Carers NSW Australia

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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

2020 National Carer Survey

Summary Report

ABOUT CARERS NSW

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

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

www.carersnsw.org.au
https://twitter.com/CarersNSW
https://www.facebook.com/carersnewsouthwales/

ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across Australia, there are approximately 2.65 million informal carers, around 10.8% of the population; 861,600 primary carers and 1.79 million non-primary carers (ABS 2019a).

This report was prepared by the Carers NSW Policy and Research team in October 2020 in partnership with the National Carer Network.

For more information contact:

Carers NSW Australia
02 9280 4744
contact@carersnsw.org.au

Carers TAS Australia
1800 422 737
intake@carerstasmania.org

Carers SA Australia
1800 422 737
info@carerssa.com.au

Carers VIC Australia
1800 514 845
reception@carersvictoria.org.au

Carers Australia ACT
02 6296 9900
carers@carersact.org.au

Carers QLD Australia
07 3900 8100
info@carersqld.com.au

Carers WA
1300 227 377
info@carerswa.asn.au

Carers NT Australia
1800 422 737
carersnt@carersnt.asn.au

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Contents

List of figures

List of tables

List of abbreviations

%SM	Percentage of Scale Maximum
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
Auslan	Australian Sign Language
CALD	Culturally and Linguistically Diverse
FS	Hawthorne Friendship Scale
GP	General Practitioner
IWB	International Wellbeing Group
K5	Kessler Psychological Distress Scale (5 items)
K10	Kessler Psychological Distress Scale (10 items)
LGBTQI+	Lesbian, gay, bisexual, transgender, queer, intersex and other sexuality, sex and gender diverse
LOTE	Language other than English
N	Number of respondents
NDIS	National Disability Insurance Scheme
NSW	New South Wales
NT	Northern Territory
PWI	Personal Wellbeing Index
QLD	Queensland
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers
SPSS	Statistical Package for the Social Sciences
TAS	Tasmania
VIC	Victoria
WA	Western Australia

Foreword

Carers NSW has a long history of conducting surveys to better understand the needs and experiences of carers across New South Wales. The results from the biennial Carers NSW Carer Survey are central in informing Carers NSW service design and delivery, our systemic advocacy to the NSW and Australian governments and our involvement in further research.

This year Carers NSW partnered with each of the state and territory Carer Associations to deliver the Carer Survey nationally for the first time. Conducted during the height of COVID-19 lockdown across the country, and concurrent with the launch of the new in-person services under the Carer Gateway, the 2020 National Carer Survey provides critical insights into the lives of Australia's carers in 2020.

In time for National Carers Week, I am pleased to present the Carers NSW *2020 National Carer Survey: Summary report,* which provides an overview of high-level national findings from the Survey with some state and territory comparisons highlighted throughout.

This report comes at a critical time, with new carer support services on offer across the country, ongoing Royal Commissions into aged care and disability services highlighting key gaps for carers, and the ongoing COVID-19 crisis presenting key challenges and opportunities for Australia's carers and the organisations and service systems that support them.

I hope this report improves both the care services sector's and the community's understanding and appreciation of the vast contribution carers make to our society and economy, and most importantly, to the people they care for. The considerable rates of psychological distress, social isolation and financial hardship reported, and the many experiences of exclusion from service planning, should also serve to motivate those of us providing services to carers to better respond to their needs.

I would like to extend a special thank you to the National Carer Network for their support in delivering the first National Carer Survey, in particular Carers South Australia, Carers Victoria and Carers Tasmania, who assisted closely with the Survey design and development. I would also like to thank the other members of the 2020 National Carer Survey Reference Committee, who are listed by name in the report, for their invaluable input and expertise. Thank you also to the NSW Department of Communities and Justice for funding this important piece of work, and to the Macquarie University Faculty of Arts Human Research Ethics Committee for providing ethical approval.

Carers NSW also wishes to acknowledge Dr Lukas Hofstaetter and Sarah Judd-Lam for leading the design and delivery of the 2020 National Carer Survey and in producing this report. Thank you also to Dr Isaac Addo, Emma Wishart, Kate Lawrence, Andy Currums, Melissa Docker, Madeleine Gearside and Grace Cherrington for their support with Survey promotion, data entry and data analysis.

Finally, and most importantly, I would like to acknowledge and thank every carer who took the time to participate in the 2020 National Carer Survey. We value your time and are grateful for your openness in sharing your views and experiences with us, especially during such a challenging year. The information you have provided will help Carers NSW and the National Carer Network provide and advocate for better support for all carers.

Elena Katrakis
CEO
Carers NSW
October 2020

Executive summary

The biennial Carers NSW Carer Survey, funded by the NSW Department of Communities and Justice, 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. In 2020 the Carer Survey was conducted nationally for the first time, with the support of the National Carer Network.

The 2020 National Carer Survey builds on the successes of the previous Carer Surveys by expanding the evidence base regarding carers' experiences and support needs, with its new national scope presenting additional opportunities to better understand and support all carers.

The Carers NSW *2020 National Carer Survey: Summary report* provides an overview of high-level national findings from the Survey regarding caring relationships, carers' experiences accessing services, carer health and wellbeing, and carer employment. Some state and territory comparisons are highlighted throughout to indicate national variation, with further comparative analysis between the states and territories and between various cohorts of carers to be completed in future.

The 2020 National Carer Survey received a total of 7,735 valid responses from carers in every state and territory of Australia, with particularly high response rates among carers in South Australia, New South Wales, Victoria and Tasmania. More than 1,300 carers (17.7%) completed and returned a paper copy of the Survey, with the remaining majority completing the Survey online. The Survey was promoted through the state and territory Carer Associations' member and client networks, as well as key stakeholder and sector contacts, and some paid advertising was conducted to reach carers who were not currently connected to carer services.

Carers were able to complete the Survey between April and June 2020, when many Australians were in lockdown due to government Coronavirus (COVID-19) restrictions. Data collection also coincided with the commencement of in-person services under the new national Carer Gateway from April 2020. The timing of the Survey has therefore enabled Carers NSW and the National Carer Network to obtain a critical snapshot of carers' lives during an unprecedented national crisis and in the early stages of significant carer support reforms.

Of the 7,735 Survey respondents, 92.8% were current carers and 7.2% were former carers. Most respondents (93.2%) were primary carers, those individuals providing the most support to the person(s) they care for. More females (81.7%) than males (17.7%) responded to the Survey, reflecting the larger proportion of primary carers in the overall population who are female. The mean age of respondents was 58.3 years, with the eldest Survey respondent being 94 years of age.

Respondents were most likely to care for their child, including adult children (45.1%), and/or partner (37.0%) and one in four respondents (25.9%) cared for more than one person. The most common group of people being cared for by survey respondents were people with physical disability (36.1%), followed by people with a chronic condition (29.2%) and people living with a mental illness (26.4%).

In line with previous Carers NSW Carer Surveys, this sample cannot be considered representative of the broader Australian carer population of 2.65 million, which limits the generalisability of the findings presented. However, a wide range of caring experiences were evident across the sample, including relatively strong representation from diverse cohorts of carers. Among Survey respondents were 108 young carers aged 25 years and under, 142 Aboriginal and/or Torres Strait Islander carers, 196 LGBTQI+[1] carers and 340 culturally and linguistically diverse (CALD) carers..

The findings presented in this summary report raise important implications for governments, service providers, employers and the broader community at a time of considerable challenge and change for carers across Australia. 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, the other state and territory Carer Associations and our key partners and stakeholders.

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

2020 National Carer Survey: Key findings

- The typical respondent was a female primary carer of working age with a high school education, not participating in paid employment.
- The typical person being cared for was an adult son with physical disability who is not able to be left alone for more than a few hours.
- Most respondents provided 40 or more hours of care per week, and more than half had been caring for 20 years or more.
- Nearly half of the carers who responded were experiencing high or very high psychological distress, and one in three felt highly socially isolated.
- One in three respondents said they never get time out from their caring responsibilities, with only around half having enough time to keep on top of other responsibilities.
- It was relatively uncommon for carers to be asked about their own needs when accessing services or on behalf of the person they care for, and services were much less likely to meet carers' needs than the needs of the people being cared for.
- The most common challenges carers experienced when accessing services were getting information about what services are available, and the time and energy it took to organise services. Waiting periods to access services were also a common challenge.
- One in four carers reported spending more money than they made in the past 12 months.
- Exiting employment and reducing working hours were common impacts of caring on carers' career trajectories.

Methodology

Building on a tradition of carer surveys dating back to the 1976 *Dedication* report by the Council on the Ageing, which led to the organisation's establishment, Carers NSW has conducted a biennial survey of carers across NSW since 2002. Since 2014, the Carers NSW Carer Survey has been developed with the input of an expert reference committee made up of sector representatives and leading researchers in the field of caring, and has been conducted with university ethics approval.

In 2020 the Carer Survey was conducted nationally for the first time, with the support of the National Carer Network. The 2020 National Carer Survey builds on the successes of the previous Carer Surveys by expanding the evidence base regarding carers' experiences and support needs, with its new national scope presenting additional opportunities to better understand and support all carers.

Compared to prior Carer Surveys, the 2020 National Carer Survey has obtained a broader scope, achieved a considerably larger and more diverse sample, and has improved its inclusivity and the comparability of results over time. The overall structure and many of the key questions included in the Survey are consistent with the Carers NSW 2018 Carer Survey, however a number of expanded and additional questions were included to greater reflect the current context of caring and to capture new evidence in under-researched areas.

Following on from a successful qualitative sub-study conducted alongside the Carers NSW 2018 Carer Survey with hard-to-reach culturally and linguistically diverse (CALD) carers from emerging communities, young carers aged 25 years and under were identified as a priority group for additional data collection to complement Survey results. Twenty-eight young carers participated in online interviews and focus groups, with a full report published in July 2020 and available online at https://www.carersnsw.org.au/research.

Project oversight

The 2020 National Carer Survey was developed by the Carers NSW Research team in close collaboration with an expert Reference Committee. Dr Lukas Hofstaetter, Research and Development Officer, was listed as the Chief Investigator. The 2020 National Carer Survey Reference Committee was made up of leading carer researchers from four universities, representatives of the National Carer Network, NSW Government representatives, and carer representatives. The full membership list included:

As listed partner investigators:

- Associate Professor Hugh Bainbridge, UNSW Business School
- Ms Kirsten Baird-Bate, carer representative
- Dr Margaret Boulos, Carers Victoria
- Ms Dianne Brookes, carer representative
- Associate Professor Myra Hamilton, formerly of the Social Policy and Research Centre, UNSW Sydney, now with the Centre of Excellence in Population Ageing Research (CEPAR) at The University of Sydney
- Ms Sarah Judd-Lam, Manager Policy and Research, Carers NSW
- Dr Jack Lam, The University of Queensland Institute for Social Science Research (ISSR)
- Ms Marianne Lewis, Carers South Australia
- Associate Professor Kate O'Loughlin, The University of Sydney Charles Perkins Centre
- Dr Abner Poon, School of Social Sciences, UNSW Sydney
- Ms Cathy Thomson, Social Policy and Research Centre, UNSW Sydney
- Dr Melanie Zeppel, formerly Centre for Economic Impacts of Genomic Medicine, Macquarie University

As stakeholder representatives:

- Ms Karen Turvey, NSW Department of Communities and Justice
- Mr Tim Duck, NSW Ministry of Health
- Ms Isabella Dillon Savage, NSW Ministry of Health
- Mr David Brennan, Carers Tasmania
- Ms Teresa Delany, Carers Tasmania
- Ms Annie Hayward, formerly Carers Victoria
- Ms Anne Muldowney, formerly Carers Victoria

The qualitative young carer sub-study was guided by an additional Young Carer Project Advisory Group, comprising academics specialising in young carer research (including, but not limited to, representatives of the 2020 National Carer Survey Reference Committee), young carer representatives and Carers NSW staff. Members of this group are also listed below:

- Associate Professor Myra Hamilton, formerly of the Social Policy and Research Centre, UNSW Sydney, now with the Centre of Excellence in Population Ageing Research (CEPAR) at The University of Sydney
- Dr Abner Poon, School of Social Sciences, UNSW Sydney
- Dr Karen Hutchinson, Centre for Healthcare Resilience and Implementation Science, Macquarie University
- Ms Cathy Thomson, Social Policy and Research Centre, UNSW Sydney
- Ms Paula Gleeson, Centre for Carers Research, Institute for Public Policy and Governance, University of Technology, Sydney
- Alex Berger, former young carer
- Amanda Sharma, former young carer
- Sarah Judd-Lam, Carers NSW
- Sienna Aguilar, Carers NSW
- Natalie Steinhardt, Carers NSW

Survey instrument

The questions in the 2020 National Carer Survey focused on the following areas: the caring relationship (including information on the person cared for), the caring role, access to and experiences of services and supports, employment, health, wellbeing and social connectedness, and financial wellbeing. These focus areas were selected due to their relevance in relation to carers' needs, both nationally and internationally, and their importance for informing systemic advocacy and carer support services (see Woods and McCormick 2018, Yeandle et al. 2017).

The 2020 National Carer Survey questionnaire built on the framework established in previous Carer Surveys with an added section designed to better understand participants' caring roles. Changes to the questionnaire were included following in-depth consultation with the Reference Committee and reflect recent developments in the service landscape, as well as up-to-date, best practice approaches to research with carers. Added questions have been carefully designed in order to generate new information to address identified gaps in the literature and current policy challenges.

The questionnaire was structured as follows, with a complete copy of the paper version included in Appendix A.

- Screening questions
- Section 1: The caring relationship
- Section 2: Your caring role
- Section 3: Services and support
- Section 4: Paid work
- Section 5: Your health and wellbeing
- Section 6: About you

To improve the future comparability over time, the 2020 National Carer Survey provided all respondents with the option to register to participate in the 2022 National Carer Survey by providing their contact details (name, email, and/or postal address). The registration for this follow-up study was entirely voluntary, and participation in the Survey was possible without the provision of personal details, in order to preserve anonymity. A total of 3,049 Survey respondents opted to be contacted directly for the next Survey in 2022, providing an unprecedented opportunity for Carers NSW to directly track the experience of particular carers over time.

In addition to substantial input and review by the Reference Committee, the revised questionnaire was piloted with a total of 10 carers, including Carers NSW staff with caring responsibilities and Carers NSW Carer Representatives.[2] Feedback was used to further refine and finalise the questions.

Recruitment and data collection

Sampling for the Survey was based upon self-identification as someone who is, or has been, providing unpaid care. Participants were recruited through the websites and social media accounts of Carers NSW and the other state and territory Carer Associations and through their printed and email newsletters, as well as member and client databases and broader stakeholder networks. Media releases and paid social media promotion were also utilised to broaden the reach of the Survey beyond carers already in contact with carer services.

To maximise reach and inclusivity, the Survey was conducted using the online survey platform Survey Monkey as well as distributed paper copies. The paper version of the survey questionnaire (included in Appendix A) functioned as the blueprint for the online version. With the exception of the question ranking the effort required for care tasks (Question 22), where due to technical reasons a different rating score was used in the online version, variation between the survey versions are minimal.

The Survey was made available online using Survey Monkey from 1 April 2020 until 30 June 2020 to coincide with the distribution of paper surveys and reply paid envelopes by post to members of some state and territory Carer Associations. Public promotion of the Survey was, however, delayed until 1 May 2020 in order to avoid confusion with the launch of in-person Carer Gateway services across Australia from 6 April 2020. Promotion centred on the online version of the Survey, but paper copies were made available on request to individual carers, groups of carers and organisations supporting carers. Respondents were provided with the option of entering a prize draw to win one of eight iPads (one drawn for each state and territory) when completing the Survey.

In total, 11,872 paper questionnaires were distributed on request to organisations, support groups, at events, and to individuals. To homogenise the collected data and simplify the cleaning process, the data collected in returned paper surveys was manually entered by members of the Carers NSW Policy & Research team with the support of additional part time staff and a university intern. Data entry training was provided and was conducted through a dedicated copy of the online version of the Survey.

The final dataset was exported from Survey Monkey and cleaned, coded, and analysed using SPSS 22 statistical software. Further analysis will be undertaken and published in future by the Carers NSW Research team, National Carer Network and other members of the 2020 National Carer Survey Reference Committee.

Ethics approval

Ethics approval for the 2020 National Carer Survey was obtained from the Macquarie University Faculty of Arts Human Research Ethics Committee (ref. no. 52020623314360).

Participants were asked to complete a questionnaire by themselves, online or in print, about their experiences of caring for a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing. Participation in the survey was entirely voluntary and providing contact details was optional and only related to entering the prize draw or registering to participate in the 2022 follow up study.

Potential participants were fully informed of the nature and content of the survey, with particular emphasis on the anonymous and voluntary nature of participation. A copy of the Participant Information and Consent Form is included in Appendix B.

Completing the questionnaire took approximately 25 minutes and was not limited to a specific time or place. Respondents could withdraw at any point from the survey without consequences by not

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

completing/submitting the questionnaire. After having submitted a response, carers who had provided their contact details had the opportunity to request the deletion of their data.

For the qualitative young carer study, participants were recruited through established contacts with Carers NSW and by referral from other participants and supporting organisations. Participants were asked to take part in a focus group or individual (semi-structured) online interview about their experiences as a young carer.

Response

In total, 8,592 responses were received, including online and paper responses. Removing identifiable duplicates, out of scope responses and empty surveys reduced the final number of responses to 7,735.

Three screening questions were included at the beginning of the Survey to ensure that all respondents were living in Australia and are or were providing care for a family member, friend or neighbour who has a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who needs care due to ageing. A total of 534 respondents were excluded from completing the survey on the basis of their responses to these screening questions.[3] An additional 82 responses were excluded from analysis due to being submitted more than once, and 241 responses were excluded because they submitted an empty survey.

Of the final sample of 7,735 valid responses, 7,178 were current carers, and 557 former carers without a current caring role. 6,363 completed the online version and 1,372 completed the paper version. A detailed breakdown and comparison of response rates with the prior three Carers NSW Carer Surveys is included in Table 1.

Table 1. Response rate in comparison to the 2014, 2016, and 2018 Carer Surveys

	2020 Survey (Australia)		**2020 Survey, NSW sample**		**2018 NSW Survey**		**2016 NSW Survey**		**2014 NSW Survey**	
	N	%	N	%	N	%	N	%	N	%
Total responses	8,592	-	-	-	2,146	-	2,519	-	2,228	-
Valid responses	7,735	90	1,714	-	1,830	85	2,081	83	1,797	81
- **Online responses***	6,363	82	1,170	68	971	53	1,273	61	1,072	60
- **Paper responses***	1,372	18	544	32	859	47	808	39	723	40
- **Former carers***	557	7	125	7	124	7	657	32	146	6
- **Current carers***	7,178	93	1,589	93	1,706	93	1,958	94	1,684	94
- **Carer association members***	2,868	37	599	35	1,010	55	1,120	57	829	49

*Percentages are relative to valid responses.

While the total number of national responses in 2020 cannot be directly compared to 2018, 2016 and 2014, the proportions and the comparison of the NSW sample indicates that the rate of current carers who responded to the survey was similar to previous years. The NSW sample is of similar size to previous surveys, but the participation of Carers NSW members has declined over time. Only one third of the respondents (2,868 in total) were members of a state or territory Carer Association. While member engagement may be lower than anticipated, this result also shows that the recruitment of non-affiliated respondents was successful overall.

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[3] This included respondents who indicated that they had not cared for someone due to illness or disability (e.g. foster parents), who were paid care workers, and who were formal volunteers.

Limitations

Several limitations apply to the methodology outlined in this section. Most notably, due to the respondents self-selecting into the survey, the sample cannot be considered statistically representative, and caution should be used when generalising findings to the broader population of carers in Australia. The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC, see ABS 2019a) is the most reliable source of population level estimates regarding carers in Australia.

Given that a number of regular communication channels were utilised to engage members, clients and other stakeholders affiliated with the state and territory Carer Associations, the resulting sample is likely to over-represent primary carers, and carers who identify themselves as carers and already have contact with supports and services. Hidden carers, carers who are not in receipt of support, or carers who are socially isolated are much less likely to have responded to the survey. Due to response bias, it can be assumed that people with more pronounced experiences (positive or negative) were more likely to respond.

In the development phase, it was also identified that, due to the length of the questionnaire and the formal English required in order to elicit accurate responses, carers who lacked confidence in reading and writing in English were likely to be excluded.

Results

This section outlines the high-level national results from all six sections of the 2020 National Carer Survey, with some state and territory comparisons noted with reference to Appendix C. Further analysis examining the relationship between variables and comparing the results relating to specific cohorts of carers will be undertaken in future and reported in subsequent publications.

Respondent profile

Highlights

- The typical respondent was a female primary carer of working age with a high school education, but not participating in paid employment.
- A range of carers from different cultural backgrounds, of different sexualities, ages, and socioeconomic status responded to the survey.
- Respondents came from every state and territory in Australia, and from across urban, regional and remote areas.

Compared to the average carer in Australia, respondents to the 2020 National Carer Survey were more likely to be primary carers and more likely to be female, older, and have lower educational attainment. They were also less likely to be employed and more likely to have a disability. These key demographic differences must be considered when interpreting findings from other sections of the Survey.

Selected demographic characteristics comparing results from the Carers NSW 2020 National Carer Survey with population level estimates from the 2018 SDAC are summarised in Table 2.

Table 2. Demographic characteristics of sample, compared to ABS population estimates

		2020 National Carer Survey		**Population estimate (ABS 2019a)**
		N	Valid %	%
Total carers		7,735	-	(2.65 mil.)
Primary carer		6,485	93.2	32.5
Gender	Female	4,727	81.7	57.3
	Male	1,024	17.7	42.7
	Non-binary/other	15	0.3	Not provided
Age	Mean (years)	58.3		51.2
	Up to 24 years	103	1.8	7.0
	25 to 64 years	3,554	61.9	56.0
	65+ years	2,086	36.3	34.0
Education	Bachelor or higher	1,892	17.5	25.6
	Certificate/diploma	2,034	14.0	34.3
	High school	805	35.4	11.9
	< High school	1,007	33.0	28.0
Employment	Employed	2205	35.8	53.7
	Unemployed	527	8.6	3.3
	Not in labour force	3430	55.7	42.9
Disability*		1944	34.2	32.1

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

Table 3 presents demographic characteristics showing the diversity of respondents in the 2020 National Carer Survey. Most carers who responded to the Survey identified as Australian, and spoke only English, however 4.4% of respondents were identified as being of a culturally or linguistically diverse (CALD) background[4]. After Australian, the five most commonly identified cultural backgrounds were; English/British (4.2%), Italian (1.7%), Greek (0.7%), Chinese, Indian, New Zealand, and German (each 0.5%). The five most common languages other than English (LOTE) spoken at home were Italian, Greek, German, and Auslan. With regard to sexuality, 2.7% of carers identified as bisexual, lesbian, gay, homosexual, queer, or non-binary.

Table 3. Demographic characteristics showing respondent diversity

		N	**Valid %**
Cultural background	Australian/Australian and other	4,351	77.4
Aboriginal and/or Torres Strait Islander status	Aboriginal and/or Torres Strait Islander	142	2.0
LOTE		545	9.4
CALD		340	4.4
Sexuality	Lesbian, gay, or homosexual Straight or heterosexual Bisexual Queer Different identity*	196	2.7
Remoteness Area	Major Cities	2,943	51.7
	Inner Regional	1,825	32.1
	Outer Regional	804	14.1
	Remote or Very Remote	122	2.1
State or territory	Australian Capital Territory	136	1.8
	New South Wales	1,714	22.2
	Northern Territory	109	1.4
	Queensland	886	11.5
	South Australia	2,255	29.2
	Tasmania	1,024	13.2
	Victoria	1,337	17.3
	Western Australia	274	3.5

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

The geographic distribution of respondents correlates well with the overall distribution of the Australian population. Following the remoteness classification of the Australian Bureau of Statistics (ABS 2016), 51.7% of survey participants providing a postcode lived in Major cities, 32.1% in Inner Regional areas, 14.1% in Outer Regional areas, and 2.1% lived in Remote or Very Remote areas. Slightly less representative is the distribution of respondents by state or territory. Most responses were received from South Australia, followed by carers from New South Wales and Victoria. Figure 1 displays the distribution of Survey respondents by Statistical Area 3 regions (SA3, see ABS 2016).

