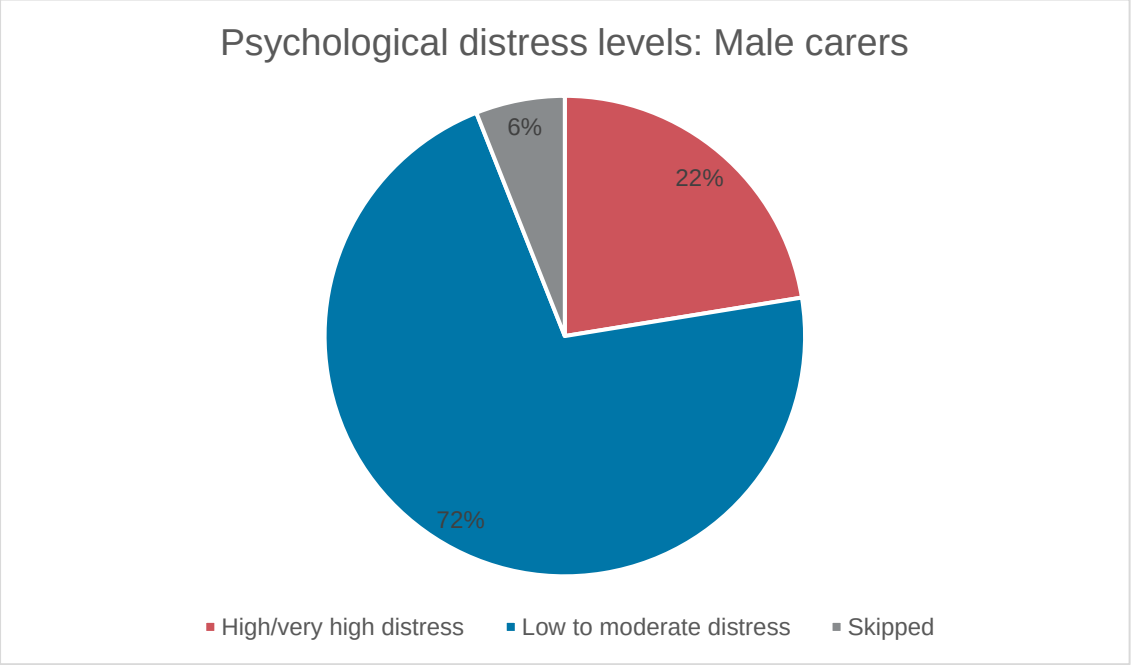

Figure 23: K-5 for male carers

The survey used the Personal Wellbeing Index (PWI)[8] to evaluate carer wellbeing. The PWI was utilised in the 2020 National Carer Survey and has also been used in other carer surveys. The PWI asked carers to rate their satisfaction with the following items on a 0-10 rating scale, with 0 being not at all and 10 being completely satisfied.

- Your standard of living
- Your health
- What you are achieving in life
- Your personal relationships
- How safe you feel
- Feeling part of your community
- Your future security
- Your life overall

The overall average wellbeing level of Tasmanian carers was 63.9%, in comparison to the average wellbeing score of Australians in 2022 which was 74.4%.[9]

When examining the results of overall satisfaction with life as a whole, 6.48 out of 10 was the mean score for satisfaction of carers.

Despite the negative impacts that caring responsibilities can have on personal wellbeing, there are certainly positive aspects of caring for others, as well as protective factors that can help reduce negative impacts on carers.

Carer quotes:

"I feel confident that I know where to go to get help."

"It can be a difficult, stressful, and lonely emotional roller coaster. I am sustained by a little sign we display "Where there is love, nothing is too much trouble, and there is always time."

[8] International Wellbeing Group (2013). Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University http://www.acqol.com.au/instruments#measures

[9] Crowe, M., Capic, T., Singh, M., Greenwood, C., Frykberg, G., Khor, S., Cummins, R.A., Fuller-Tyszkiewicz, M., Olsson, C.A., Hutchinson, D., Lycett, K. (2023). Australian Unity Wellbeing Index – Survey 39 Report. Australians' subjective wellbeing in 2022: Climate change, mental distress, mood and social connection. Geelong: Australian Centre on Quality of Life, School of Psychology, Deakin University. http://www.acqol.com.au/projects#reports.