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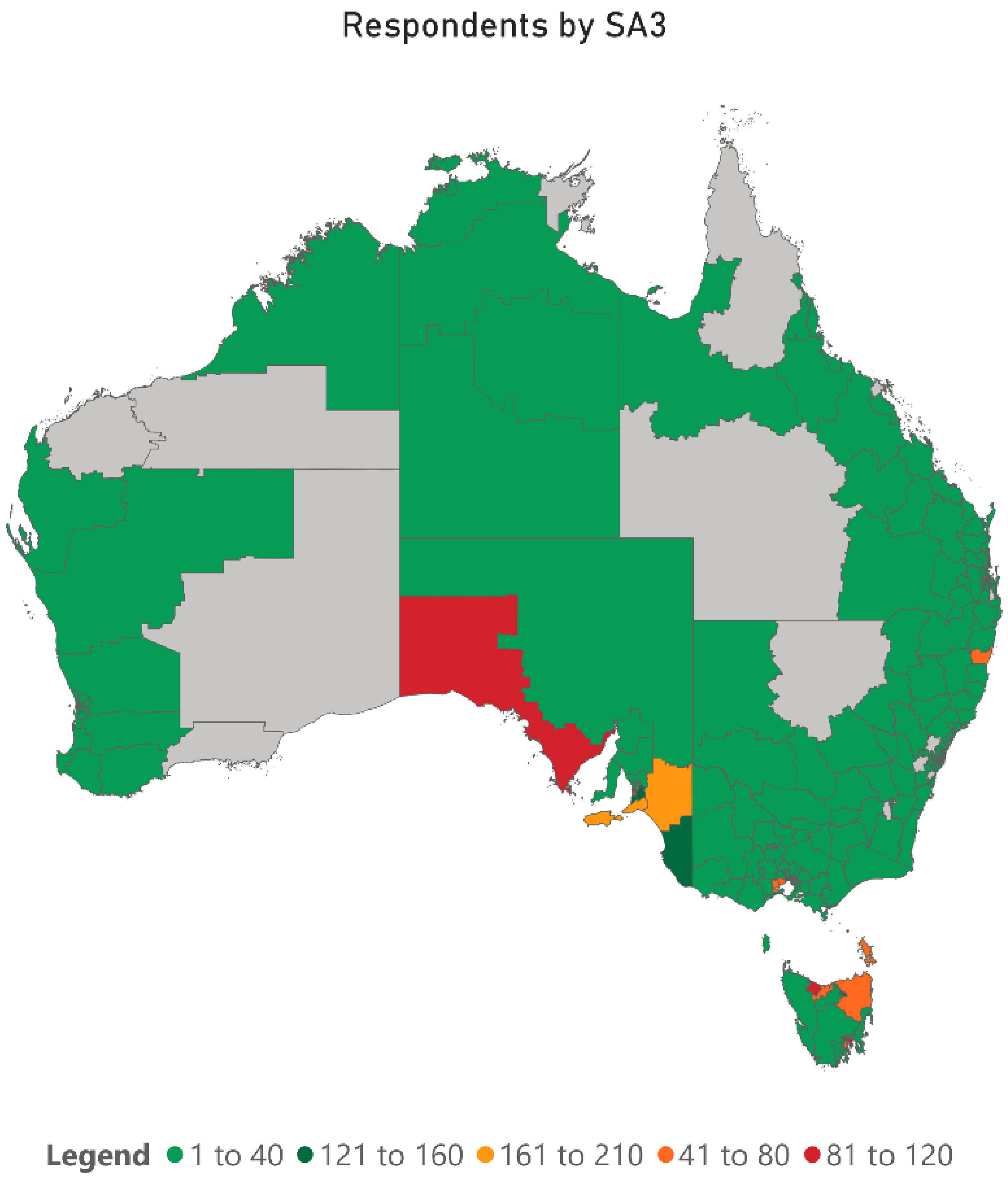
[4] CALD respondents were defined as carers who identified with cultural backgrounds not associated with main English-speaking countries (Australia, United Kingdom, Republic of Ireland, New Zealand, Canada, United States of America and South Africa), ***AND*** spoke a language other than English (including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

Figure 1. Geographic distribution of respondents by SA3 region



The caring relationship

Highlights

- Most respondents were caring for one person with no assistance from other family members or friends. One in four were caring for more than one person.
- Survey respondents were most likely to be caring for their child (including adult children), or caring for their partner.
- The most common group of people being cared for by respondents were people with physical disability, followed by people with a chronic condition and people living with a mental illness.
- The typical person being cared for was an adult son with physical disability who is not able to be left alone for more than a few hours.
- Most respondents provided 40 or more hours of care per week, and more than half had been caring for 20 years or more.

A total of 7% of respondents indicated they were not currently caring, but had in the past. The 93% of respondents who identified as a current carer reported caring for a combined total of 9,727 people – an average of 1.36 per carer. Half of all carers were the sole carer and did not receive any assistance from other family members or friends (50.1%) (**Error! Reference source not found.**).

Table 4. Characteristics of the caring relationship

		%
Carer status (N=7,735)	Current	7.2
	Former	92.8
Care arrangements (N=6,959)	I am the only one who provides care	50.1
	I provide the most care, but others help with care sometimes	43.1
	Someone else provides the most care, but I help with care sometimes	6.8
Number of persons being cared for (N=7,175)	One	74.1
	Two	18.8
	Three or more	7.1

The ages of people being cared for by Survey respondents ranged from less than 1 year old to over 100 years old, but were most likely to be aged 65 years or older. Most persons who are cared for were male (55.3%), 43.8% female, and 0.5% Non-binary. Carers were most commonly caring for their child (including adult children) (45.1%), spouses/partners (37.0%), and parents/parents in law (22.8%). Key demographic characteristics of the persons cared for are summarised in Table 5.

Table 5. Demographic characteristics of persons being cared for

		%
Gender (N=9,057)	Female	43.8
	Male	55.3
	Non-binary	0.5
Age (N=8,963)	0-19 years	27.4
	20-64 years	33.1
	65+ years	39.5
Relationship to person card for (N=7,859)	Caring for a parent/parent in law	22.8
	Caring for a partner	37.0
	Caring for a child	45.1
	Caring for a sibling	4.7

Respondents were asked to identify the conditions, disabilities, or illnesses for which the people they were caring for needed their care. Respondents were most likely to provide care for someone with physical disability (36.1%), a chronic health condition (29.2%), or mental illness (26.4%) (Table 6). Most people being cared for by respondents could not be left alone for more than a few hours (71.9%), and 24% could not be left alone at all (Table 7).

Table 6. Conditions of persons being cared for

Condition (N=7,735)	%
Caring for someone with a physical disability	36.1
Caring for someone with a chronic condition	29.2
Caring for someone with a mental illness	26.4
Caring for someone with autism	24.9
Caring for someone frail	24.7
Caring for someone with an intellectual disability	23.4
Caring for someone with sensory impairment	17.8
Caring for someone with dementia	16.7
Caring for someone with a neurological condition	15.0
Caring for someone with a brain injury	9.3
Caring for someone with a terminal illness	5.9
Caring for someone with addiction	4.1

Table 7. Length of time main person being cared for can be left alone

How long main person being cared for can be left alone (N=7,735)	%
Not at all	24.0
Less than 1 hour	13.3
Few hours	34.6
One day	11.3
Few days	10.2
More than a few days	6.5
Less than 1 hour	13.3

The majority of carers (59.1%) reported that they spent 40 or more hours per week providing care to the main person cared for. Table 8 compares the hours of care primary carers provide, showing that the primary carers responding to the 2020 National Carer Survey were more likely to be providing a significant amount of care than the primary carers captured by the 2018 SDAC.[7]

Table 8. Average hours of care provided per week, SDAC 2018, 2020 National Carer Survey

Average hours of care provided	Carer Survey (n=6343), %	SDAC 2018 (ABS 2019a), %
Less than 20 hours	22.0	43.7
20–39 hours	18.9	18.4
40 hours or more	59.1	33.2

The number of years respondents had been caring for the person(s) they cared for ranged from less than one year through to 70 years, with the mean being 12.8 years. Significantly, more than half of the carers who responded to the 2020 National Carer Survey (54.4%) had been caring for over 20 years. Similar to the hours of care provided, primary carers responding to the 2020 National Carer Survey had a significantly longer duration of care compared to the primary carers captured by the 2018 SDAC (Table 9).

Table 9. Duration of care provided, SDAC 2018, 2020 National Carer Survey

Years of care provided	Carer Survey (n=6585), %	SDAC 2018, (ABS 2019a), %
Less than 2	10.2	13
2–4	12.7	25.1
5–9	22.7	23.7
10–24	40.6	29
25 or more	13.8	6.7

For further details on state and territory data, please see Appendix C.

Services and support

Highlights

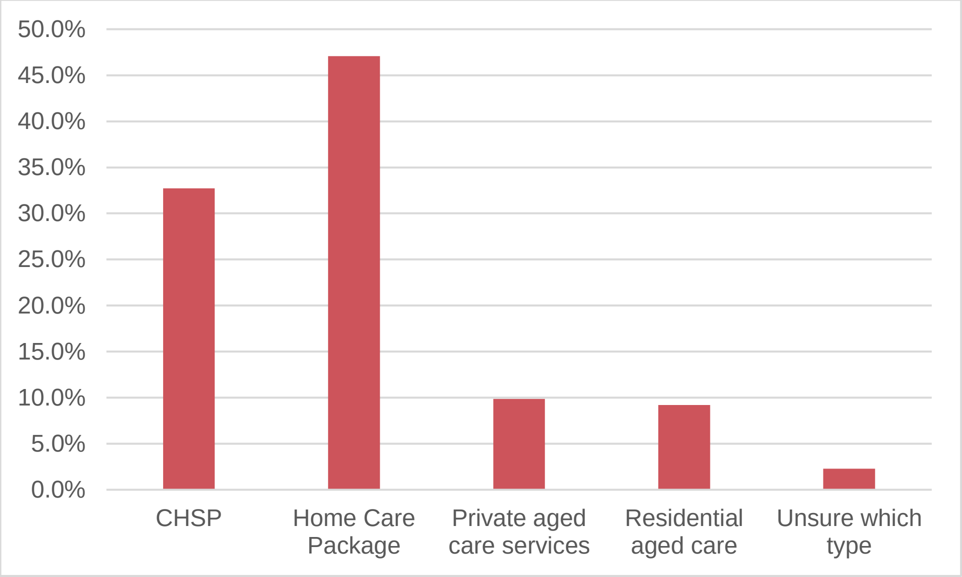
- 2,477 respondents were caring for someone using aged care services and 2,615 respondents were caring for an NDIS participant.
- Aged care and NDIS services were much less likely to meet carers' needs than the needs of the people they were caring for.
- The mental health services most commonly used by people being cared for were private psychologists and psychiatrists.
- Respondents found accessing information about aged care, disability, mental health and carer support services difficult, and coordinating those services complex and time consuming.
- Waiting periods to access services or assessment were a common challenge across all service types.
- Carers were particularly unlikely to be asked about their own needs when accompanying the person they care for to the GP, a hospital, or community service.
- Most respondents had heard of the Carer Gateway, but only a small proportion had accessed it at the time of completing the Survey.
- Carers reported having limited time away from the caring role, and most are constantly thinking about their caring responsibilities when undertaking other activities.

Aged care services

Respondents were asked whether anyone they currently care for uses aged care services, which are services designed for people over the age of 65 years (or over the age of 50 years for Aboriginal and Torres Strait Islander Australians), funded by government or purchased privately. Nearly half (49.1%) of respondents indicated that someone they were caring for was accessing aged care services of some kind, while a further 2.9% indicated that someone they were caring for needed aged care services but could not access them.

Of the 2,447 respondents caring for someone using aged care services, 39.2% reported that the person had a Home Care Package, a government funded package of support that enables the purchase of aged care services such as personal care or respite. A further 27.3% were accessing entry-level aged care services subsidised by the Commonwealth Home Support Program (CHSP), such as cleaning, community transport, or basic in-home support. Fewer than one in ten respondents indicated that the older people they were caring for were accessing private aged care services (8.2%) or living in residential aged care (7.7%) (see Figure 2).

Figure 2. Type of aged care services used



N=2,447

Information and service coordination

Carers of people using aged care services were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves and the person they care for. Around half (50.6%) had been provided with all the information they needed, while one in four (24.3%) disagreed with this statement. Just under half (49.0%) indicated that aged care services were easy to organise, with more than one in four (28%) disagreeing that this was the case (see Figure 3).

These findings indicate that a reasonably large proportion of carers are resourced and supported to access the aged care services they need; however, a significant minority require more information and support with accessing services.

Service quality and appropriateness

Most carers reported that the aged care services accessed met the needs of the person they care for (62.6%) and met their own expectations of quality and safety (66.3%). Relatively low proportions of respondents (16.9% and 13.0%) disagreed. However, fewer than half of the carers responding to this question (46.1%) agreed that the same services met their own needs as a carer, e.g. were available when they were not able to care, with more than one in four carers (26.1%) disagreeing (see Figure 3).

This indicates that, while aged care services are generally providing quality, appropriate services to older people, those services are not necessarily taking into account carers' needs, and greater flexibility and carer-inclusiveness is required.

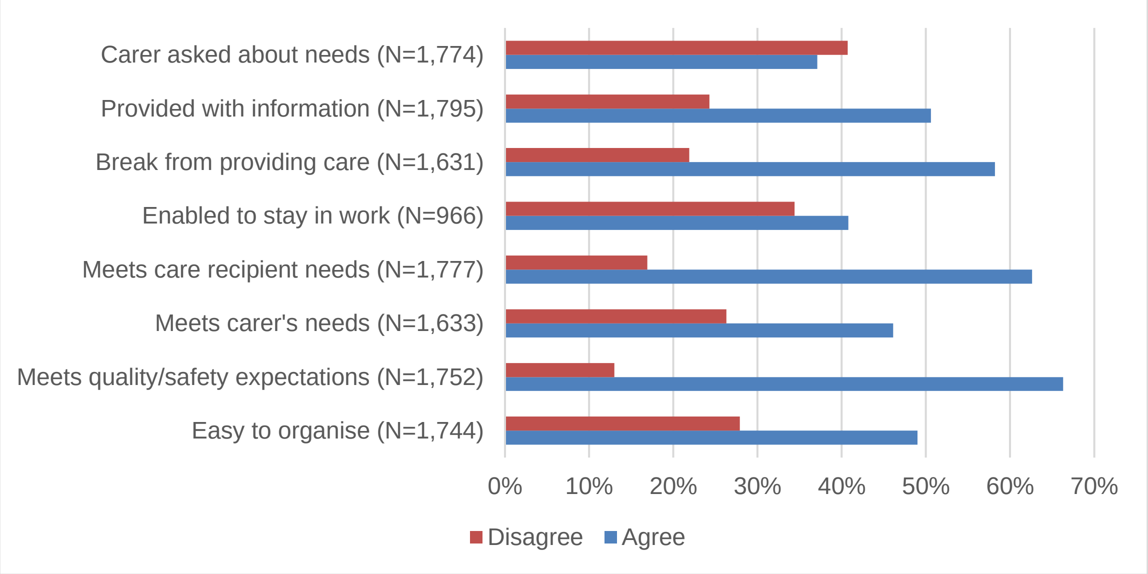
Carer inclusion and support

Meeting carers' needs requires eliciting and understanding those needs. However, only 37.1% of carers agreed that they had been asked about their own needs when the person they care for was accessing aged care services. A further 41% disagreed that this had occurred (see Figure 3).

Positively, the majority of carers did report indirect benefits of aged care services to their own situation, with 58.2% indicating that services enabled them to take a break from the caring role. One in five (21.9%) did not find this to be the case. While not all respondents were employed or seeking to be employed, a large proportion (40.8%) indicated that the aged care services provided to the person they care for had enabled them to keep their job or go back to work. However, just over one in three (34.4%) disagreed.

These findings indicate that many carers do not have the opportunity to convey their own needs in the context of service planning and delivery in the aged care sector, however that does not necessarily stop them from benefiting from these services as carers.

Figure 3. Carer experiences and perceptions of aged care services



Challenges accessing aged care services

All respondents caring for someone who was accessing, or who needed to access, aged care services were asked whether they or the person they cared for had experienced any of a range of commonly identified challenges when seeking to access aged care services. Nationally the five most common issues reported were:

- There was a long waiting period to access services (30.4%)
- It was difficult to find information about what services were available and how to access them (26.8%)
- It took too much time and energy to organise services (22.5%)
- There was a long waiting period to get assessed (21.1%)
- The person being cared for did not want to use services (21.0%)

For state and territory comparisons, please see Appendix C.

Disability services

Respondents were asked whether they were caring for someone who received support through the National Disability Insurance Scheme (NDIS), which provides government funded services to people under the age of 65 years who have a significant and permanent disability. A total of 2,615 respondents (44.1%) to that question reported caring for someone who has an NDIS plan (known as an ‘NDIS participant’), while another 6.7% indicated that the person they care for needs NDIS support but does not receive it. A further 1.8% reported accessing disability services outside the NDIS.

Information and service coordination

Carers of NDIS participants were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves and the person they care for. A very similar proportion agreed that they were provided with the information they needed by the local area coordinator or NDIS planner (37.2%) as disagreed with this (36.8%), suggesting a degree of inconsistency in service experience. One in three carers of NDIS participants (33.5%) agreed that the supports included in the NDIS plan were easy to organise, while 40.5% disagreed (see Figure 4).

Service quality and appropriateness

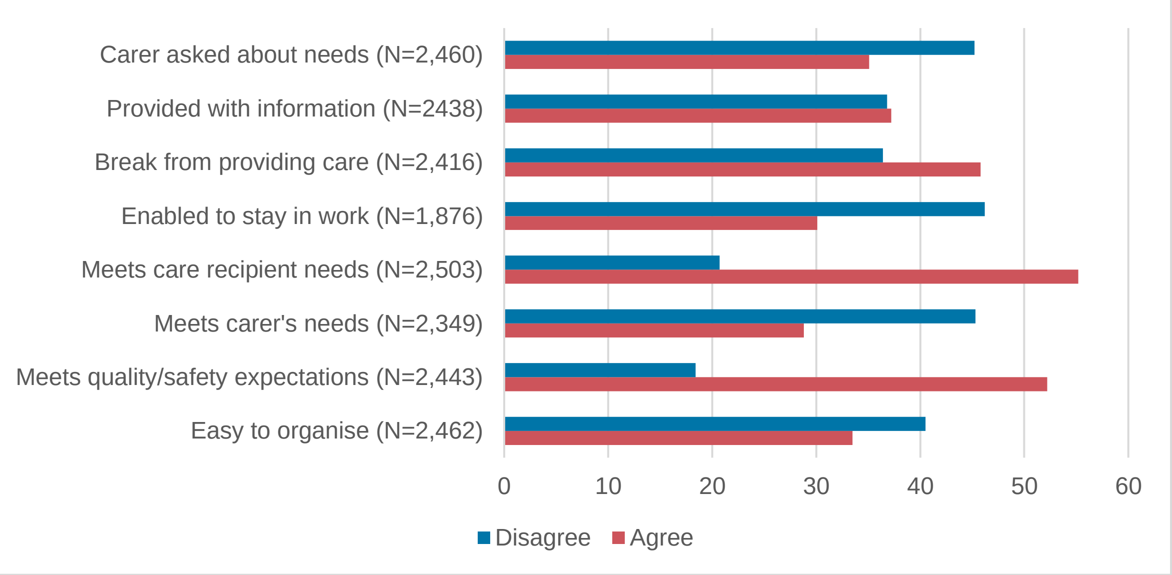
More than half (55.2%) of carers of NDIS participants indicated that the supports provided met the needs of the person they care for, with one in five (20.7%) disagreeing that this was the case. Again, just over half (52.2%) agreed that those support met their expectations of quality and safety, with fewer than one in five (18.4%) disagreeing (see Figure 4).

Supports provided under the NDIS plan were much less likely to meet the needs of the carers themselves, at 28.8% agreement, with 45.3% of carers disagreeing that their needs were met. The considerable difference between the capacity of NDIS supports to meet the needs of carers compared to the person cared for reflects the person-centred approach of the NDIS, but also indicates that carers needs should be taken into account more often (see Figure 4).

Carer inclusion and support

Despite a relatively low rate of carer inclusion by local area coordinators and NDIS planners, a reasonably high proportion (45.8%) of carers indicated that NDIS supports enabled them to take a break from the caring role. However, more than one in three (36.4%) disagreed that this was the case. Fewer than one in three carers (30.1%) reported that NDIS supports had enabled them to stay in, or return to work, with nearly half (46.2%) disagreeing. These findings suggest considerable variation between individual NDIS plan outcomes.

Figure 4. Carer experiences and perceptions of the NDIS



Challenges accessing disability services

Carers of NDIS participants were asked whether they or the person they care for had experienced any of a range of common challenges in attempting to access NDIS services. The five most commonly reported challenges were as follows:

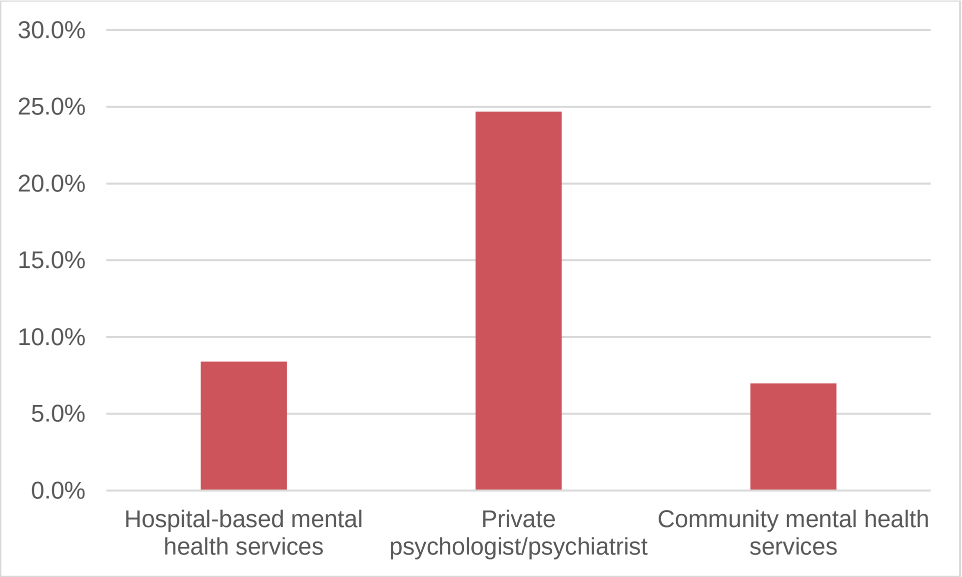
- It was difficult to find information about what services were available and how to access them (36.1%)
- It took too much time and energy to organise the services (32.9%)
- The person being cared for did not receive enough funding in their NDIS plan (28.2%)
- There was a long waiting period to access services (27.2%)
- There was a long waiting period to get assessed (23.0%)

For state and territory comparisons, please see Appendix C.

Mental health services

Respondents were asked whether they cared for someone who uses mental health services, including government funded community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health or living with a mental illness. Approximately one in four respondents (24.7%) was caring for someone who was accessing a private psychologist or psychiatrist, however hospital-based mental health services were much less utilised by respondents (8.4%), as were community mental health services (7.0%) (see Figure 5). A further 6.5% of respondents indicated that the person they care for was in need of mental health services but not able to access them.

Figure 5. Type of mental health services accessed



N=2,638

Information and service coordination

Carers of people accessing mental health services were asked to respond to a range of statements about the nature, quality and impacts of those services on themselves and the person they care for. Around one in three (33.4%) reported that they had been provided with all the information they needed when the person they cared for was accessing mental health services, while 42.6% disagreed that this had been the case (see Figure 6).

It was relatively common for respondents to report that mental health services were easy to organise (39.7%), however a similar proportion of carers, and still more than one in three (35.5%), disagreed with this statement, suggesting considerable variation between individual situations. Further analysis will examine whether factors such as the types of mental health services accessed and the reported condition(s) and care needs of the person being cared for impacted this result.

Service quality and appropriateness

Nearly half of respondents (47.2%) indicated that mental health services met the needs of the person they cared for, with just over one in four (26.4%) disagreeing that this was the case. Approximately half (50.8%) indicated that those services also met their own expectations for quality and safety, with approximately one in five (22.4%) disagreeing (see Figure 6).

Mental health services were, however, very unlikely to meet the carer's needs, at only 15.0%, while the majority of respondents (59.2%) disagreed that their own needs were met. This may relate in part to the high proportion of respondents supporting someone who was accessing private psychology or psychiatry services which are generally delivered confidentially and one-on-one with the individual requiring support.

Carer inclusion and support

Carers were also unlikely to have been asked about their needs when mental health services were being provided, again possibly a result of the types of services being rated according to this criterion. One in four (26.4%) carers said they had been asked about their needs, while the majority (56.8%) had not (see Figure 6).

Mental health services, unlike the disability and aged care services reported on earlier, were unlikely to provide carers a break from the caring role or enable them to stay in, or return to work. Again, this is likely due in large part to the type of services which were most commonly accessed by the people being cared for, which are not designed to have this outcome. Whether or not other types of mental health services supported these outcomes will be explored in future analysis.

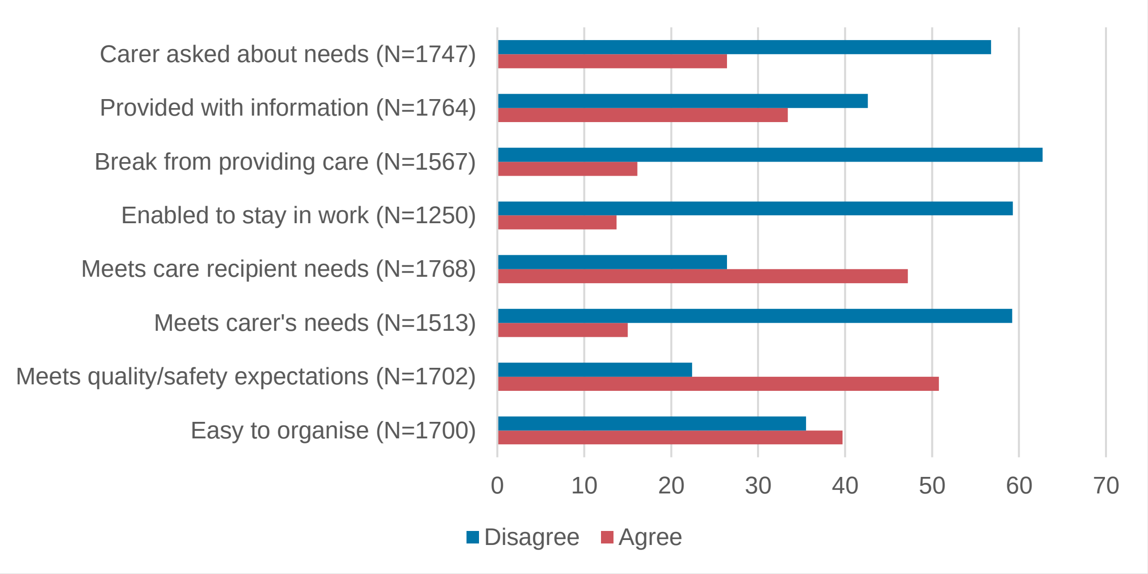
Challenges accessing mental health services

Carers of people accessing mental health services were asked whether they or the person they care for had experienced any of a range of commonly reported challenges when accessing mental health services. The most commonly reported challenges in response to this question were:

- There was a long waiting period to access services (32.9%)
- It was difficult to find information about what services were available and how to access them (28.7%)
- The cost of services (including co-payments) was too high (23.7%)
- The person being cared for did not want to use services (23.4%)
- It took too much time and energy to organise the services (21.4%)

Interestingly, while the challenges regarding finding information and organising services were similar to challenges carers experienced in other service sectors, the costs of services and resistance from the person being cared for were more prominent, again reflecting the nature of the mental health sector and the type of mental health services being reported.

Figure 6. Carers' experiences and perceptions of mental health services



For state and territory comparisons, please see Appendix C.

Health care services

All respondents were asked about the ways in which they are engaged and supported when the person they care for is accessing health care services, including a general practitioner (GP) or family doctor, community health service and services within a hospital.

Primary health care services

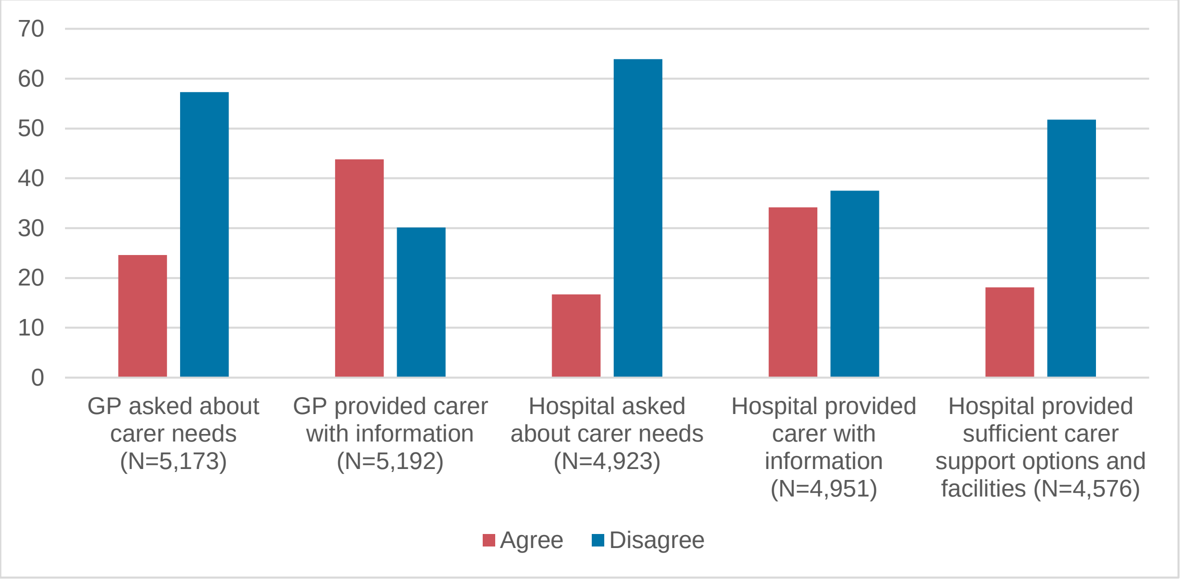
When accompanying the person they cared for to visit a GP, one in four respondents (24.6%) reported being asked about their own needs as a carer, with the majority (57.3%) disagreeing that this had occurred. However, GPs were much more likely to have provided carers with the information they needed, at 43.8%, with fewer than one in three (30.1%) disagreeing (see Figure 7). This indicates that GP practice varies, but there remains a missed opportunity in many cases for carers' needs to be identified when presenting with the person they care for.

Public health care services

Carers were even more likely to report being asked about their needs in a hospital or community health care setting (16.7%), where the majority (63.9%) disagreed that this occurred. Hospital and community health care settings were also less likely than primary health care settings to produce the information carers needed, with one in three carers (34.2%) reporting that they had received this information. A similar proportion (37.5%) disagreed that required information had been provided, suggesting variation in practice across individual situations. Variation in results according to the condition(s) and care needs of the person being cared for and the location of carers will be examined more closely in future analysis.

Carers were also asked about support options and facilities that may be available in the hospital or community health care setting, such as seating, overnight rooms and transport support. Just under one in five (18.1%) respondents indicated that the availability of these supports was sufficient, approximately half (51.8%) did not agree that supports available for carers were sufficient.

Figure 7. Carer inclusion in health service settings



For state and territory comparisons, please see Appendix C.

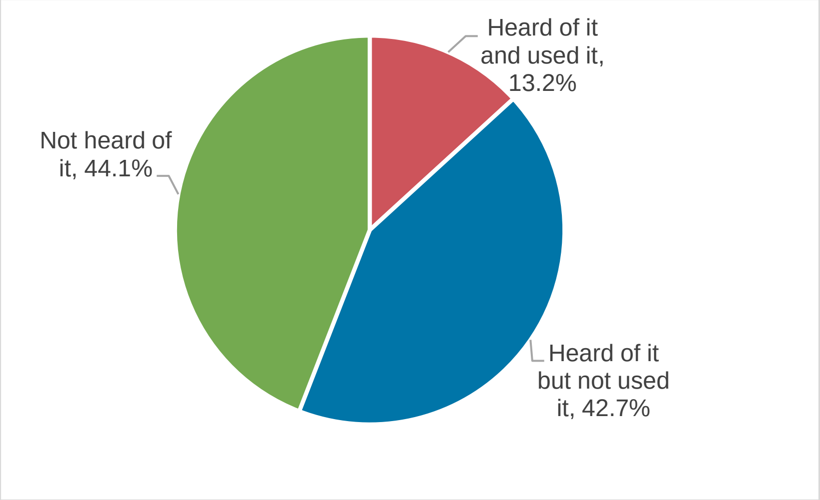
Carer support services

The 2020 National Carer Survey was conducted between April and June 2020, concurrent with the launch of a range of new, in-person services under the national Carer Gateway. It was therefore timely to ask respondents about their awareness of these services, so that results can be compared in future years as the service system matures. Carers' current use of, and need for, the most common types of carer support services were also captured to allow for comparison over time, as use of Carer Gateway services develop and other associated service reforms (e.g. in the aged care and disability sectors) progress.

Awareness and use of Carer Gateway

All respondents were asked whether they had heard of the Carer Gateway. The majority of respondents (55.9%) had heard of the Carer Gateway, but only a small proportion (13.2% of respondents) had used it at the time they completed the Survey. A further 44.1% of respondents had not yet heard of the Carer Gateway (see Figure 8).

Figure 8. Awareness and use of Carer Gateway



N=5,607

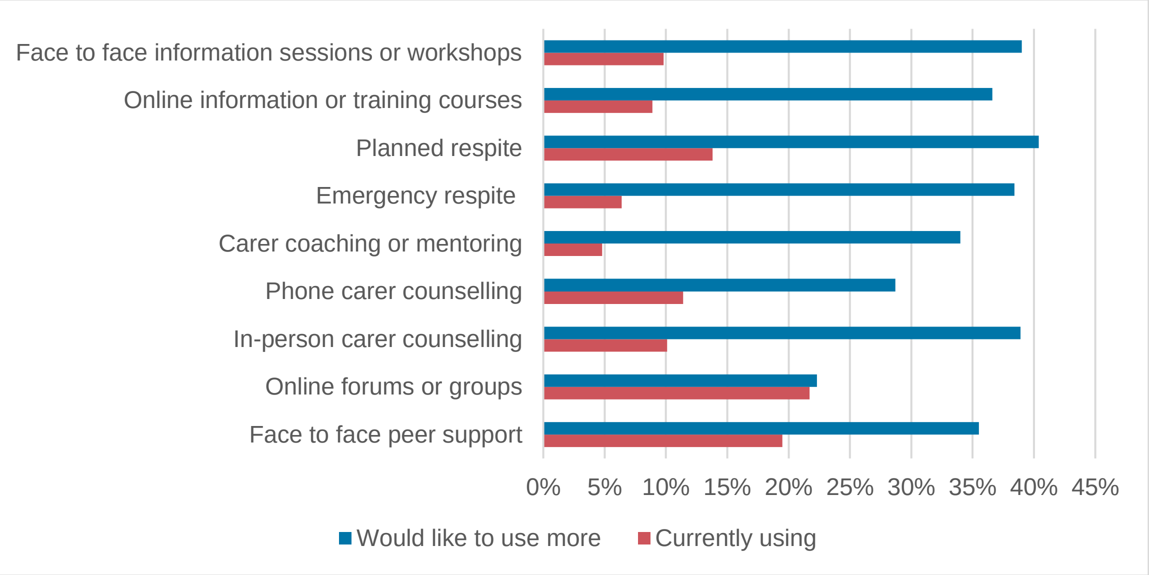
Use of and demand for carer support services

Respondents were asked which of a range of common carer-specific support types they currently used and which they would like to use more. The most commonly used types of carer support were online forums or groups (21.7%), planned respite (13.8%) and carer counselling over the phone (11.4%) or in person (10.1%). Fewer than one in ten respondents used the other kinds of carer supports listed (see Figure 9).

However, low usage did not equate to low need or interest, as the carer support types that respondents most wanted to use more included emergency respite (38.4%), online information or training courses (36.6%), face to face peer support (35.5%) and carer coaching or mentoring (34.0%). Demand for these service types was in some cases many times greater than the rate of usage, suggesting great potential in increasing access to these kinds of supports, which is an intention of the Carer Gateway rollout.

Planned respite and phone-based carer counselling also ranked highly as supports that carers wanted to use more, at 40.4% and 38.9% respectively. Both of these services are also on offer under the Carer Gateway.

Figure 9. Use of and demand for carer support service types



N=4,293

Challenges accessing carer support services

Respondents were asked which if any of a range of commonly reported challenges they had experienced when trying to access carer support services. The five most commonly identified challenges were:

- It was difficult to find information about what services were available and how to access them (32.0%)
- There was a long waiting period to access services (26.3%)
- It took too much time and energy to organise the services (25.5%)
- The services available did not meet my needs (25.2%)
- The service received was at a lower level than what was required (21.9%)

For state and territory comparisons, please see Appendix C.

Time out from the caring role

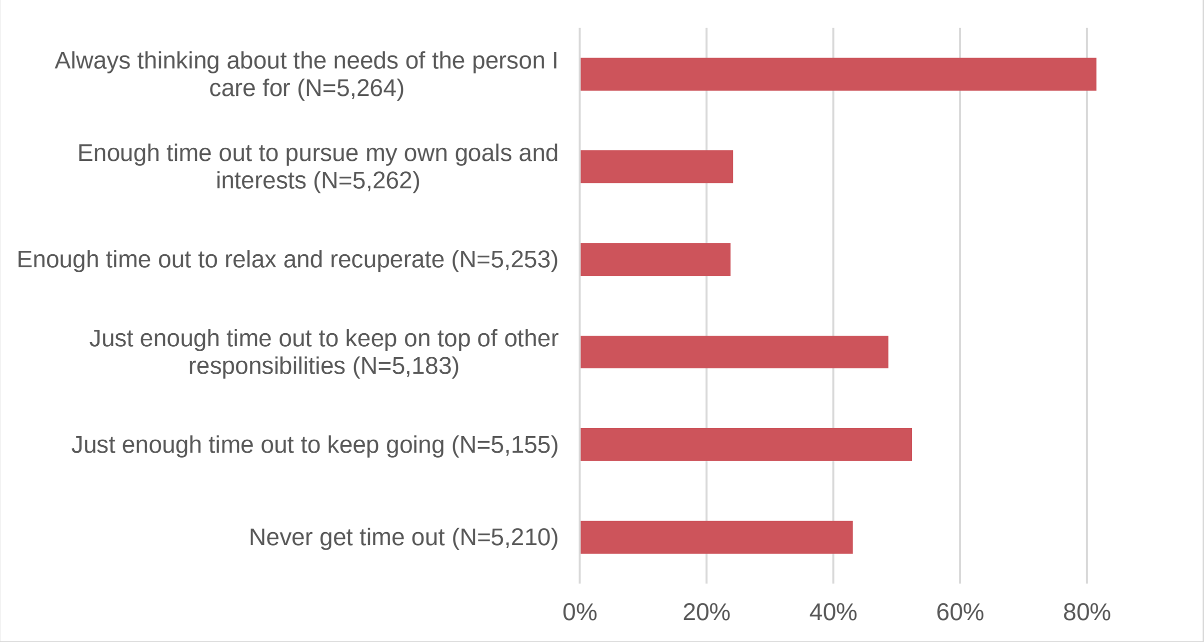
Respondents were asked in detail about the quantity and quality of their time out from the caring role. Concerningly, 43.1% of respondents indicated that they never get time out from their caring responsibilities. However, one in three (34.0%) disagreed or strongly disagreed with this statement. Even when respondents had time away from their caring responsibilities, the vast majority (81.5%) were still mentally and emotionally engaged in the caring role, thinking continually about the needs of the person they care for (see Figure 10).

Whether or not time away from the caring role was quality time to commit to other pursuits was also explored. Just over half (52.4%) of respondents agreed or strongly agreed that they were able to take just enough time out from their caring responsibilities to keep going, while just under half (48.7%) were in agreement that they had enough time away from the caring role to keep on top of other responsibilities. This left approximately one in four respondents unable to take enough time out of their caring role to keep going, or keep on top of other responsibilities (25.4% and 29.5% respectively).

Unsurprisingly, more than half (55.3%) of respondents disagreed or strongly disagreed that they had enough time out from caring to relax and recuperate, and just over half (52.1%) were unable to have enough time out to pursue their own goals and interests. Accordingly, approximately one in four respondents were able to relax and recuperate and pursue their own goals and interests during their time away from the caring role (23.8% and 24.2% respectively).

What these results demonstrate is that, on the whole, carers' time away from the caring role is limited in both quantity and quality. Carers' experiences of time away from the caring role are also diverse and will likely be influenced by a range of factors to be explored in future analysis and publications. It is troubling to note that many carers are simply unable to prioritise their own needs and interests due to the time demands associated with their caring responsibilities. Future analysis will examine to what extent this lack of 'me time' contributes to carers' own health and wellbeing outcomes.

Figure 10. Quantity and quality of time out from the caring role

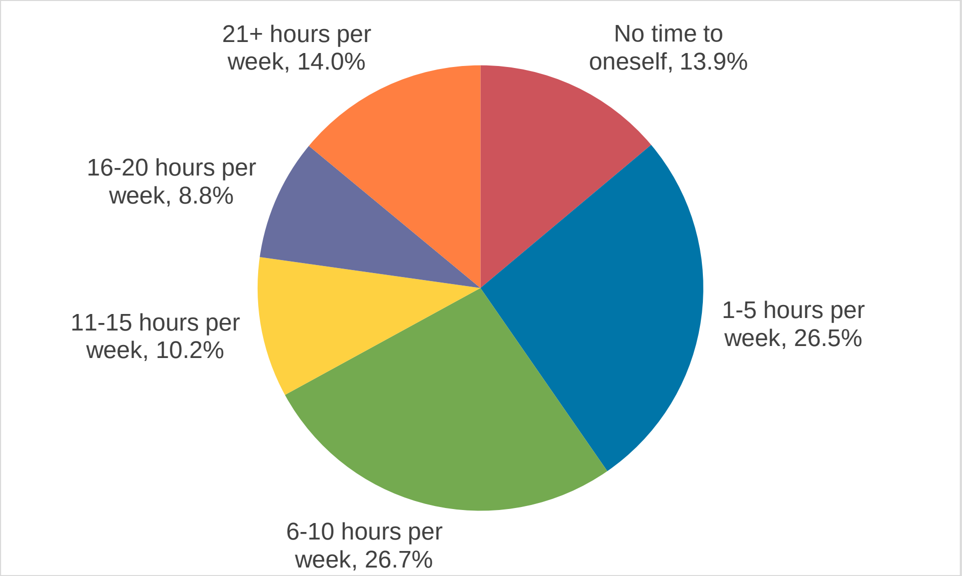


Hours per week to oneself

Respondents were asked about the time they generally have to themselves, i.e. pursuing activities of their choice not relating to caring responsibilities, work or to household and other chores. This time was estimated in hours per week. Of the 4,638 carers who responded to this question, the average hours per week carers had to themselves was 12 hours, which equates to a half day.

More than one in ten respondents (13.9%) indicated that they had no time at all to themselves each week, while one in four (25.5%) had 5 hours per week or less. A further one in four (26.7%) had between 6 and 10 hours per week to themselves (see Figure 11). Further analysis will explore the variables that influence this time, such as the condition of the person cared for and the care tasks undertaken.

Figure 11. Hours per week to oneself



N=4,638

Paid work

Highlights

- Undertaking higher education made it more likely for carers to be in paid employment.
- The typical working carer worked 27 hours per week in a permanent position.
- Half of all working carers had used flexible start/finish times in their current jobs, 44% had used carer’s leave.
- The most common career impacts of caring on respondents’ paid work were exiting employment and reduced working hours.
- The biggest obstacle to respondents finding a job was the time needed outside of work to maintain caring responsibilities.

As outlined in Table 10, 35.8% of current carers reported being in paid employment, while 8.6% are unemployed and 55.7% of carers are not participating in the labour force. The majority (57.1%) of those not in the labour force were aged 65 years and over, and therefore may have retired. Women are more likely to combine work and care, while most male carers are not participating in the labour force.

Working carers, unsurprisingly, have a lower mean age, and participation in the labour market is higher among those with higher education. Only a third of carers with a disability or long-term health condition are in employment.

Table 10. Selected demographic categories by labour force status

		Employed (%)	Unemployed (%)	Not in labour force (%)
Total (N=6,162)		35.8	8.6	55.7
Age (Mean)		51.0 years	51.5 years	64 years
Gender	**Female (N=4,727)**	37.8	9.0	53.2
	Male (N=1,024)	22.8	7.0	70.2
	Non-binary (N=15)	13.3	13.3	73.3
Education	**Bachelor or higher (N=1,892)**	51.5	9.8	38.6
	Certificate/diploma (N=2,034)	35.3	9.3	55.3
	High school (N=805)	20.4	8.6	71.1
	Less than high school (N=1,007)	16.2	5.5	78.4
Disability (N=1,944)		27.6	11.9	60.5

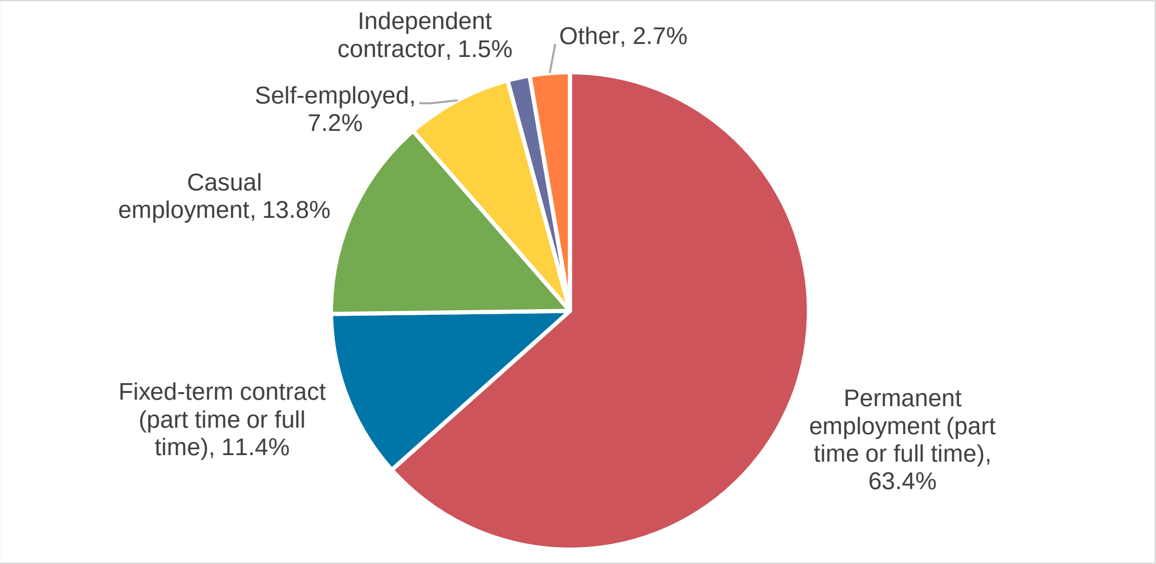
While most carers had left the labour market at 65, 11.6% of carers at retirement age were still in employment or looking for jobs. However, 37.9% of carers aged 26 to 64 were not participating in the labour market (Table 11).

Table 11. Age (broad groupings) by labour force status

	Employed (%)	Unemployed (%)	Not in labour force (%)
Up to 25 years old (N=108)	36.1	27.8	36.1
26 to 64 years old (N=3,550)	51.2	10.9	37.9
65+ years old (N=2,086)	7.7	3.9	88.4

Working carers spent on average 27.8 hours per week undertaking paid work. Of the 2,175 carers in paid employment who responded to the question, most were in permanent positions (63.4%) (see Figure 12).