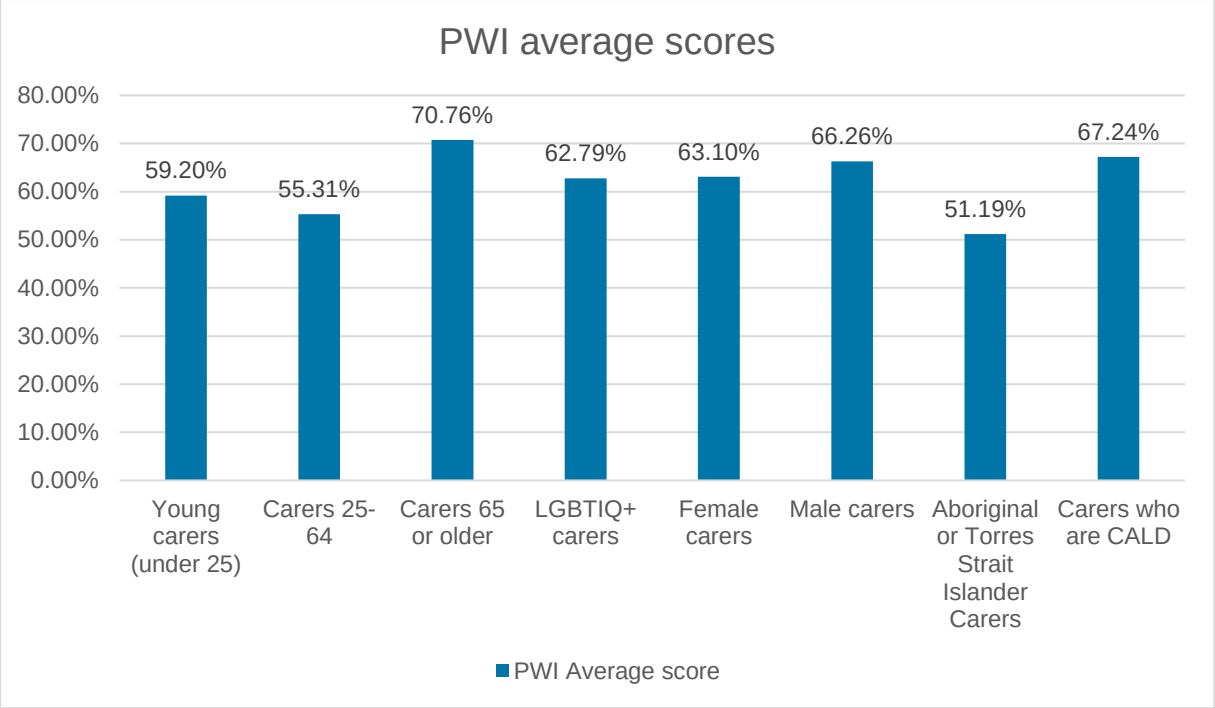

Figure 24: PWI average scores for different carer groups

Overall, carers who identified as Aboriginal or Torres Strait Islander had the lowest levels of wellbeing (51.19%) amongst all carer cohorts.

We know that regardless of their caring responsibilities, many carers have their own health concerns or disability. The survey asked carers some questions about their health.