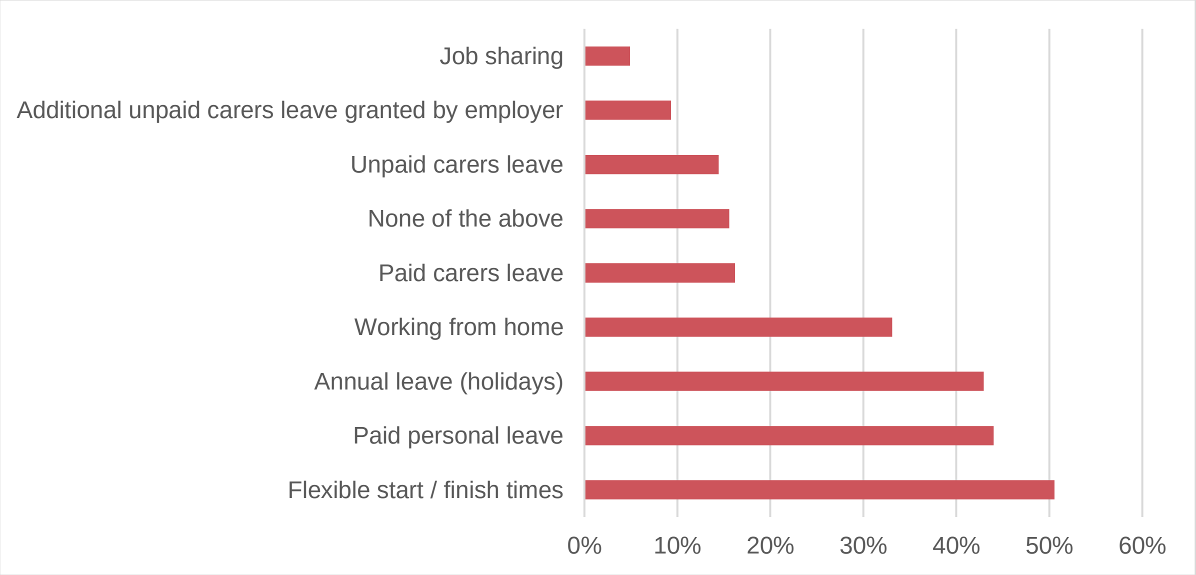
Figure 12. Carers' employment types



N=2,175

More than half of all working carers had used flexible start/finish times in their current jobs. A third of employed carers were working from home, which may have been impacted by COVID-19 restrictions in place at the time of data collection. Relatively few (15.6%) had not used any flexible work arrangements. Around one in ten working carers reported using other flexible work arrangements, such as flexible work days. Carers' use of flexible work arrangements is shown in Figure 13.

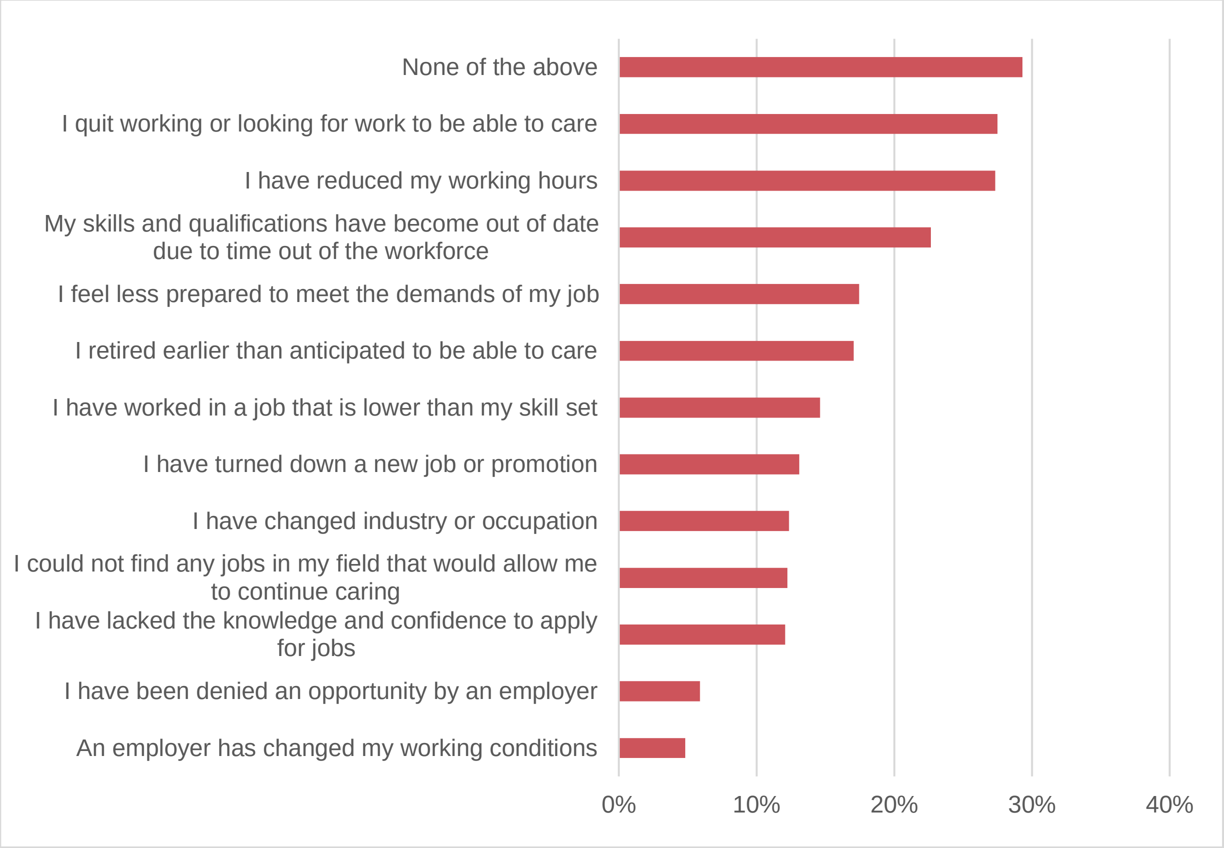
Figure 13. Use of flexible work arrangements



N=2,175

Impacts of caring responsibilities on career progression were widely felt by respondents. Only 29.0% reported that caring had not impacted their career. The most common impact reported (27.5% of respondents) was having to quit paid work in order to care. Combined with having to retire early to continue caring, 44.5% of carers reported having left the workforce due to their caring responsibilities. The second most common impact (27.4% of respondents) was reducing working hours, followed by not being able to keep skills/qualifications up to date, which was reported by 17.4% of working carers (see Figure 14).

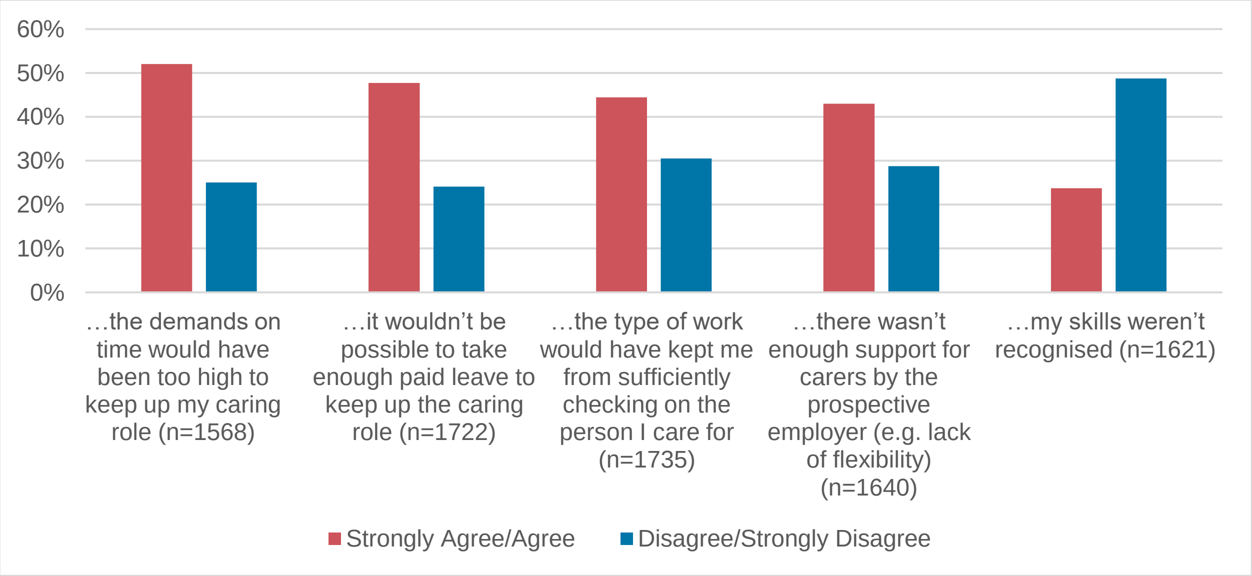
Figure 14. Career impacts



N=5,725

The demands that caring responsibilities place on carers' time was also found to be the most common barrier to finding work. Roughly half of carers participating in the labour force agree with the statements that the demands on time would have been too high to keep up the caring role, and that it wouldn't be possible to take enough paid leave to keep up the caring role. A further 43.0% of carers indicated that a lack of support by their prospective employer as an obstacle to finding a job (see Figure 15).

Figure 15. Barriers to finding a job



Health, wellbeing and carer recognition

Highlights

- Nearly half of the carers who responded reported high or very high psychological distress, an increase since the Carers NSW 2018 Carer Survey.
- One third of respondents felt highly socially isolated.
- Carer wellbeing is considerably lower than that of the general population.
- Most respondents felt that their family members and friends recognised and valued their caring role, but less than one in five felt recognised and valued by government.

The 2020 National Carer Survey included three validated scales designed to measure health and wellbeing. The domains measured were subjective wellbeing (the Personal Wellbeing Index), psychological distress (Kessler 5-Item Scale of Psychological Distress) and social connectedness (the Friendship Scale). It should be noted that these health and wellbeing measurements are likely to have been impacted by widespread restrictions on gathering and public movement in many parts of Australia at the time the Survey was conducted, due to the first wave of the COVID-19 pandemic. Results should therefore be interpreted carefully.

Subjective wellbeing

The Personal Wellbeing Index (PWI, Cummins et al. 2003, IWB 2013) measures satisfaction with life across seven domains, which can either be assessed individually, or collectively as an overall indication of personal wellbeing. Values are calculated to be expressed in the range from 0 to 100% for each domain and the overall index. Table 12 shows the mean scores for the overall index and for each of its domains, as well as a comparison to the scores calculated for the general population of Australia (the 'normative mean', obtained from Khor et al., 2020).

Survey respondents reported the lowest satisfaction on the measures of what they are achieving in life, future security, and their health, however the greatest difference to the general population was found in the domain of satisfaction with personal relationships. Overall, respondents' satisfaction with life was 18.2 percentage points lower than for the general Australian population.

Table 12. Carers PWI scores in comparison to the general population

Dimension	2020 National Carer Survey mean (%SM) (N=5,569)	2020 normative mean (Kohr et al 2020) (%SM)	Difference (% points)
PWI	57.2	75.4	-18.2
Standard of living	65.7	78.1	-12.4
Health	52.7	74.5	-21.8
Achieving in life	51.6	73.4	-21.9
Personal relationships	55.1	79.6	-24.4
Personal safety	69.3	79.6	-10.3
Community connectedness	53.4	71.2	-17.8
Future security	52.4	71.2	-18.8

Table 13 compares mean overall wellbeing scores by selected carer demographics. The lowest average wellbeing score was recorded by respondents identifying as non-binary/gender diverse. Overall subjective wellbeing was significantly higher in older carers compared to carers younger than 65 years, with a difference of 10.6 percentage points. Similarly, the wellbeing of carers living remotely was reported to be better than that of the majority living in major urban areas.

Table 13. Wellbeing by selected carer demographics

Carer Demographic		PWI (mean %SM)
Gender	Female (N=4,424)	56.3
	Male (N=939	60.9
	Non-binary (N=13)	50.2
Age (broad groupings)	up to 25 (N=99)	58.1
	26 to 64 (N=3,394)	53.4
	65+ (N=1,864)	64.0
Remoteness area	Major Cities (N=2,782)	55.5
	Inner Regional (N=1,671)	58.7
	Outer Regional (N=744)	58.7
	Remote or Very Remote (N=108)	62.8

Psychological distress

Psychological distress was measured using the Kessler 5-Item Scale of Psychological Distress (K5), which is categorised to indicate low to moderate, or high to very high levels of psychological distress. The K5 scale is an adaption of the Kessler 10-item Scale of Psychological Distress (Kessler et al 2003), developed by the Australian Bureau of Statistics to provide a population-level screening tool for psychological wellbeing that is culturally safe for surveys including Aboriginal and Torres Strait Islander respondents (see ABS 2012). Previous versions of the Carers NSW Carer Survey and many general surveys use the K10 scale, which yields comparable data, however the analytical categorisation is necessarily less detailed than in the K10.

Overall, nearly half of all respondents (47.7%) reported high or very high psychological distress. This represents a concerningly high prevalence of psychological distress, and an increase compared to the Carers NSW 2018 Carer Survey. Parts of this increase can most likely be attributed to the COVID-19 pandemic. Subjective wellbeing, however, seemed to be less affected by the stress of the pandemic, as the score of the PWI is stable (albeit on an already low level), compared to the Carers NSW 2018 Carer Survey (see Table 14).

Table 14. K10/K5 and PWI scores, 2020 and 2018

	2020 National Carer Survey	2020 National Carer Survey (NSW sample only)	2018 Carer Survey (NSW)
K5/K10 score indicating high/very high distress, % of carers	47.7%	50.0%	45.7%
Mean K5/K10 %SM	33.0%	34.4%	30.7%
Mean PWI %SM	56.5%	55.5%	54.3%

Social connectedness

The social connectedness experienced by carers was measured using the “Friendship Scale” (Hawthorne 2000). This scale provides a measure of overall social connection/isolation. Its six questions explore the degree to which a person has found it easy to relate to others over the past four weeks; if they have felt isolated from other people; if they had someone to share their feelings with; the ease with which the person has been able to get in touch with others if they needed to; whether the person felt separated from others in the past four weeks; and, if they felt alone and friendless. Scores on the friendship scale can be categorised into five levels, ranging from “Highly socially isolated” to “Highly socially connected” (for details see Hawthorne 2006).

Figure 16 shows the scores reported by respondents in the 2020 National Carer Survey in comparison to a representative community sample obtained from Hawthorne et al. 2013. More than one third of carers reported being highly socially isolated, with another 25% reporting only low levels of social support. These findings confirm the results obtained from the PWI dimension on satisfaction with personal relationships, and demonstrate that social isolation is a central issue affecting the wellbeing of carers, especially during the COVID-19 pandemic.

Figure 16. Social isolation/connectedness among carers

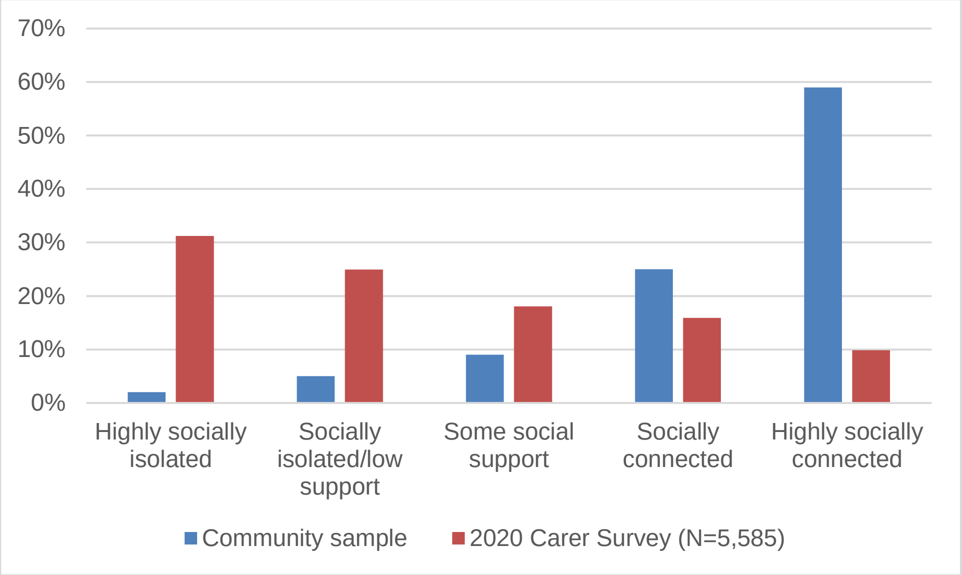


Table 15 shows a comparison of Friendship Scale scores by selected demographic groups in the 2020 National Carer Survey. The highest rates of social isolation are reported by non-binary/gender diverse carers, followed by young carers. The highest rates of social connectedness were reported by older carers, female carers and carers living in remote or very remote areas.

Table 15. Social isolation/connectedness among selected demographics

		Friendship Scale - Category				
		Highly socially isolated	**Socially isolated/ low support**	**Some social support**	**Socially connected**	**Highly socially connected**
Gender	**Female (N=4,506)**	33%	25%	18%	15%	9%
	Male (N=954)	25%	26%	18%	18%	13%
	Non-binary (N=15)	47%	20%	20%	7%	7%
Age	**up to 25 (N=102)**	43%	30%	17%	6%	4%
	26 to 64 (N=3,432)	37%	24%	17%	14%	8%
	65+ (N=1,923)	20%	26%	20%	20%	14%
Remoteness Area	**Major Cities (N=2,818)**	33%	26%	17%	15%	9%
	Inner Regional (N=1,721)	30%	23%	19%	17%	11%
	Outer Regional (N=761)	31%	26%	19%	15%	9%
	Remote or Very Remote (N=114)	22%	22%	16%	25%	15%

Carers were asked about their satisfaction with personal relationships in further detail (see Table 16). On average, the most satisfactory relationships exist with friends and partners. Compared by age, older carers are more satisfied with their relationships than young carers. Male carers tend to be more satisfied in their relationships with their partners, and to a lesser extent with their children, while female carers report the reverse.

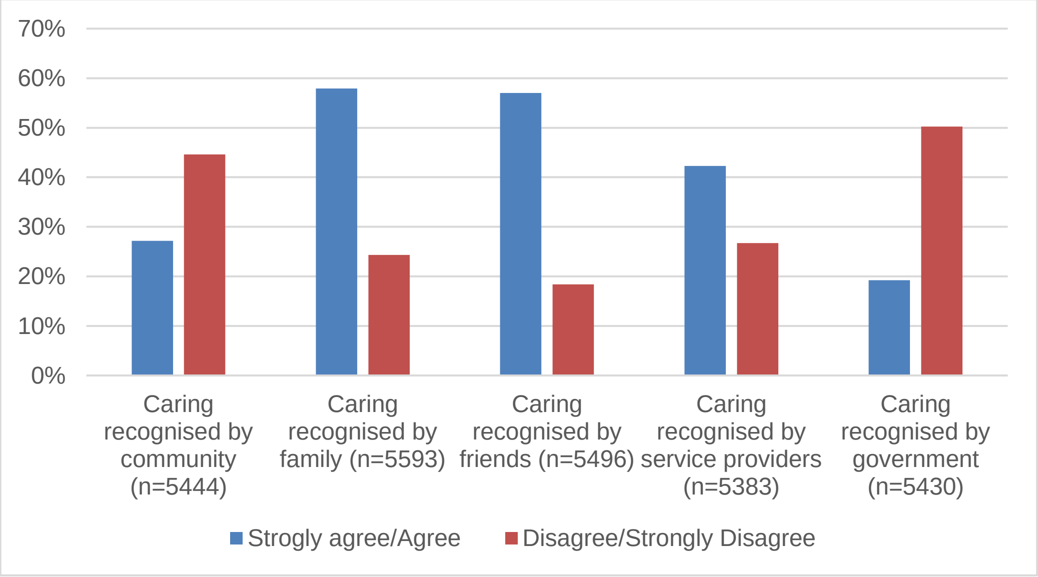
Table 16. Relationship satisfaction, mean %

		Relationship satisfaction with partner	Relationship satisfaction with parents	Relationship satisfaction with children	Relationship satisfaction with friends
All carers	**(n=5407)**	48.7	35.0	61.6	61.6
Gender	**Female (n=4457)**	46.6	37.4	62.6	61.4
	Male (n=952)	58.5	24.0	57.2	62.8
	Non-binary (n=13)	27.7	27.7	18.5	50.8
Age group	**up to 25 (n=103)**	29.3	59.5	-	59.5
	26 to 64 (n=3450)	46.6	46.9	60.5	57.2
	65+ (n=1854)	53.8	11.4	66.5	70.0

Carer recognition

All respondents to the Survey were asked to what extent they agreed that their caring role was recognised and valued by their community, family, friends, service providers, and governments. More carers disagreed with the statement that their caring role was recognised by the community (45% negative answers) or by the government (50% negative answers). However, carers generally reported feeling recognised by family members and friends, and - to a lesser extent - by service providers.

Figure 17. Carers' agreement with being recognised and valued



Finances and financial wellbeing

Highlights

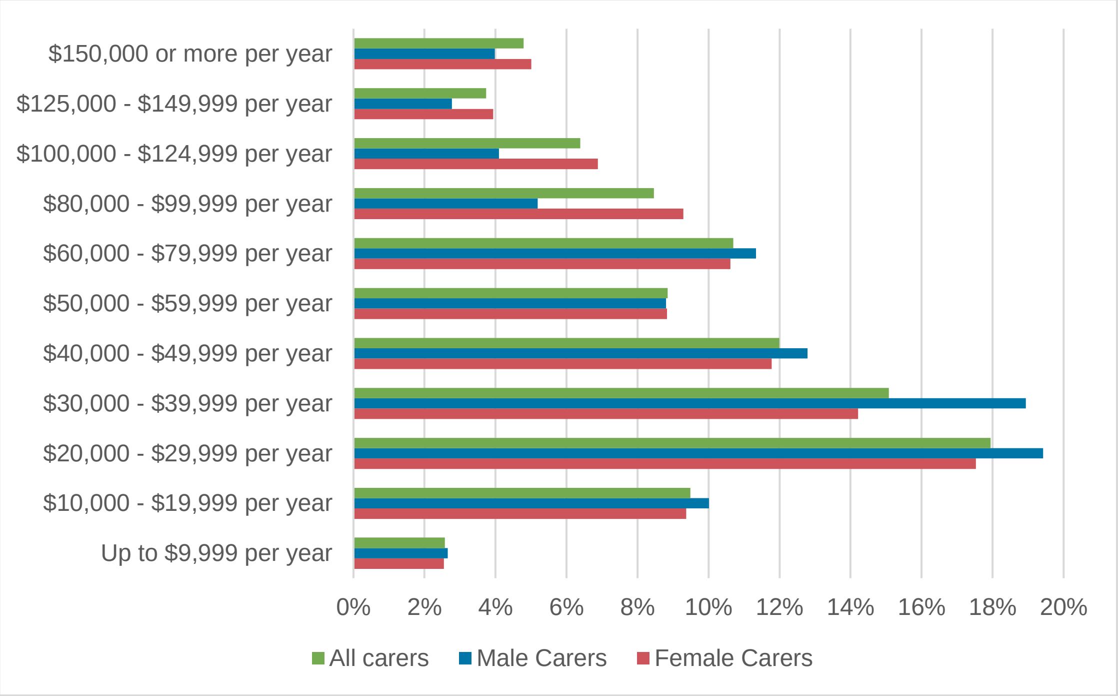
- Most households represented had a gross income of less than $50,000 per year and received some form of Government income support.
- One in four carers receiving the Carer Payment were experiencing financial distress.
- Most carers were contributing financially to the costs of care for the persons they care for.

As detailed earlier in this report, caring can have a significantly negative impact on some carers' employment and income opportunities. The employment situation of many carers, and subsequently their income, may have been further affected by the economic impacts of COVID-19. However, it should be noted that data collection for the Survey occurred relatively early in the pandemic and therefore may not be reflective of the full extent of the present recession.

Respondent income

Figure 14 shows the variation in gross household income among respondents. Carers responding to the 2020 National Carer Survey were more likely to live in lower income households than the general population. Indeed, the majority (57.1%) were living in households with an income of less than $50,000 before tax (gross income). For comparison, the mean annual gross household income in Australia in 2018 was $107,172 (ABS 2019b). Male carers (51.0%) were slightly more likely than female carers (43.7%) to live in households with a gross income of less than $40,000 per year. Future analysis will explore factors that may contribute to this variation.

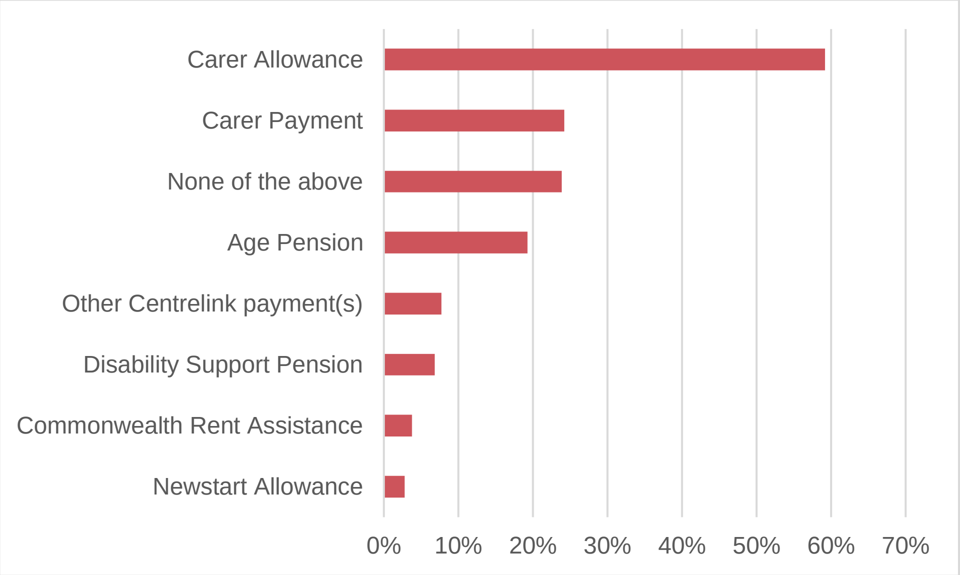
Figure 18. Gross household income, by gender



N=4,385

Due to their relatively low incomes, many carers are eligible for income support payments. Figure 15 shows that only one in four carers was not receiving any income support payments, while the majority of respondents were receiving the Carer Allowance (currently up to $131.90 per fortnight), and one in four carers was receiving the Carer Payment (up to $944.30 per fortnight for singles, or $1,423.60 combined for couples, including the Pension and Energy supplements).[5]

Figure 19. Receipt of income support payments



N=5,665

Receiving an income support payment was more common in regional and remote areas than in major cities, as Table 17 shows. Young carers were least likely to receive any income support, but were also more likely than other age groups of carers to receive a non-carer specific income support payment.

Table 17. Receipt of income support payments, by selected carer demographics

	Age (broad groupings)			Remoteness area			
	up to 25 (N=102)	26 to 64 (N=3,482)	65+ (N=2,024)	Major Cities (N=2,879)	Inner Regional (N=1,766)	Outer Regional (N=784)	Remote or Very Remote (N=117)
Carer Allowance	21.6%	60.0%	59.6%	56.9%	62.2%	61.4%	66.7%
Carer Payment	17.6%	29.8%	15.0%	21.6%	28.3%	26.0%	21.4%
Newstart/ Jobseeker	6.9%	3.8%	0.7%	2.7%	2.2%	4.5%	2.6%
Age Pension	-	0.9%	52.0%	14.6%	25.3%	23.2%	22.2%
Disability Support Pension	5.9%	8.4%	4.3%	6.1%	7.2%	8.8%	6.8%
Commonwealth Rent Assistance	4.9%	4.2%	3.2%	3.3%	4.9%	3.8%	0.9%
Other Centrelink payment(s)	16.7%	9.0%	5.2%	7.2%	7.9%	9.2%	8.5%
None of the above	49.0%	28.6%	14.6%	28.2%	18.8%	18.5%	19.7%

Financial stress and distress

To measure the extent of financial security among carers, the 2020 National Carer Survey included a set of questions on financial stress used by the ABS in its Household Expenditure survey (ABS 2017), and, more recently and with slight modifications, in the General Social Survey (ABS 2020). The indicators of financial stress are:

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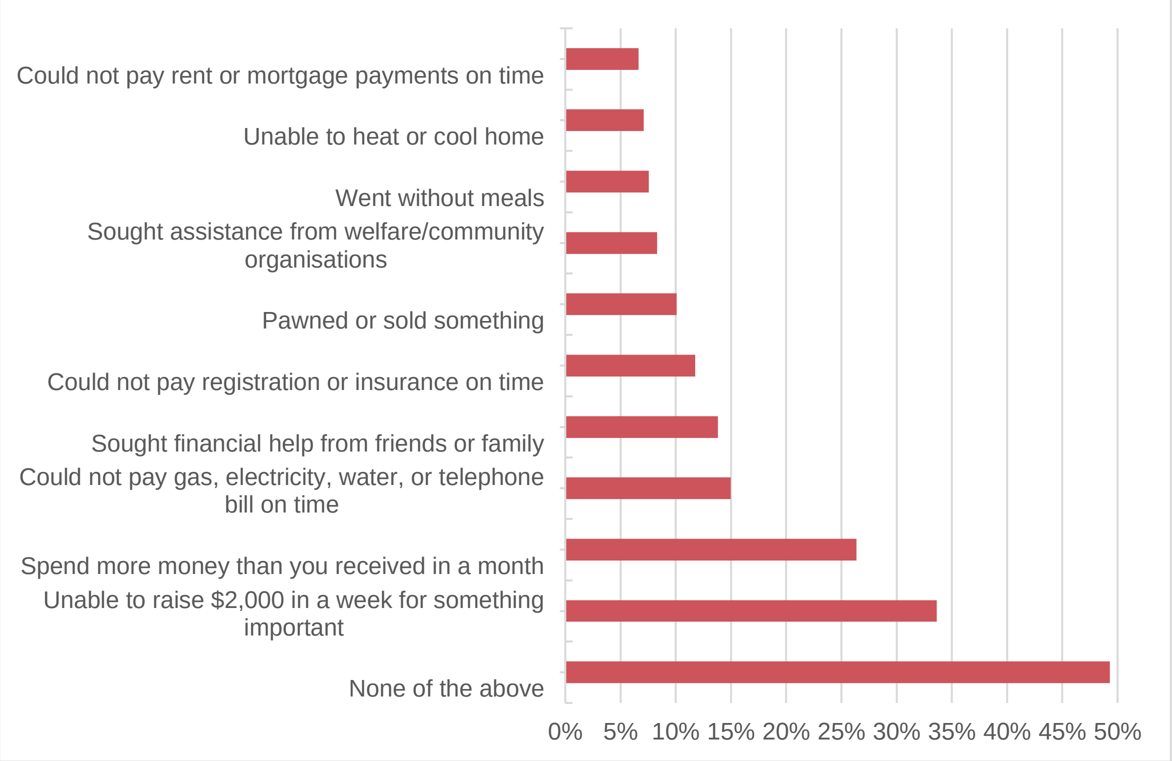
[5] Carer Allowance can be received on its own or in addition to another Centrelink payment. All Carer Payment recipients also receive Carer Allowance as a supplement.

- Being unable to raise $2,000 in a week for something important
- Spending more money than received
- Not being able to pay a gas, electricity or telephone bill on time
- Not being able to pay car registration or insurance on time
- Having pawned or sold something
- Going without meals
- Being unable to heat one's home
- Seeking assistance from welfare/community organisations
- Seeking financial help from friends or family

A household is considered to be in financial *distress* if they experience four or more of the above indicators of financial *stress* within a 12 month period.

Figure 16 shows that the most common indicator of financial stress experienced by Survey respondents was to be unable to raise $2,000 in a week if needed, which applies to one in three carer households, compared to one in four of all Australian households (ABS 2020). This suggests both a lack of personal savings reserves and a lack of personal connections that can provide financial assistance.

Figure 20. Experiences of financial stress



N=5,506

Just over half (50.7%) of respondents experienced at least one form of financial stress in their household in the year prior to completing the Survey, compared to only one in five (21.8%) of Australian households (ABS 2020). A total of 14.4% of respondents experienced more than 4 instances of financial stress in their household – and were therefore considered to be in financial distress – in the prior 12 months.

The highest levels of financial distress were reported by respondents receiving the Newstart Allowance (recently renamed 'Jobseeker') and Disability Support Pension, with more than one in four Carer Payment recipients reporting financial distress (see Table 18). Only 6.8% of those not receiving any income support payment would be considered as experiencing financial distress.

Table 18. Financial stress and distress among recipients of income support

	All carers (n=5506)	Carer Allowance (n=3202)	Carer Payment (n=1332)	Newstart/ Jobseeker (n=151)	Age Pension (n=1022)	Disability Support Pension (n=373)	None of the above (n=1302)
No experience of financial stress in past 12 months	49.3%	43.8%	31.4%	16.6%	64.9%	30.6%	62.5%
One financial stress experience in past 12 months	19.6%	20.4%	19.6%	22.5%	20.0%	14.7%	17.9%
Two financial stress experiences in past 12 months	10.1%	11.1%	13.0%	15.2%	7.7%	11.8%	8.2%
Three financial stress experiences in past 12 months	6.6%	7.0%	8.3%	13.2%	3.2%	11.5%	4.6%
Four or more financial stress experiences in past 12 months	14.4%	17.6%	27.8%	32.5%	4.2%	31.4%	6.8%

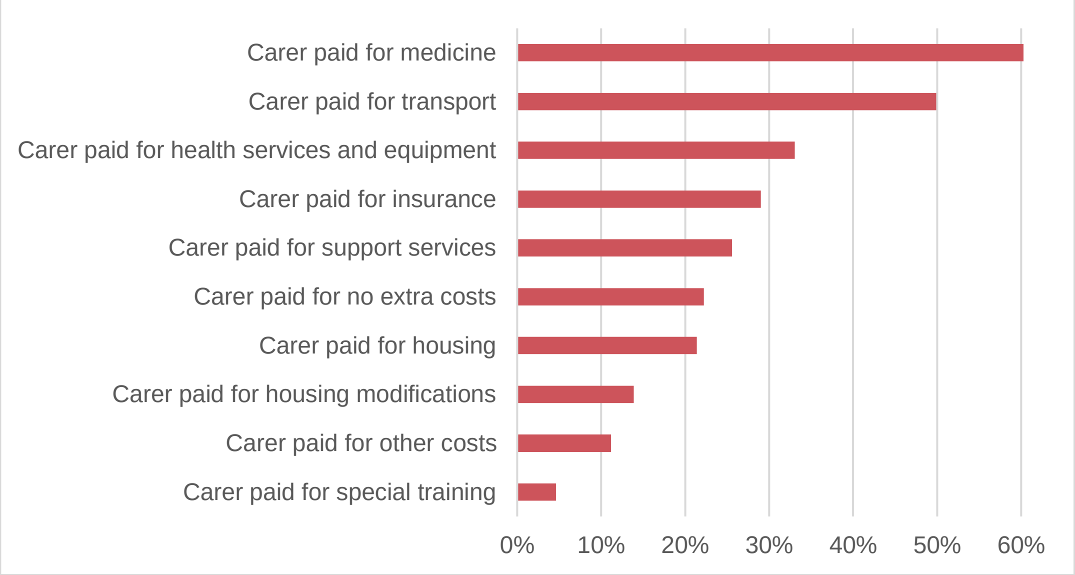
As detailed in Table 19, financial distress was more prevalent in larger households, with a quarter of respondents in households of five or more persons reporting four or more financial stress indicators. Unsurprisingly, unemployed carers reported the highest rate of financial distress when compared to their working peers and those voluntarily outside the labour force. Carers not in the labour force were less likely overall to experience any financial stress than employed carers, despite reporting a slightly higher incidence of financial distress.

Table 19. Financial stress and distress by household size and labour force status

	Household size					Labour force participation		
	1 Person Household (n=456)	2 Person Household (n=2427)	3 Person Household (n=951)	4 Person Household (n=748)	5 or more Person Household (n=591)	Employed (n=1945)	Unemployed (n=483)	Not in labour force (n=3078)
No experience of financial stress in past 12 months	55.5%	56.9%	44.8%	38.1%	32.0%	47.7%	26.9%	53.8%
One financial stress experience in past 12 months	19.7%	18.6%	20.5%	21.3%	19.3%	21.3%	18.6%	18.7%
Two financial stress experiences in past 12 months	10.3%	8.4%	10.1%	13.1%	14.0%	12.0%	12.4%	8.6%
Three financial stress experiences in past 12 months	4.4%	5.2%	6.4%	9.8%	9.1%	7.5%	11.2%	5.3%
Four or more financial stress experiences in past 12 months	10.1%	10.8%	18.2%	17.8%	25.5%	11.6%	30.8%	13.6%

One potential contributing factor to carers' financial stress is their high rate of expenditure on the costs of care. Almost two thirds of carers reported contributing financially to the costs of medicine for the person they cared for, with half contributing to their transport costs. Just over one in five (22.2%) carers did not incur any additional costs relating to their caring role.

Figure 21. Financial contributions to care costs



N=5525

The low average incomes among caring households and their corresponding high rates of financial stress highlight the need for ongoing and additional financial support for carers. This need has become even more pressing in light of the COVID-19 pandemic and its economic fallout.

Conclusion

This summary report has provided an overview of high-level national results from the Carers NSW 2020 National Carer Survey, with some reference to state and territory variations. A valid sample of 7,735 current and former carers of diverse circumstances and backgrounds responded to the Survey, resulting in important insights into the impacts on carers of ongoing sector reforms, and providing an overall snapshot of the demographic and socio-economic characteristics of carers across Australia at a time of unprecedented public health challenges.

As in previous Carers NSW Carer Surveys, respondents generally reported long term, high intensity caring roles requiring them to provide considerable support. New questions highlighted the true impact of caring responsibilities on carers' time for themselves and for other responsibilities, with many having no time away from the caring role.

Carer recognition, which has been tracked in Carers NSW Carer Surveys since 2012 following the introduction of carer recognition legislation, was reported to be high in the context of personal relationships. However, carers' sense of being recognised and valued by governments was relatively low.

The Survey found that across aged care, disability, mental health and health services, carer inclusion is variable, and that these services often do not meet carers' needs, even when they provide quality support to the person being cared for. Carers consistently reported challenges in finding information about services and organising services for themselves and the people they care for. Waiting times for services and assessments were also identified as a common barrier to accessing support.

Perhaps unsurprising given the timing of the Survey, psychological distress was high and wellbeing was low, as was social connectedness. Psychological distress had also increased since the Carers NSW 2018 Carer Survey, indicating potentially adverse impacts of the stress associated with the early stages of the COVID-19 crisis in Australia.

While caring responsibilities continue to take many carers out of the paid workforce prematurely, the uptake of flexible work arrangements to balance paid work and care was relatively high. Financial hardship, explored in greater depth in 2020 compared with prior Carers NSW Carer Surveys, was concerningly high, and may have been affected by the economic fallout from COVID-19.

The findings from the Carers NSW 2020 National Carer Survey provide a timely and informative snapshot of the lives of Australian carers during COVID-19 and offer the first detailed national analysis of carers' health and wellbeing and their experiences of inclusion and support within key reforming service systems.

Analysis and reporting will continue following the publication of this summary report, with findings to be used by Carers NSW and the National Carer Network to advocate for improved support and recognition for all carers.

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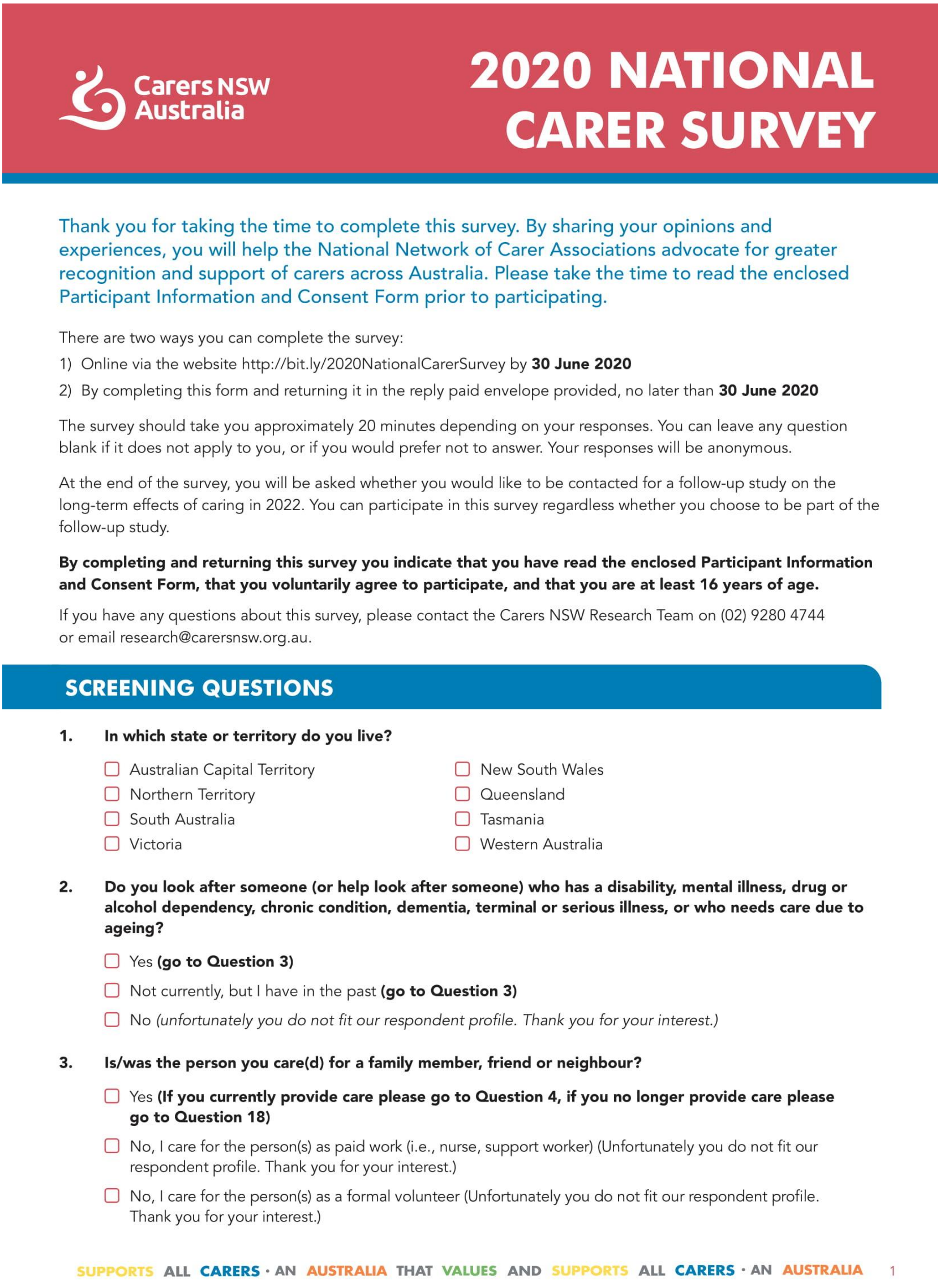
Appendix A: 2020 National Carer Survey Questionnaire



Carers NSW Australia

2020 NATIONAL CARER SURVEY

Thank you for taking the time to complete this survey. By sharing your opinions and experiences, you will help the National Network of Carer Associations advocate for greater recognition and support of carers across Australia. Please take the time to read the enclosed Participant Information and Consent Form prior to participating.

There are two ways you can complete the survey:

1) Online via the website http://bit.ly/2020NationalCarerSurvey by **30 June 2020**
2) By completing this form and returning it in the reply paid envelope provided, no later than **30 June 2020**

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

At the end of the survey, you will be asked whether you would like to be contacted for a follow-up study on the long-term effects of caring in 2022. You can participate in this survey regardless whether you choose to be part of the follow-up study.

By completing and returning this survey you indicate that you have read the enclosed Participant Information and Consent Form, that you voluntarily agree to participate, and that you are at least 16 years of age.

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

SCREENING QUESTIONS

1. In which state or territory do you live?

☐ Australian Capital Territory
☐ Northern Territory
☐ South Australia
☐ Victoria
☐ New South Wales
☐ Queensland
☐ Tasmania
☐ Western Australia

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

☐ Yes **(go to Question 3)**

☐ Not currently, but I have in the past **(go to Question 3)**

☐ No *(unfortunately you do not fit our respondent profile. Thank you for your interest.)*

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

☐ Yes **(If you currently provide care please go to Question 4, if you no longer provide care please go to Question 18)**

☐ No, I care for the person(s) as paid work (i.e., nurse, support worker) (Unfortunately you do not fit our respondent profile. Thank you for your interest.)

☐ No, I care for the person(s) as a formal volunteer (Unfortunately you do not fit our respondent profile. Thank you for your interest.)

SECTION 1: THE CARING RELATIONSHIP

4. How many people do you care for? _____

The following questions are about the person/people you care for because of their needs arising from a disability, chronic condition, mental ill health or advanced age. If you care for more than one person, please complete both columns, thinking about the **two** people you provide the **most** care for.

PERSON 1

5. What is this person's gender?

☐ Female
☐ Male
☐ Non-binary / gender diverse
☐ Their gender identity isn't listed.
They identify as: ______________________
☐ Prefer not to say

6. How old is this person?

__________ years

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

They are my:
☐ Parent or parent in law
☐ Partner or spouse
☐ Child (incl. adult son or daughter)
☐ Brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify:

____

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

____

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

☐ Yes, they speak

____

☐ No, English only

PERSON 2

5. What is this person's gender?

☐ Female
☐ Male
☐ Non-binary / gender diverse
☐ Their gender identity isn't listed.
They identify as: ______________________
☐ Prefer not to say

6. How old is this person?

__________ years

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

They are my:
☐ Parent or parent in law
☐ Partner or spouse
☐ Child (incl. adult son or daughter)
☐ Brother or sister
☐ Grandparent
☐ Friend
☐ Neighbour
☐ Other, please specify:

____

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

____

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

☐ Yes, they speak

____

☐ No, English only

PERSON 1 (continued)

10. Is this person of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

11. For what conditions / disabilities / illnesses does this person need your care?
Please tick all that apply, even if the person you care for has not received an official diagnosis.

☐ Physical disability
☐ Sensory impairment (e.g. loss of hearing or loss of vision)
☐ Frailty due to ageing
☐ Intellectual disability
☐ Autism Spectrum Disorder
☐ Mental illness
☐ Drug or alcohol dependency
☐ Dementia
☐ Chronic health condition
☐ Terminal or serious illness
☐ Acquired brain injury, stroke
☐ Neurological condition (e.g. epilepsy, Parkinson’s disease, multiple sclerosis)
☐ Other, please specify:

____

12. Do you and the person you care for live in the same household?

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

____

PERSON 2 (continued)

10. Is this person of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

11. For what conditions / disabilities / illnesses does this person need your care?
Please tick all that apply, even if the person you care for has not received an official diagnosis.

☐ Physical disability
☐ Sensory impairment (e.g. loss of hearing or loss of vision)
☐ Frailty due to ageing
☐ Intellectual disability
☐ Autism Spectrum Disorder
☐ Mental illness
☐ Drug or alcohol dependency
☐ Dementia
☐ Chronic health condition
☐ Terminal or serious illness
☐ Acquired brain injury, stroke
☐ Neurological condition (e.g. epilepsy, Parkinson’s disease, multiple sclerosis)
☐ Other, please specify:

____

12. Do you and the person you care for live in the same household?

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

____

PERSON 1 (continued)

13. Do any other family members / friends help take care of this person?

- ☐ I am the only one who provides care
- ☐ I provide the most care, but others help with care sometimes
- ☐ Someone else provides the most care, but I help with care sometimes

14. How long can this person be left alone?

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

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

__________ hours per week

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

- ☐ Less than 1 year
- ☐ __________ years

PERSON 2 (continued)

13. Do any other family members / friends help take care of this person?

- ☐ I am the only one who provides care
- ☐ I provide the most care, but others help with care sometimes
- ☐ Someone else provides the most care, but I help with care sometimes

14. How long can this person be left alone?

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

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

__________ hours per week

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

- ☐ Less than 1 year
- ☐ __________ years

17. Have you previously cared for anyone who you are no longer caring for?

- ☐ Yes
- ☐ No **(Please go to Question 22)**

18. Please indicate who you have previously cared for, but are no longer caring for. If you cared for more than one person in the past, please think of the person you cared for most recently:

- ☐ Parent or parent in law
- ☐ Partner or spouse
- ☐ Child (incl. adult son or daughter)
- ☐ Brother or sister
- ☐ Grandparent
- ☐ Friend
- ☐ Neighbour
- ☐ Other, please specify: ______________________________________

19. How long did you care for this person?

- ☐ Less than 1 year
- ☐ __________ years

20. How long ago did this caring role end?

- ☐ Less than a year ago
- ☐ __________ years ago

21. **Why did this caring role end?**

Please tick all that apply.