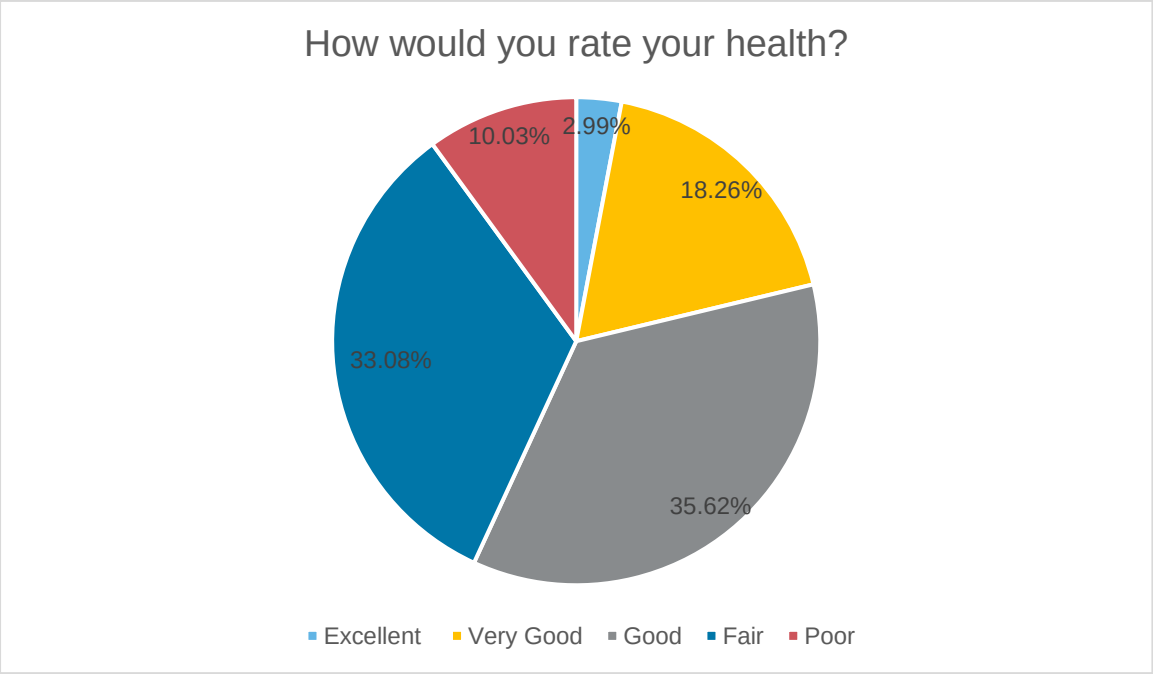

Figure 25: Carer health self-ratings

Most carers rated their health as being good (35.62%) and 33.08% as fair. Only a small proportion (2.99%) indicated they had excellent health and 18.26% reported their health as very good. Unfortunately, 10.03% said their health was poor.

The next question explored this further, asking *"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?"*

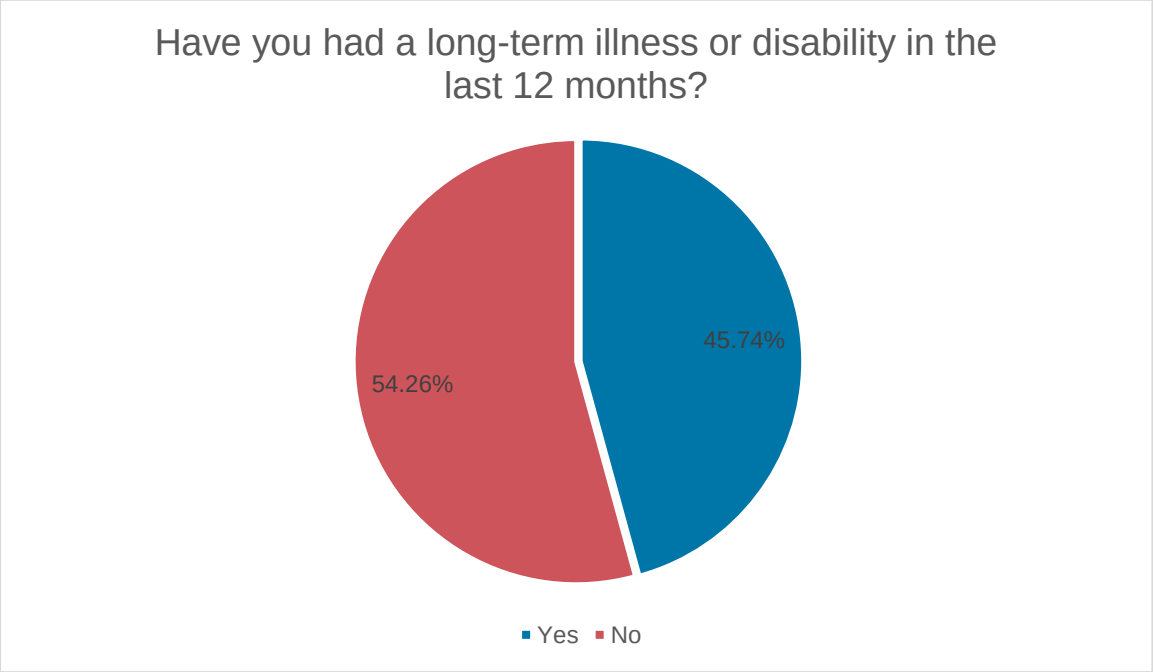

Figure 26: Own significant health concern or disability in the last 12 months

Other quotes from carers:

"I see much value in what I do and the impact I'm having on the life of the one I care for. I like being her carer and appreciate all the help we receive from services and our community. It is, however, the hardest thing I've ever done and requires me to give more than I have sometimes. The cost required to be a carer isn't necessarily financial in our situation, but it is taken from every other area of my life, which I pay by choice, however more support is needed for me, and for carers in roles like mine, to be able to do this for the long term."

"My carers organisation has been of wonderful support to me in my caring role, I find this service very beneficial."

"I love my son unconditionally even with all his little quirks, I worry every day of what will happen to him when I fall off the perch, who will care for him as I have done over the years without selfishness."

6. Conclusion

This report has provided an overview of the Tasmanian results from the 2022 National Carer Survey, sharing some of the insights, challenges and needs experienced by Tasmanian carers. It builds upon the findings from the 2020 National Carer Survey.

The results of both the 2020 and 2022 National Carer Surveys will be used to advocate for improved support and rights for Australian carers.

Carers Tasmania is grateful for the opportunity to be involved in this important work and looks forward to the 2024 National Carer Survey.