☐ The person I cared for no longer required care
☐ The person I cared for passed away
☐ Someone else took over the caring role, please tell us who (e.g. their child, sibling, or friend)

____

☐ I couldn't continue caring
☐ Other, please specify: ______________________________

If you are a former carer, and you are not **currently** providing care for someone, please go to Question 40.

SECTION 2: YOUR CARING ROLE

22. **Please tick all the types of support you provide to the person(s) you care for. Please also rank the 5 tasks that require the most effort from you (5 = most effort, 1 = less effort).**

Please tick all that apply.

	Tick	Rank
Personal care (e.g. eating, showering, dressing)	☐	____
Mobility (e.g. walking, getting out of bed)	☐	____
Communication (e.g. reading, writing, helping them articulate themselves in conversations)	☐	____
Interpreting or translating for them from or into another language	☐	____
Advocacy (e.g. helping them dispute a treatment or a decision)	☐	____
Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings)	☐	____
Help with organising finances (e.g. helping them budgeting, assisting with online banking)	☐	____
Handling their finances (e.g. making financial decisions for them, managing their accounts)	☐	____
Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf)	☐	____
Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers)	☐	____
Health care (e.g. assisting with taking medication, injections, or wound care)	☐	____
Transport (e.g. driving them to appointments, taking public transport with them)	☐	____
Household chores (e.g. cleaning, cooking, shopping)	☐	____
Property maintenance (e.g. mowing lawns, cleaning gutters)	☐	____
Social support (e.g. helping them to engage in relationships and in the community)	☐	____
Checking on them, seeing whether they are okay	☐	____
Behavioural support (e.g. dealing with behaviours such as aggression or social withdrawal)	☐	____
Other, please specify: ____	☐	____

23. **Do you feel confident that you have the necessary skills for what you are doing in your caring role?**

☐ Very confident ☐ Confident ☐ Somewhat confident ☐ Not at all confident ☐ Prefer not to say

24. **Please tell us how your caring role has affected your relationships with the person you care for, your family or friends?**

SECTION 3: SERVICES AND SUPPORT

25. **Does someone you care for currently use aged care services?**
Please tick all that apply

Aged care services are services designed for people over the age of 65 years (or over the age of 50 years for Aboriginal and Torres Strait Islander Australians). They may be government funded or purchased privately.

☐ No, nobody that I care for currently needs aged care services **(Please go to Question 28)**
☐ Yes, someone I care for uses entry-level, aged care services subsidised by the Commonwealth Home Support Program (CHSP), such as cleaning, community transport, or basic in-home support
☐ Yes, someone I care for has a Home Care Package (Level 1, 2, 3 or 4), a government funded package of support that enables them to purchase aged care services, such as personal care, or respite
☐ Yes, someone I care for pays for aged care services privately, such as cleaning, or in-home support
☐ Yes, someone I care for lives in residential aged care, for example a nursing home or care facility
☐ Someone I care for is receiving aged care services, but I don't know which services they are using
☐ Other, please specify: ________________________________ **(Please go to Question 27)**
☐ Someone I care for needs aged care services but is currently unable to access these services **(Please go to Question 27)**

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

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**N/A**
When the person I care for accesses aged care services…						
…I am asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…I am provided with all the information I need	☐	☐	☐	☐	☐	☐
The aged care services received by the person I care for…						
…give me a break from providing care	☐	☐	☐	☐	☐	☐
…enable me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…meet the needs of the person I care for	☐	☐	☐	☐	☐	☐
…meet my needs as a carer (e.g. are available when I can't provide care)	☐	☐	☐	☐	☐	☐
…meet my expectations for quality and safety	☐	☐	☐	☐	☐	☐
…are easy to organise	☐	☐	☐	☐	☐	☐

27. Have you or the person(s) you care for experienced any of the following challenges with aged care services? Please tick all that apply.

☐ The person I care for was not eligible for the required services
☐ The service received was at a lower level than what was required
☐ There was a long waiting period to get assessed
☐ There was a long waiting period to access services
☐ The services required were not available locally
☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
☐ There were concerns about the quality or safety of the services
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ The person(s) I care for did not want to use services
☐ Other, please describe:______________________________
☐ None of the above

Please leave any comments you might have on your experience with aged care services:

____

____

____

28. Does someone you care for currently receive support through the National Disability Insurance Scheme (NDIS)? Please tick all that apply.

The National Disability Insurance Scheme (NDIS) provides government funded services to people under the age of 65 years who have a significant or permanent disability.

☐ No, nobody I care for currently needs disability services **(Please go to Question 31)**
☐ Yes, someone I care for has a National Disability Insurance Scheme plan (NDIS plan)
☐ Someone I care for needs the NDIS, but has not been able to access these services to date **(Please go to Question 30)**
☐ Someone I care for uses disability services outside of the NDIS **(Please go to Question 30)**
☐ Other, please specify: ______________________________ **(Please go to Question 30)**
☐ I don't know **(Please go to Question 30)**

29. How much do you agree with the following statements?

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**N/A**
The local area coordinator (LAC) / NDIS planner…						
… asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…provided me with all the information I needed	☐	☐	☐	☐	☐	☐

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The supports included in the NDIS plan (for the person I care for)…						
…give me a break from providing care	☐	☐	☐	☐	☐	☐
…enable me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…meet the needs of the person I care for	☐	☐	☐	☐	☐	☐
…meet my needs as a carer (e.g. are available when I can't provide care)	☐	☐	☐	☐	☐	☐
…meet my expectations for quality and safety	☐	☐	☐	☐	☐	☐
…are easy to organise	☐	☐	☐	☐	☐	☐

30. **Have you or the person(s) you care for experienced any of the following challenges with the NDIS or other disability services?** Please tick all that apply.

☐ The person I care for was not eligible for the NDIS
☐ The person I care for did not receive enough funding in their NDIS plan
☐ Services outside the NDIS (either in addition to, or instead of the NDIS) were not available
☐ There was a long waiting period to get assessed
☐ There was a long waiting period to access services
☐ The services required were not available locally
☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ The person(s) I care for did not want to use services
☐ Other, please describe:______________________________
☐ None of the above

Please leave any comments you might have on your experience with disability services:

31. Does someone you care for currently use mental health services?

Please tick all that apply

Mental health services include government funded community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health or living with a mental illness.

- ☐ No, nobody I care for currently needs mental health services **(Please go to Question 34)**
- ☐ Yes, someone I care for uses hospital based mental health services as admitted patient or in out-of-hospital care
- ☐ Yes, someone I care for sees a private psychologist or psychiatrist
- ☐ Yes, someone I care for uses community mental health services, such as drop-in clinics, or rehabilitation programs
- ☐ Someone I care for needs mental health services but has not been able to access these services to date **(Please go to Question 33)**
- ☐ I don't know **(Please go to Question 33)**
- ☐ Other, please specify: ______________________ **(Please go to Question 33)**

32. How much do you agree with the following statements?

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**	**N/A**
When the person I care for accesses mental health services…						
…I am asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…I am provided with all the information I need	☐	☐	☐	☐	☐	☐
The mental health services received by the person I care for…						
…give me a break from providing care	☐	☐	☐	☐	☐	☐
…enable me to keep my job, or go back to work	☐	☐	☐	☐	☐	☐
…meet the needs of the person I care for	☐	☐	☐	☐	☐	☐
…meet my needs as a carer (e.g. are available when I can't provide care)	☐	☐	☐	☐	☐	☐
…meet my expectations for quality and safety	☐	☐	☐	☐	☐	☐
…are easy to organise	☐	☐	☐	☐	☐	☐

33. **Have you or the person(s) you care for experienced any of the following challenges with mental health services?** Please tick all that apply.

☐ The person I care for was not eligible for the required services
☐ The service received was at a lower level than required
☐ There was a long waiting period to access services
☐ The services required were not available locally
☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ The person(s) I care for did not want to use services
☐ Other, please describe:______________________________
☐ None of the above

Please leave any comments you might have on your experience with mental health services:

____

____

____

The following questions are about when the person you care for accesses health services, including a general practitioner (GP) or family doctor, community health services and services within a hospital. Please indicate how much you agree with the following statements:

34. **How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When I accompany the person I care for to visit a GP…						
…I am asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…I am provided with all the information I need	☐	☐	☐	☐	☐	☐
When I accompany the person I care on a visit to the hospital or community health service…						
…I am asked about my needs as a carer	☐	☐	☐	☐	☐	☐
…I am provided with all the information I need	☐	☐	☐	☐	☐	☐
…there are sufficient support options and facilities for carers (e.g. seating, overnight rooms, transport support)	☐	☐	☐	☐	☐	☐

35. **Please leave any comments you might have on your experience with health services:**

____

____

____

36. **Which of the following carer support services do you currently use? Which would you like to use more?**

Support type	I am currently using this support	I would like to use this support more
Carer peer support (face to face carer support groups)	☐	☐
Online forums or groups	☐	☐
In-person carer counselling (counselling designed specifically to address challenges relating to the caring role)	☐	☐
Carer counselling over the phone	☐	☐
Carer coaching or mentoring (working on personal goals and resilience relating to the caring role, one-to-one)	☐	☐
Emergency respite (care in a facility or in the home provided when you are suddenly unable to provide care for a period of time)	☐	☐
Planned respite (care in a facility or in the home booked in advance so that you are able to participate in other activities or take a longer break from caring)	☐	☐
Carer specific online information or training courses	☐	☐
Carer specific face-to-face information sessions or workshops	☐	☐
Other, please specify: ____________________	☐	☐

37. **Have you heard of the Carer Gateway?**

☐ No
☐ Yes, and I have used it (e.g. called the 1800 number, visited the website, accessed services from a Carer Gateway Service Provider in my local area)
☐ Yes, but I have not used it

Please leave any comments you might have on your experience with the Carer Gateway:

____

____

____

38. **How much do you agree with the following statements:**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I never get time out from my caring responsibilities	☐	☐	☐	☐	☐	☐
I am able to take just enough time out from my caring responsibilities to keep going	☐	☐	☐	☐	☐	☐
I am able to take just enough time out from my caring responsibilities to keep on top of other responsibilities, e.g. household chores	☐	☐	☐	☐	☐	☐
I am able to regularly take enough time out from my caring responsibilities to properly relax and recuperate	☐	☐	☐	☐	☐	☐
I am able to take enough time out from my caring responsibilities to pursue my own goals and interests	☐	☐	☐	☐	☐	☐
When I have time away from my caring responsibilities I am still constantly thinking about the needs of the person I care for	☐	☐	☐	☐	☐	☐

39. **Have you experienced any of the following challenges with carer support services?** Please tick all that apply.

☐ The service received was at a lower level than what was required
☐ There was a long waiting period to access services
☐ The services I needed were not available locally
☐ The services available did not meet my needs (e.g. available when I needed them)
☐ There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity)
☐ I was concerned about the quality or safety of the services available
☐ The cost of services (including co-payments) was too high
☐ It was difficult to find information about what services were available and how to access them
☐ It took too much time and energy to organise the services
☐ I don't see myself as a carer
☐ My caring role is a private matter
☐ The person I care for does not think I need or want services
☐ There is not enough transport to the services
☐ I do not want or need any or more services to help me in my care role
☐ Service providers think the person I care for is the only one who needs help
☐ I can't organise another carer or respite to take enough time out
☐ None of the above
☐ Other, please tell us:________________________________

SECTION 4: PAID WORK

40. Which of the following have you experienced as a result of your caring role? Please tick all that apply.

☐ I have lacked the knowledge and confidence to apply for jobs effectively
☐ My skills or qualifications have become out of date due to time out of the workforce
☐ I feel less prepared to meet the demands of my job
☐ I have worked in a job lower than my skillset
☐ I reduced my working hours
☐ I changed industry/occupation
☐ I turned down a new job or promotion
☐ I quit working or looking for work to be able to care
☐ I retired earlier than anticipated to be able to care
☐ I could not find any jobs in my field that would allow me to continue with my caring responsibilities
☐ I have been denied an opportunity by an employer
☐ An employer has changed my working conditions
☐ None of the above
☐ Other, please specify: ____

41. What is your occupation? ____

42. Do you currently have a paid job?

☐ Yes
☐ No, but I am looking for work **(Please go to Question 49)**
☐ No, and I am not looking for work **(Please go to question 50)**

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

________ hours

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

44. Which of the following apply to you?

☐ I am a permanent employee (either part time or full time)
☐ I have a fixed-term contract (either part time or full time)
☐ I have a casual job
☐ I am self-employed
☐ I am an independent contractor
☐ Other, please specify: ____

If you are a former carer, and you are not **currently** providing care for someone, please go to Question 50.

45. **How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I have to miss caring activities due to the amount of time I must spend on my job	☐	☐	☐	☐	☐	☐
I am often so emotionally drained when I finish work that it affects my ability to provide care	☐	☐	☐	☐	☐	☐
The behaviours that make me effective at work do not help me to be a better carer	☐	☐	☐	☐	☐	☐
I have to miss work activities due to the amount of time I must spend caring	☐	☐	☐	☐	☐	☐
Because of my caring responsibilities, I have a hard time concentrating on my job	☐	☐	☐	☐	☐	☐
Behaviour that is effective and necessary for me as a carer (e.g. being compassionate) would be counterproductive at work	☐	☐	☐	☐	☐	☐

46. **How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The job allows me to plan how I do my work	☐	☐	☐	☐	☐	☐
The job involves performing a variety of tasks	☐	☐	☐	☐	☐	☐
The results of my work are likely to significantly affect the lives of other people	☐	☐	☐	☐	☐	☐
The job involves performing relatively simple tasks	☐	☐	☐	☐	☐	☐
I have the opportunity to develop close friendships in my job	☐	☐	☐	☐	☐	☐

47. **How much do you agree with the following statements?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
Being in paid work…						
Helps me to understand different viewpoints and this helps me be a better carer	☐	☐	☐	☐	☐	☐
Makes me feel good and this helps me be a better carer	☐	☐	☐	☐	☐	☐
Helps me feel personally fulfilled and this helps me be a better carer	☐	☐	☐	☐	☐	☐
My involvement in caring…						
Helps me acquire skills and this helps me be a better employee	☐	☐	☐	☐	☐	☐
Puts me in a good mood and this helps me be a better employee	☐	☐	☐	☐	☐	☐
Encourages me to use my work time in a focused manner and this helps me be a better employee	☐	☐	☐	☐	☐	☐

48. **Which of the following flexible working arrangements are you using in your current job to accommodate your caring role?** Please tick all that apply.

☐ Flexible start / finish times
☐ Working from home
☐ Job sharing
☐ Paid personal leave (from the 10 accruable days per year to be used for sick leave and/or carers leave)
☐ Paid carers leave in addition to the 10 day entitlement
☐ Unpaid carers leave (from the 2 days most workers are entitled to)
☐ Additional unpaid carers leave granted by employer
☐ Annual leave (holidays)
☐ None of the above
☐ Other, please specify: ______________________________

49. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I had trouble finding work, because…						
…my skills weren't recognised	☐	☐	☐	☐	☐	☐
…it wouldn't be possible to respond to an emergency	☐	☐	☐	☐	☐	☐
…the type of work would have kept me from sufficiently checking on the person I care for	☐	☐	☐	☐	☐	☐
…the demands on time would have been too high to keep up my caring role	☐	☐	☐	☐	☐	☐
…there wasn't enough support for carers by the prospective employer (e.g. lack of flexibility)	☐	☐	☐	☐	☐	☐
…it wouldn't be possible to take enough paid leave to keep up the caring role	☐	☐	☐	☐	☐	☐

SECTION 5: YOUR HEALTH AND WELLBEING

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

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your standard of living	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
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	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Nervous	☐	☐	☐	☐	☐
Without hope	☐	☐	☐	☐	☐
Restless or jumpy	☐	☐	☐	☐	☐
That everything was an effort	☐	☐	☐	☐	☐
So sad that nothing could cheer you up	☐	☐	☐	☐	☐

52. **How many hours per week do you have for yourself?**

"Time for yourself" is time where you can pursue activities of your choice - that are not related to caring responsibilities, work, or to household and other chores.

________ hours

53. **How often have you experienced the following?**

	Almost always	Most of the time	About half the time	Occasionally	Not at all
During the past four weeks…					
It has been easy to relate to others	☐	☐	☐	☐	☐
I felt isolated from other people	☐	☐	☐	☐	☐
I had someone to share my feelings with	☐	☐	☐	☐	☐
	Almost always	**Most of the time**	**About half the time**	**Occasionally**	**Not at all**
I found it easy to get in touch with others when I needed to	☐	☐	☐	☐	☐
When with other people, I felt separate from them	☐	☐	☐	☐	☐
I felt alone and friendless	☐	☐	☐	☐	☐

54. **How satisfied are you with…**

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10	N/A
…your relationship with your partner?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your parents?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your children?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
…your relationship with your friends?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

55. **How much do you agree with the following statement?**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I feel that my caring role is recognised and valued by my community	☐	☐	☐	☐	☐	☐
I feel that my caring role is recognised and valued by my family	☐	☐	☐	☐	☐	☐
I feel that my caring role is recognised and valued by my friends	☐	☐	☐	☐	☐	☐
I feel that my caring role is recognised and valued by service providers	☐	☐	☐	☐	☐	☐
I feel that my caring role is recognised and valued by the government	☐	☐	☐	☐	☐	☐

56. **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, which has been made worse by your caring role?**

☐ Yes (please specify:____________________________________)
☐ If yes, what form of support would improve your health? ____________________________________

____

____

☐ No

SECTION 6: ABOUT YOU

57. How old are you? ________ years old

58. What is the postcode where you live? ________

59. What is your gender?

☐ Female
☐ Male
☐ Non-binary / gender diverse
☐ My gender identity isn't listed. I identify as: ____
☐ Prefer not to say

60. What is your cultural background? (e.g., Italian, Chinese, Australian, etc.) ________________________________

61. Do you speak a language(s) other than English at home?

☐ Yes, I speak ____ (e.g. Vietnamese, Auslan)
☐ No, English only
☐ Prefer not to say

62. Are you of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both
☐ Prefer not to say

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

☐ Less than high school (year 12 or equivalent)
☐ High school (year 12 or equivalent)
☐ Certificate / diploma
☐ Bachelor degree or higher
☐ Other, please specify: ____

64. Are you currently enrolled in any formal education?

☐ No
☐ Yes – high school
☐ Yes – TAFE / apprenticeship
☐ Yes – university
☐ Other, please specify: ____

65. Do you consider yourself to be:

☐ Lesbian, gay, or homosexual
☐ Straight or heterosexual
☐ Bisexual
☐ Queer
☐ Not listed, my sexual orientation is: ____
☐ Prefer not to say

66. How confident are you...

	Very confident	Confident	Somewhat confident	Not at all confident	N/A
…using the internet to find information about caring	☐	☐	☐	☐	☐
…using the internet to access online support services	☐	☐	☐	☐	☐
…using the internet to stay in contact with friends and family	☐	☐	☐	☐	☐

67. What is your household's yearly income (before tax)?

Please include your partner's and / or family members' typical income from all sources (e.g. wages, pension, investment income). Please tick your best estimate:

☐ Up to $9,999 per year ($1 - $189 per week)
☐ $10,000 - $19,999 per year ($190 - $379 per week)
☐ $20,000 - $29,999 per year ($380 - $579 per week)
☐ $30,000 - $39,999 per year ($580 - $769 per week)
☐ $40,000 - $49,999 per year ($770 - $959 per week)
☐ $50,000 - $59,999 per year ($960 - $1,149 per week)
☐ $60,000 - $79,999 per year ($1,150 - $1,529 per week)
☐ $80,000 - $99,999 per year ($1,530 - $1,919 per week)
☐ $100,000 - $124,999 per year ($1,920 - $2,399 per week)
☐ $125,000 - $149,999 per year ($2,400 - $2,879 per week)
☐ $150,000 or more ($2,880 per week or more)
☐ Prefer not to say

68. Including you, how many people are living in your household?

________ Children under the age of 15

________ Children aged 15 to 18

________ Adults aged 18 to 64

________ Adults aged 65 and older

69. Do you receive any payments from Centrelink? Please tick all that apply

☐ Carer Allowance (currently $131.90 per fortnight)
☐ Carer Payment (currently up to $933.40 per fortnight for singles and $1,407.00 for couples)
☐ Newstart Allowance
☐ Age Pension
☐ Disability Support Pension
☐ Commonwealth Rent Assistance
☐ Other, please specify ________
☐ I don't know
☐ None of the above

70. **In the last 12 months, did any of the following apply to you?** Please tick all that apply

☐ You would have been unable to raise $2,000 in a week for something important
☐ You could not pay rent or mortgage payments on time
☐ You spend more money than you received in a month
☐ You could not pay gas, electricity, water, or telephone bill on time
☐ You could not pay registration or insurance on time
☐ You pawned or sold something
☐ You went without meals
☐ You were unable to heat or cool home
☐ You sought assistance from welfare/community organisations
☐ You sought financial help from friends or family
☐ None of the above

71. **Did you need to pay for any of the following for the person(s) you care for at least once in the last 12 months?**

☐ Medicine
☐ Support services
☐ Transport (including parking)
☐ Insurance
☐ Housing
☐ Housing modifications
☐ Special training
☐ Health services and equipment
☐ Other, please specify: ______________________________
☐ None of the above

72. **Are you a member / affiliate member of, or registered with, the Carers Association in your state or territory (e.g. Carers NSW, Carers WA…)?**

☐ Yes
☐ No
☐ Don't know

73. **Optional: Is there anything else you would like to tell us about your experiences as a carer?**

____

____

____

____

____

You have finished the survey – thank you for your input!

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carer Gateway (1800 422 737, open Monday to Friday, 8am to 5pm), which will offer support and carer specific services in your area.

If you are in distress, please call Lifeline (13 11 14, open 24 hours, 7 days), or contact your local GP (https://www.healthdirect.gov.au/australian-health-services). In an emergency, please call 000.

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/.

74. OPTIONAL: Please participate in the follow-up study in 2022 and help us track the impact of caring over time!

If you agree to participate, we will contact you for the next carer survey in 2022. Your answers will be assigned a randomly generated unique identifier, allowing a comparison over time. No information identifying you personally will be stored in the dataset. Please refer to the accompanying Participant Information and Consent Form for details.

☐ Yes I would like to participate in the follow-up study!

Please provide your contact details below.

75. OPTIONAL: As a thank you for participating in the survey, you can win an Apple iPad 32GB Wi-Fi!

The prize will be drawn on 30 July 2020, the winner will be contacted via email.

☐ Yes I would like to participate in the prize draw!

Please provide your contact details below.

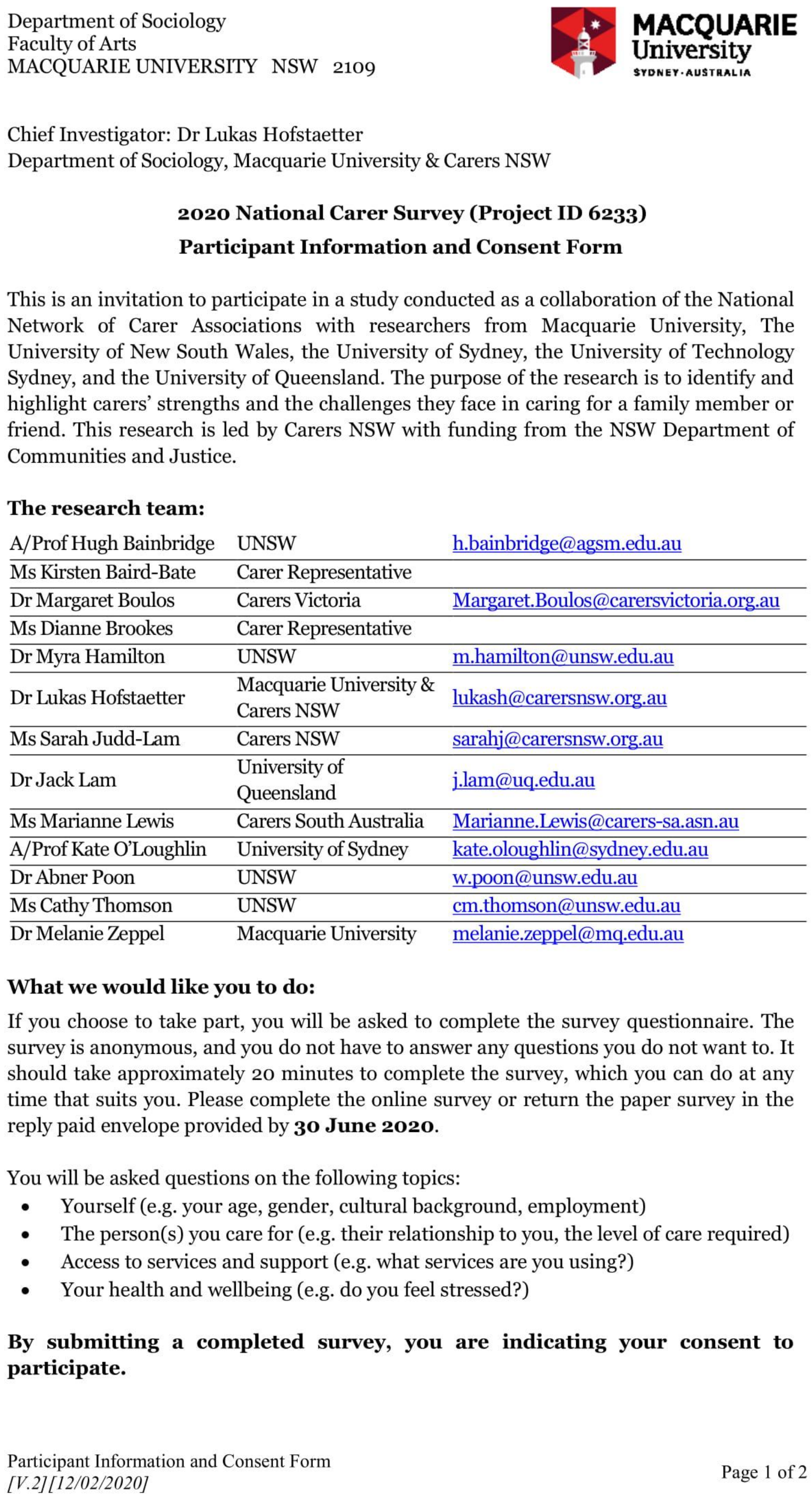
I want to participate in the follow-up study and/or the prize draw. My contact details are:

Name

Email

Street address

Appendix B: Participant Information and Consent Form



Department of Sociology
Faculty of Arts
MACQUARIE UNIVERSITY NSW 2109

Chief Investigator: Dr Lukas Hofstaetter
Department of Sociology, Macquarie University & Carers NSW

2020 National Carer Survey (Project ID 6233)

Participant Information and Consent Form

This is an invitation to participate in a study conducted as a collaboration of the National Network of Carer Associations with researchers from Macquarie University, The University of New South Wales, the University of Sydney, the University of Technology Sydney, and the University of Queensland. The purpose of the research is to identify and highlight carers' strengths and the challenges they face in caring for a family member or friend. This research is led by Carers NSW with funding from the NSW Department of Communities and Justice.

The research team:

A/Prof Hugh Bainbridge	UNSW	h.bainbridge@agsm.edu.au
Ms Kirsten Baird-Bate	Carer Representative	
Dr Margaret Boulos	Carers Victoria	Margaret.Boulos@carersvictoria.org.au
Ms Dianne Brookes	Carer Representative	
Dr Myra Hamilton	UNSW	m.hamilton@unsw.edu.au
Dr Lukas Hofstaetter	Macquarie University & Carers NSW	lukash@carersnsw.org.au
Ms Sarah Judd-Lam	Carers NSW	sarahj@carersnsw.org.au
Dr Jack Lam	University of Queensland	j.lam@uq.edu.au
Ms Marianne Lewis	Carers South Australia	Marianne.Lewis@carers-sa.asn.au
A/Prof Kate O'Loughlin	University of Sydney	kate.oloughlin@sydney.edu.au
Dr Abner Poon	UNSW	w.poon@unsw.edu.au
Ms Cathy Thomson	UNSW	cm.thomson@unsw.edu.au
Dr Melanie Zeppel	Macquarie University	melanie.zeppel@mq.edu.au

What we would like you to do:

If you choose to take part, you will be asked to complete the survey questionnaire. The survey is anonymous, and you do not have to answer any questions you do not want to. It should take approximately 20 minutes to complete the survey, which you can do at any time that suits you. Please complete the online survey or return the paper survey in the reply paid envelope provided by **30 June 2020**.

You will be asked questions on the following topics:

- Yourself (e.g. your age, gender, cultural background, employment)
- The person(s) you care for (e.g. their relationship to you, the level of care required)
- Access to services and support (e.g. what services are you using?)
- Your health and wellbeing (e.g. do you feel stressed?)

By submitting a completed survey, you are indicating your consent to participate.

At the end of this survey, you will have the option to register for participation in a follow-up study in 2022 by providing Carers NSW with contact details. These details will only be used to contact you for the follow-up study, and not for any other purpose. Your contact details will be stored in a separate database and will not be part of any analysis. If you do not wish to participate in the follow-up study you still can take part in the survey.

You can also choose to enter a prize draw. One participant from each state or territory can win an Apple iPad 32 GB WiFi. The prize draw will be conducted on **30 July 2020**, the winner will be contacted via email or post.

If you have any questions or would like assistance to complete the survey, please contact Carers NSW Research Team on (02) 9280 4744.

Possible risks, inconveniences and discomforts

It is not envisaged that you will experience any discomfort as a result of participating in this survey. However, if your participation raises any issues of concern or discomfort, you are encouraged to call either of these services:

Carer Gateway
(8am – 5pm Monday to Friday)
1800 422 737

Lifeline Australia
(24 hours)
13 11 14

In an emergency, call **Triple Zero 000**

Lifeline Text
(6pm – Midnight, 7 days a week)
0477 13 11 14

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/.

Completing the survey is completely voluntary and you may withdraw your participation at any time. Any partially completed surveys will be excluded from the final analysis. Refusal to participate will not affect your relationship with Carers NSW or any of the collaborating universities.

Benefits of the research

This research will help to direct the advocacy and support work of the National Network of Carer Associations in Australia. Findings will be used to identify areas of greatest need amongst carers across Australia, and the particular needs of different carer groups (e.g., different geographic locations, different care recipient conditions, etc.). Survey results will be published in a report that will be made publicly available online, along with factsheets. Results will also be published in a number of peer reviewed journal articles and will also be presented at relevant conferences. Each member of the research team will have access to the information collected, however, as survey responses are anonymous, you will not be personally identified in any part of the research.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Appendix C: Key findings by state and territory

Australian Capital Territory (ACT) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in the ACT.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

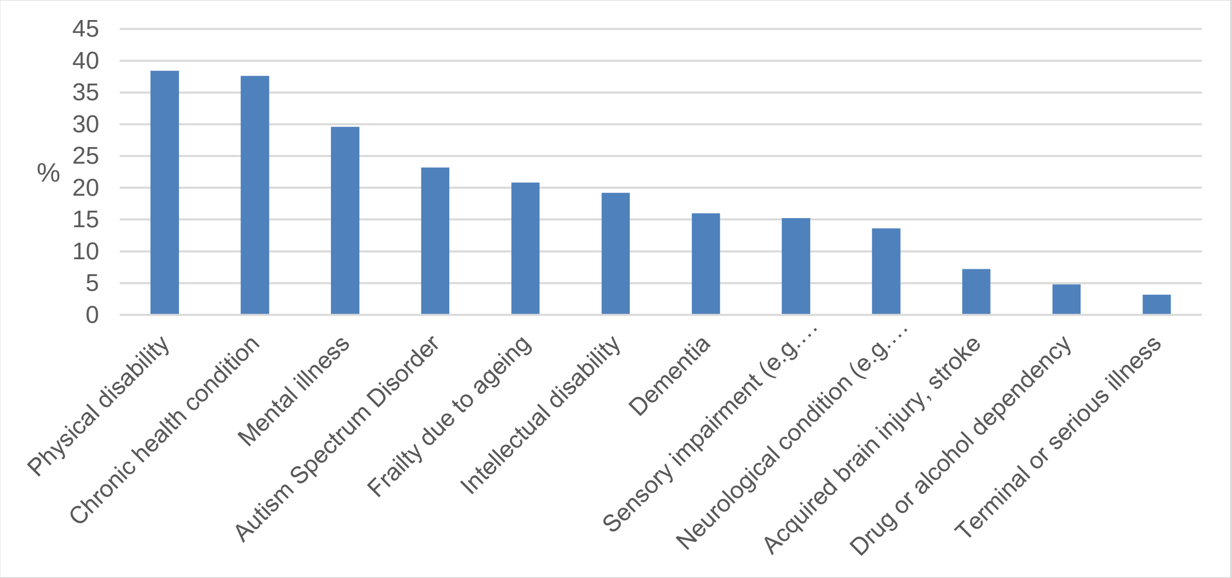


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in the ACT and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

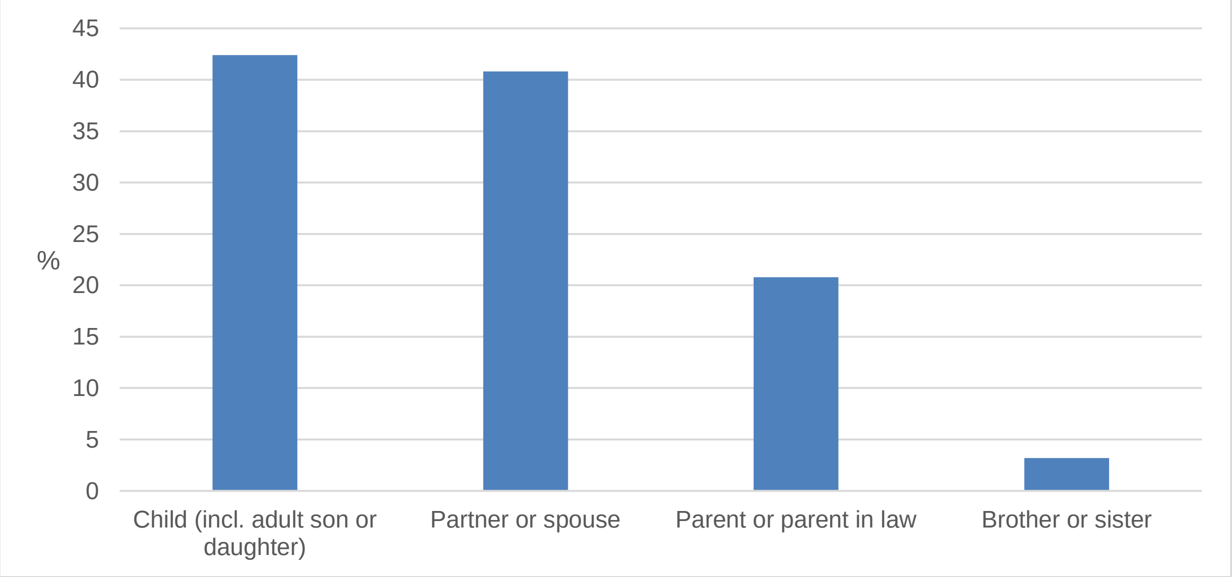


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

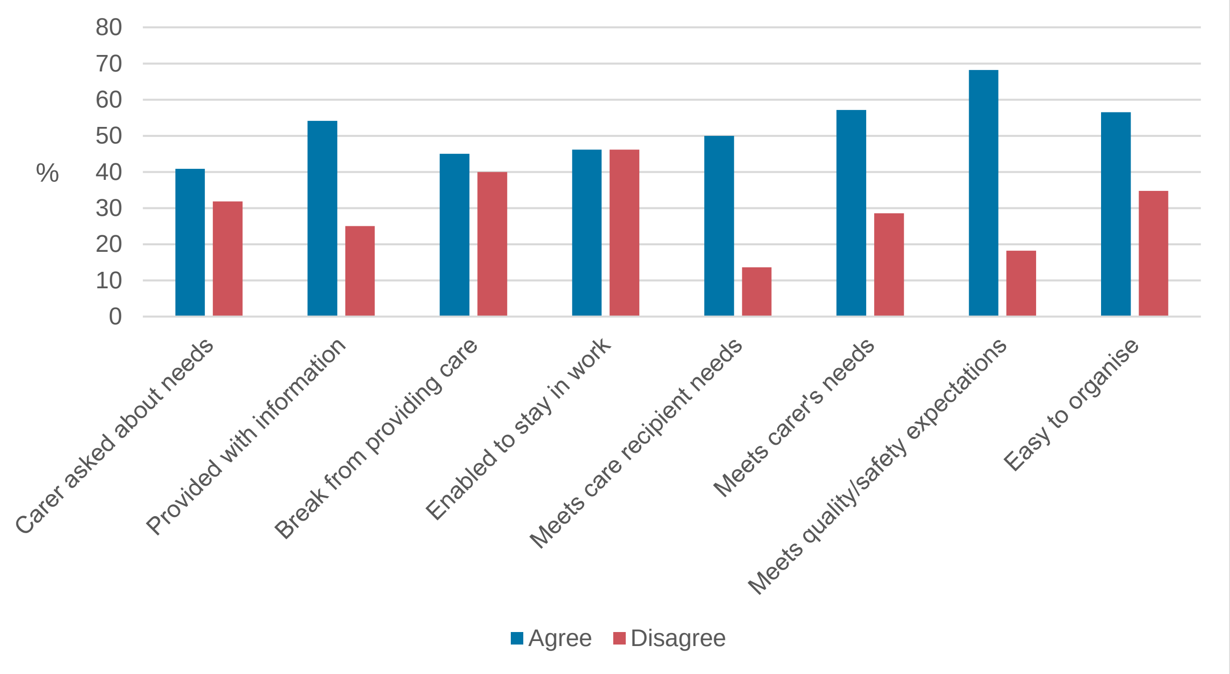


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

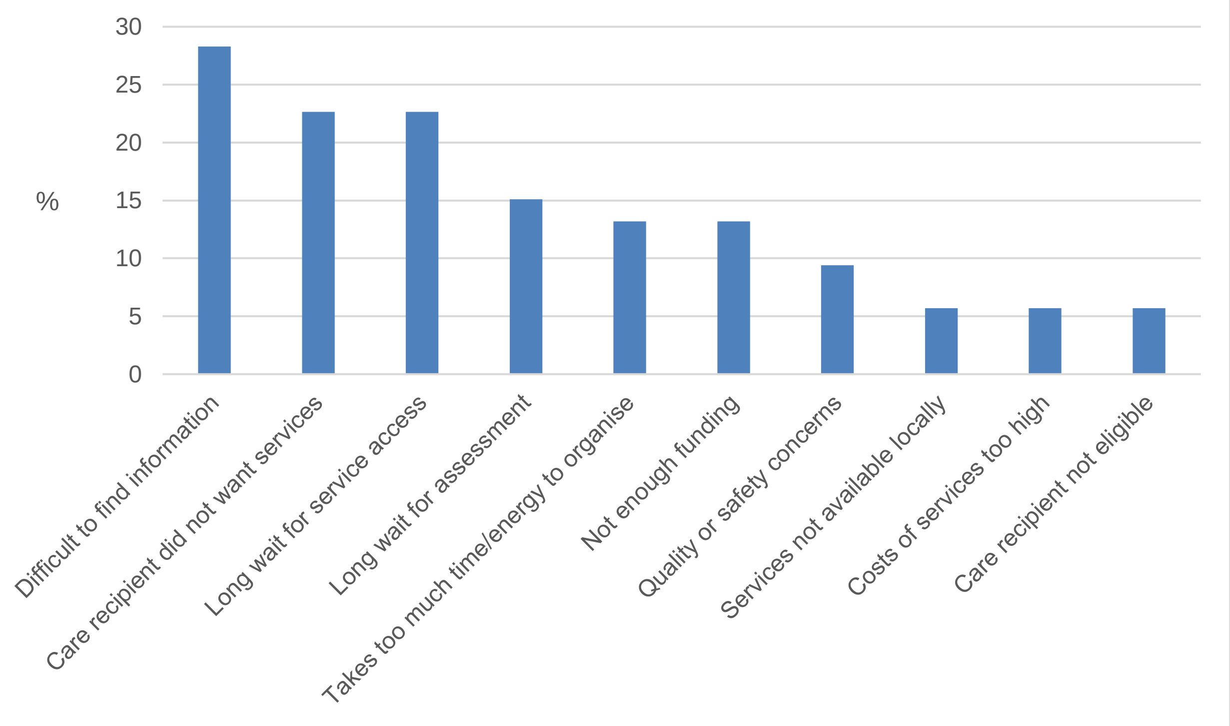


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

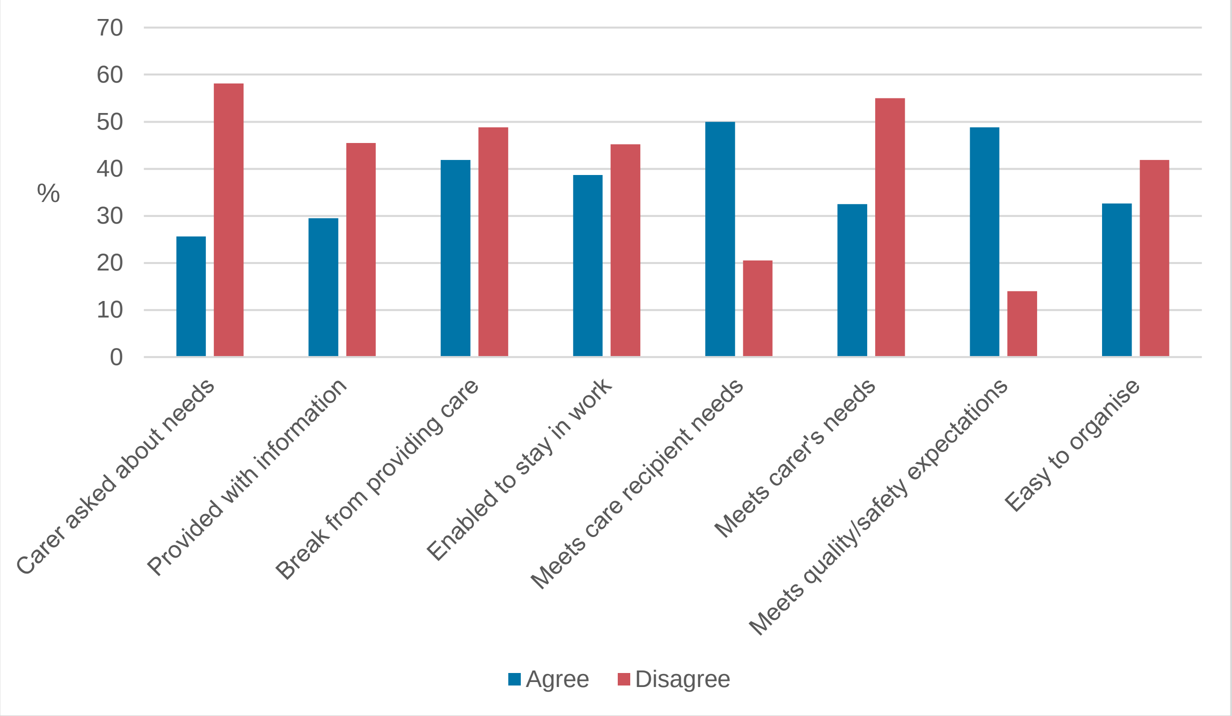


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

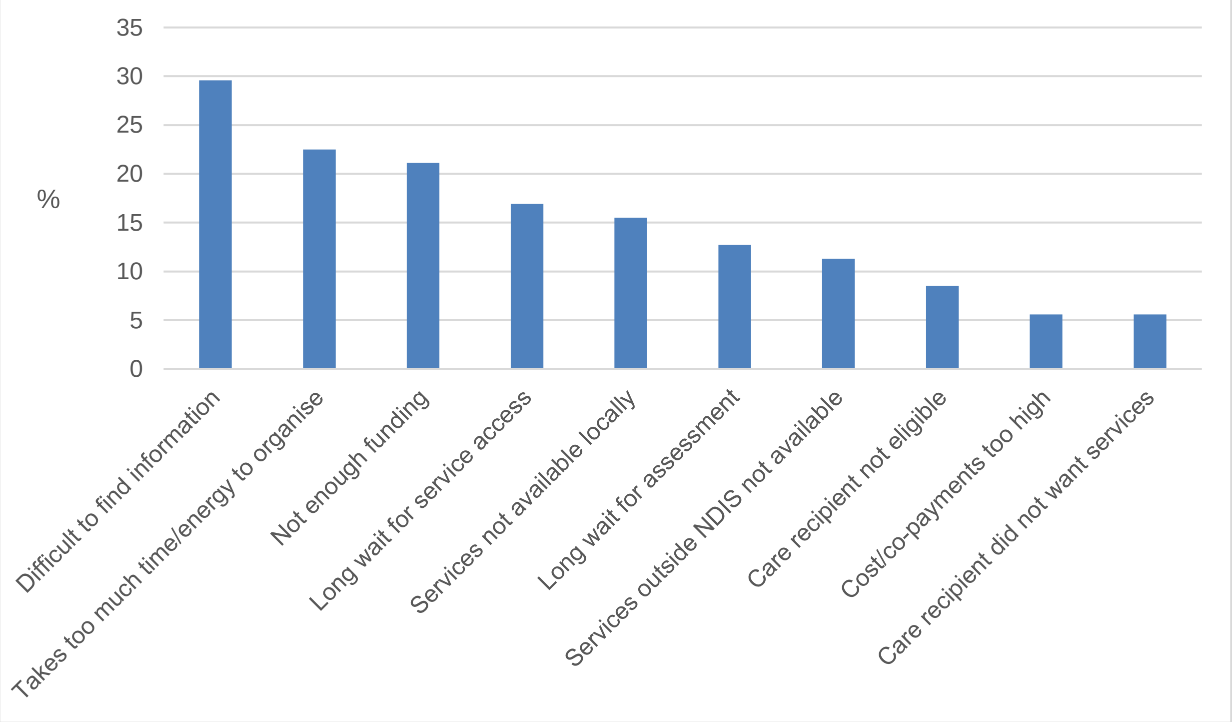


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

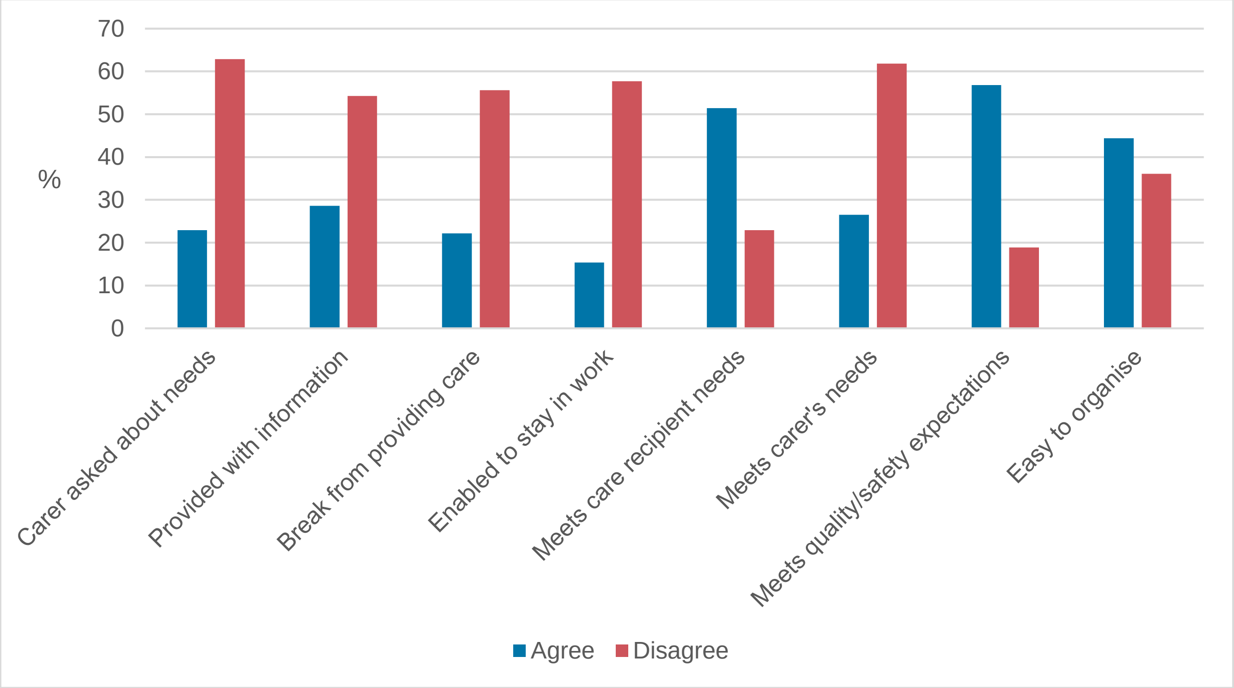


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

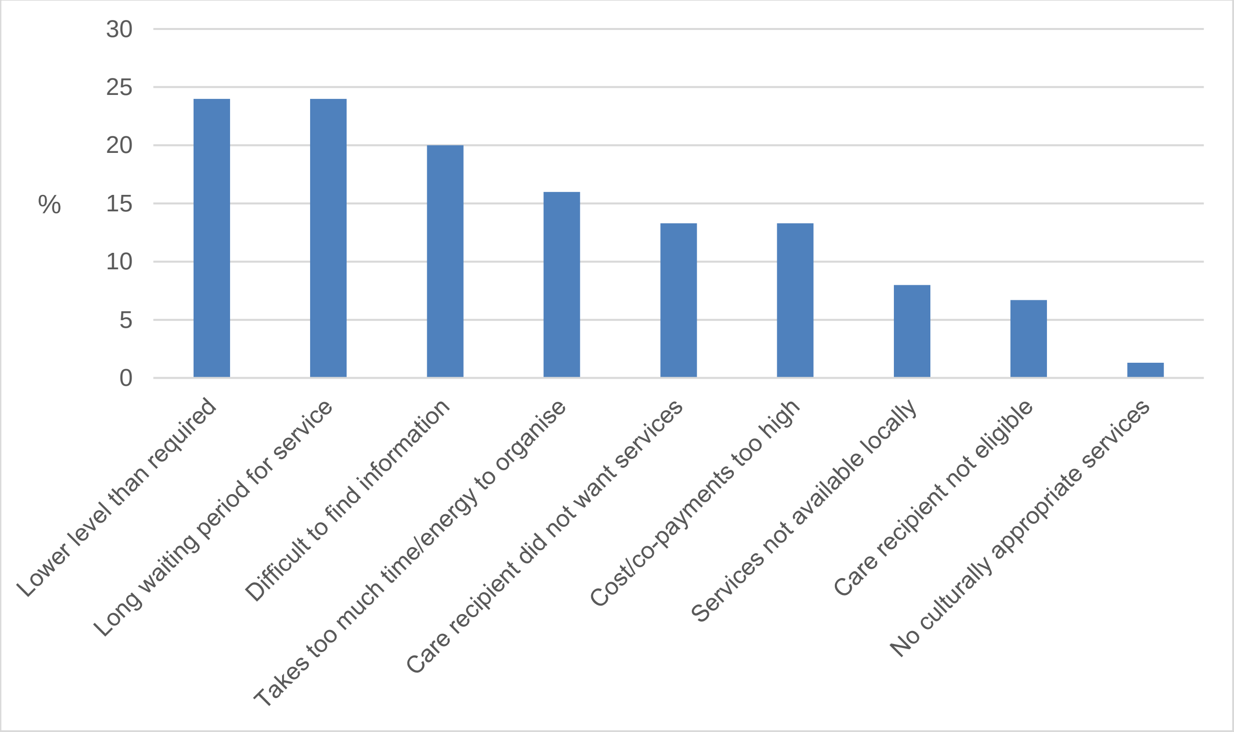


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Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

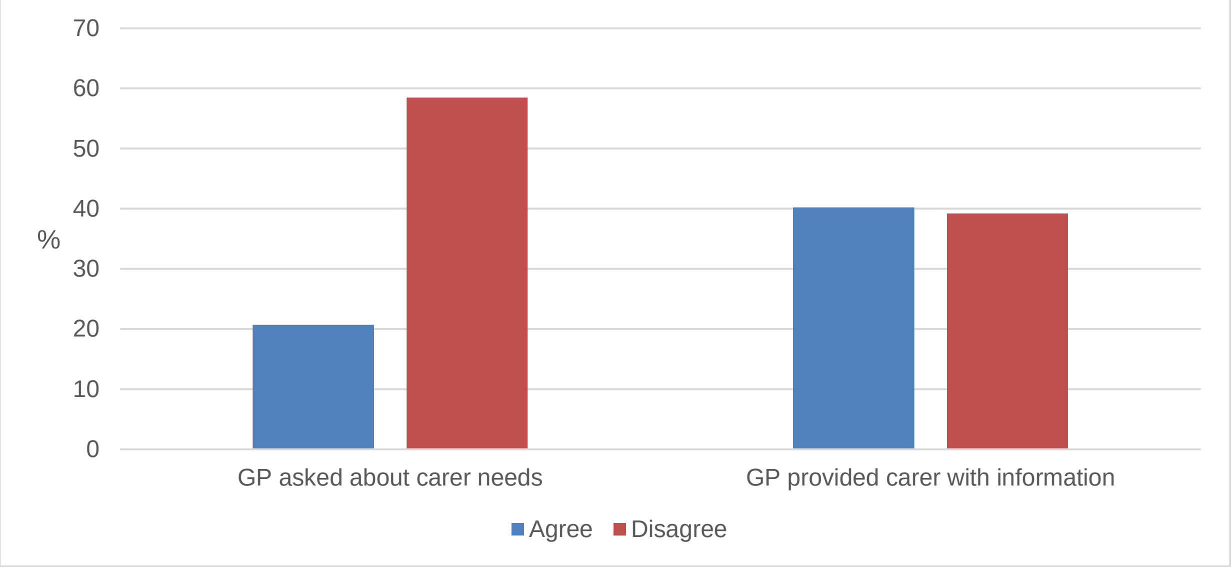


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

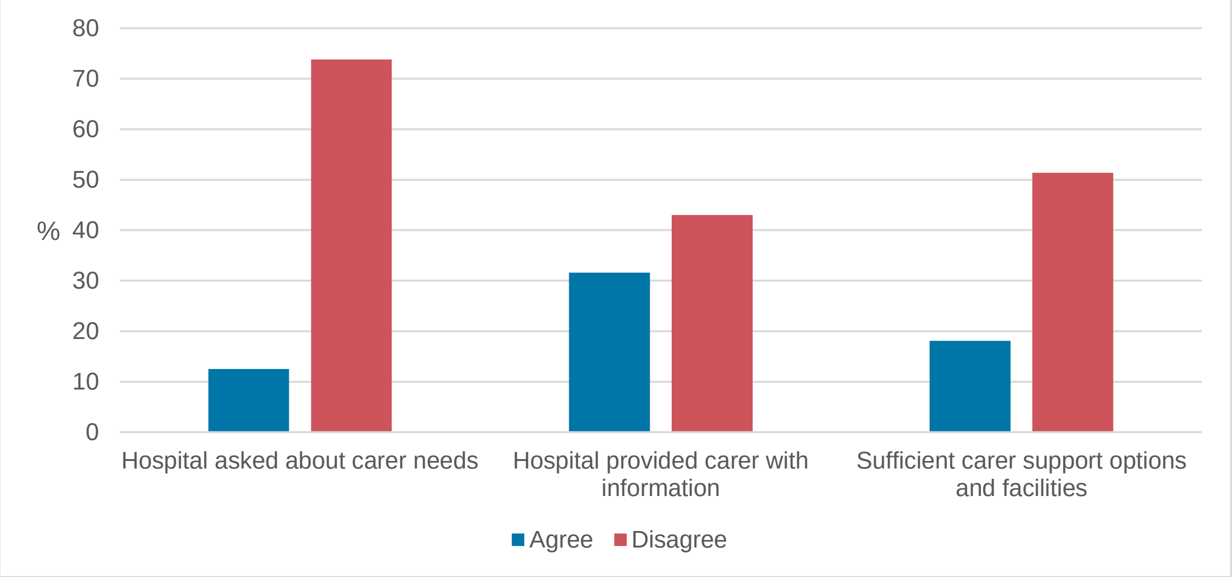
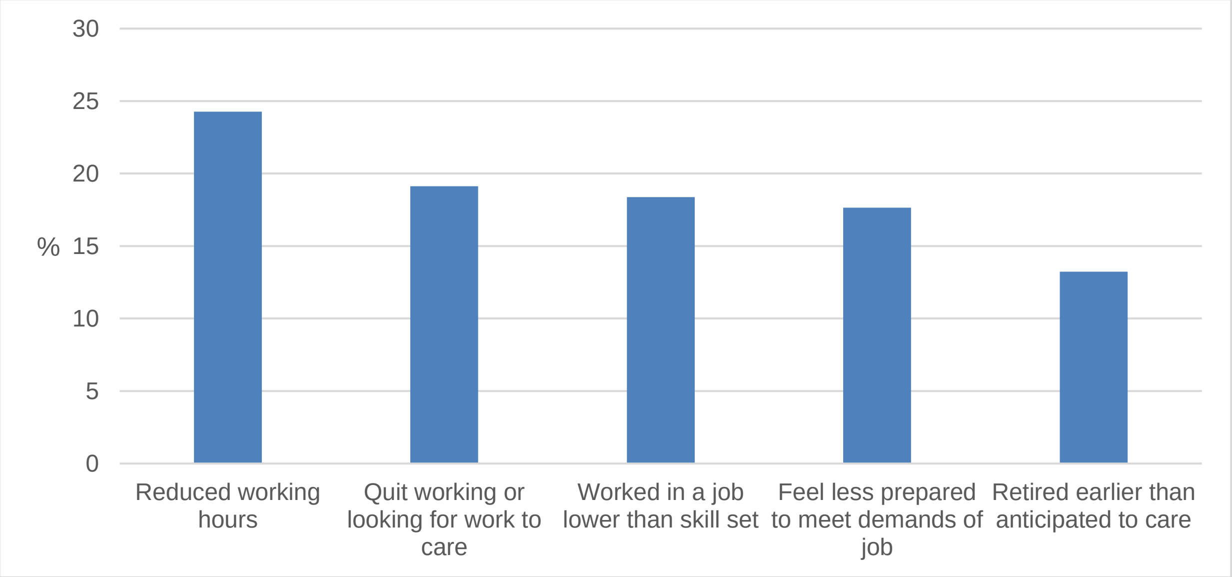


Figure 11 identifies the five most common impacts on career trajectory reported by carers in the ACT.

Figure 11: Most common impacts of caring on career trajectory



New South Wales (NSW) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in NSW.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

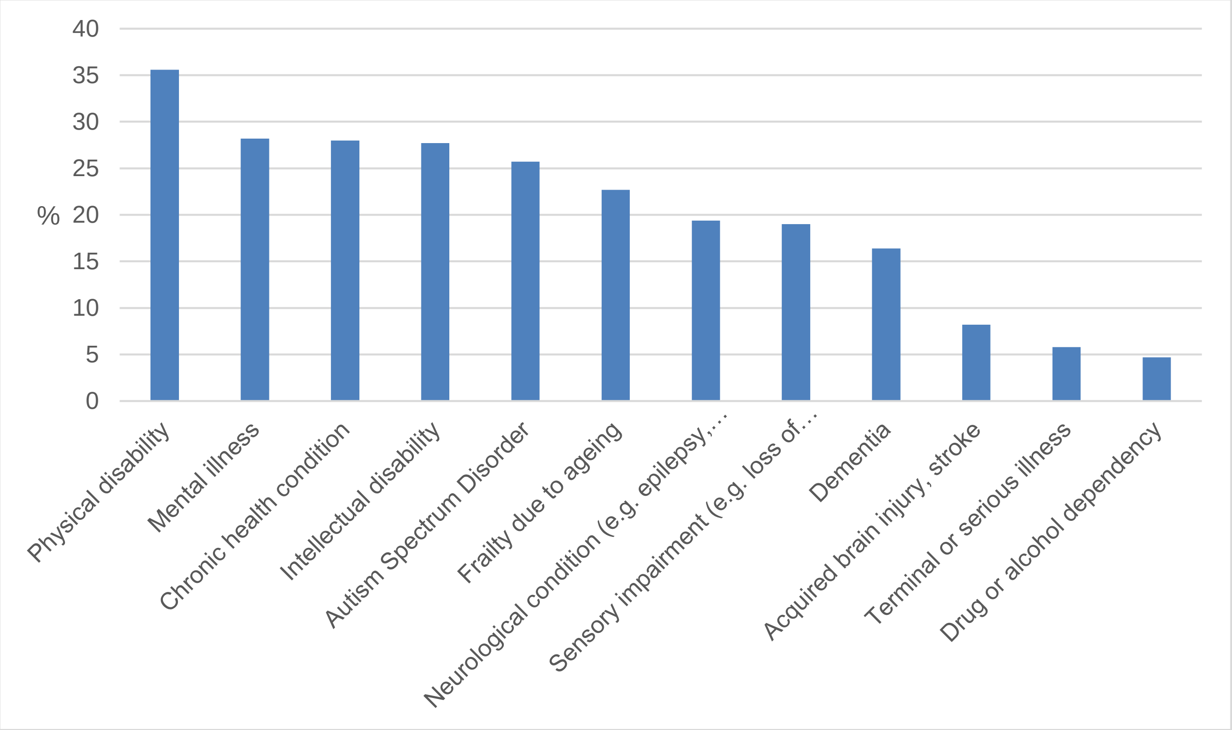


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in the NSW and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

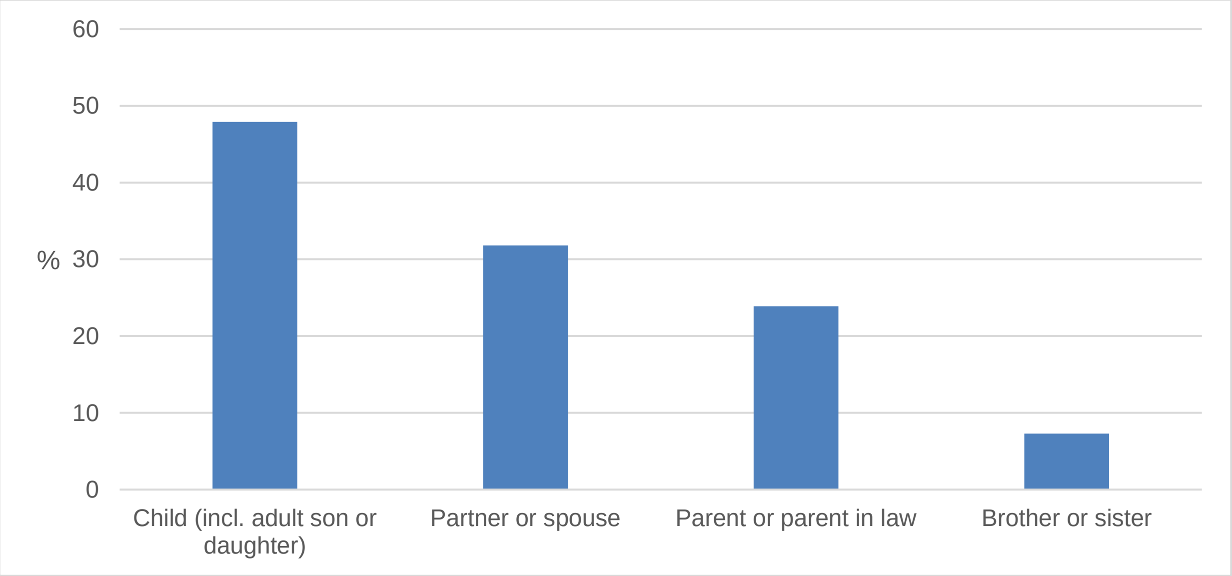


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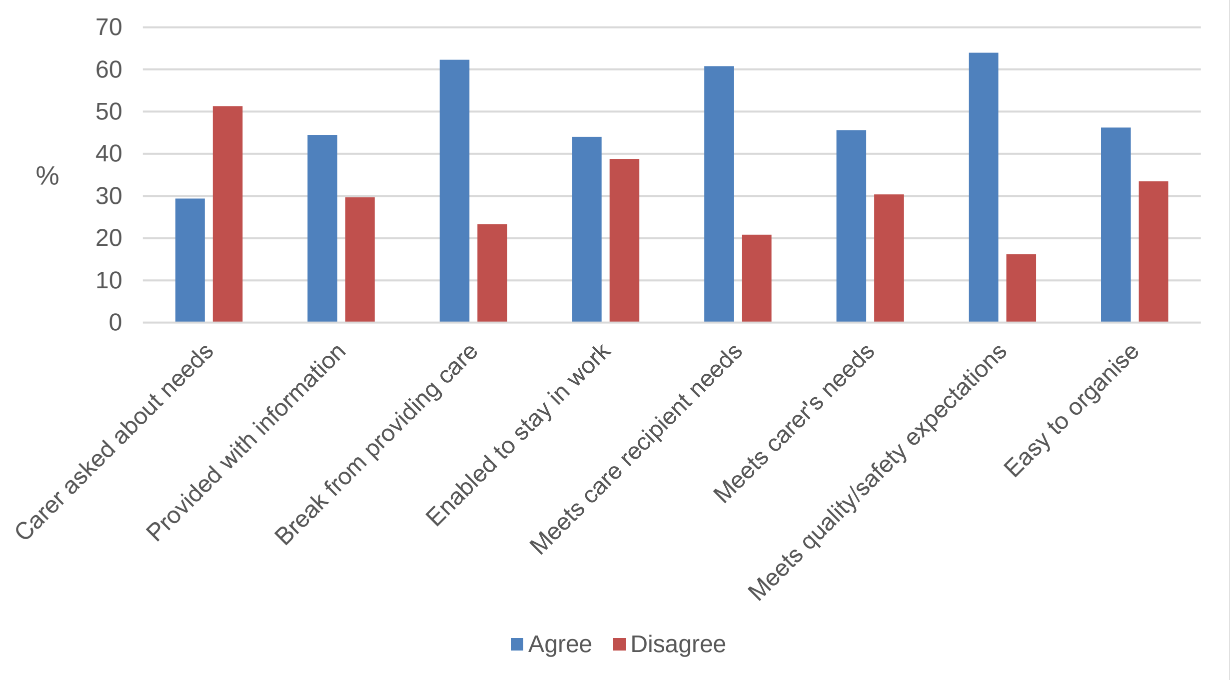
Figure 3: Carer inclusion and support in aged care services



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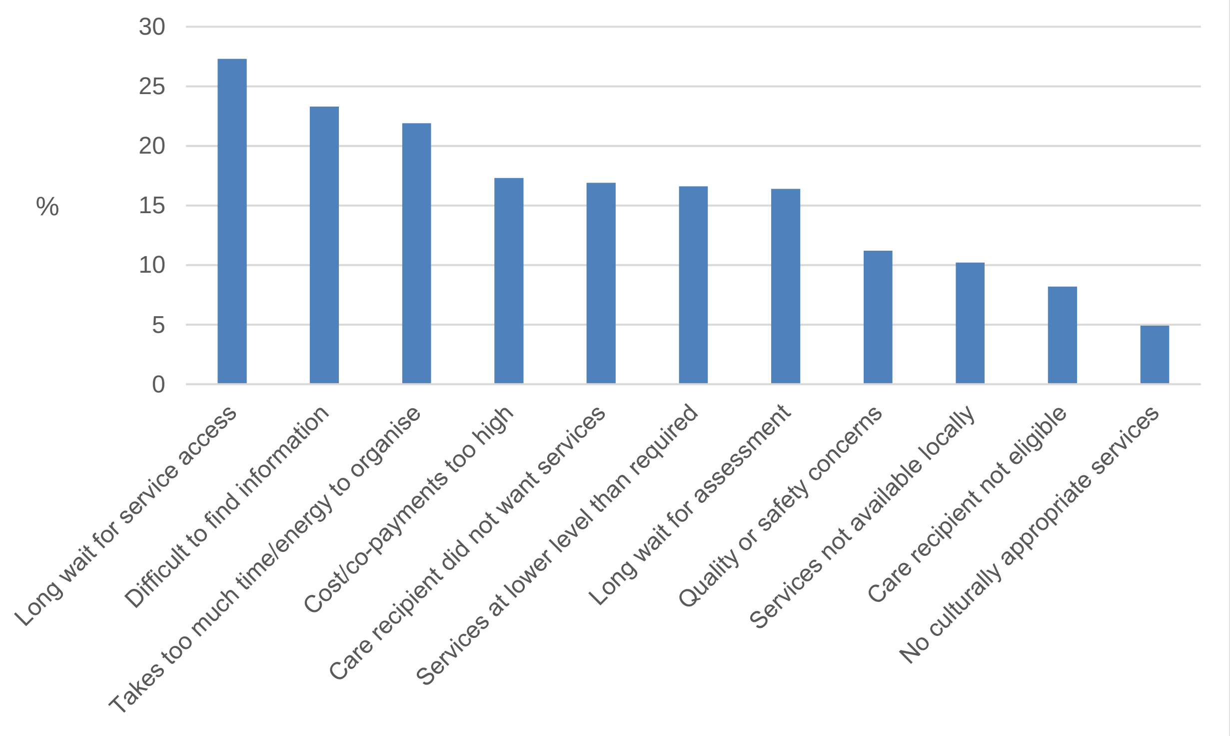

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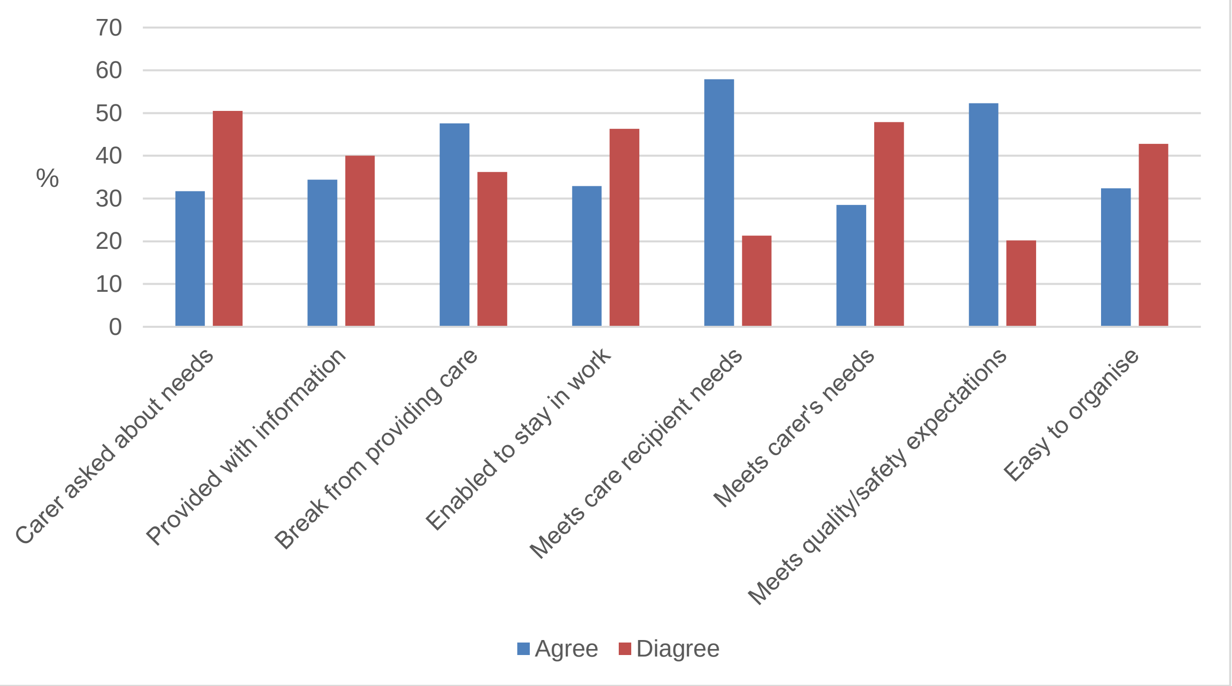

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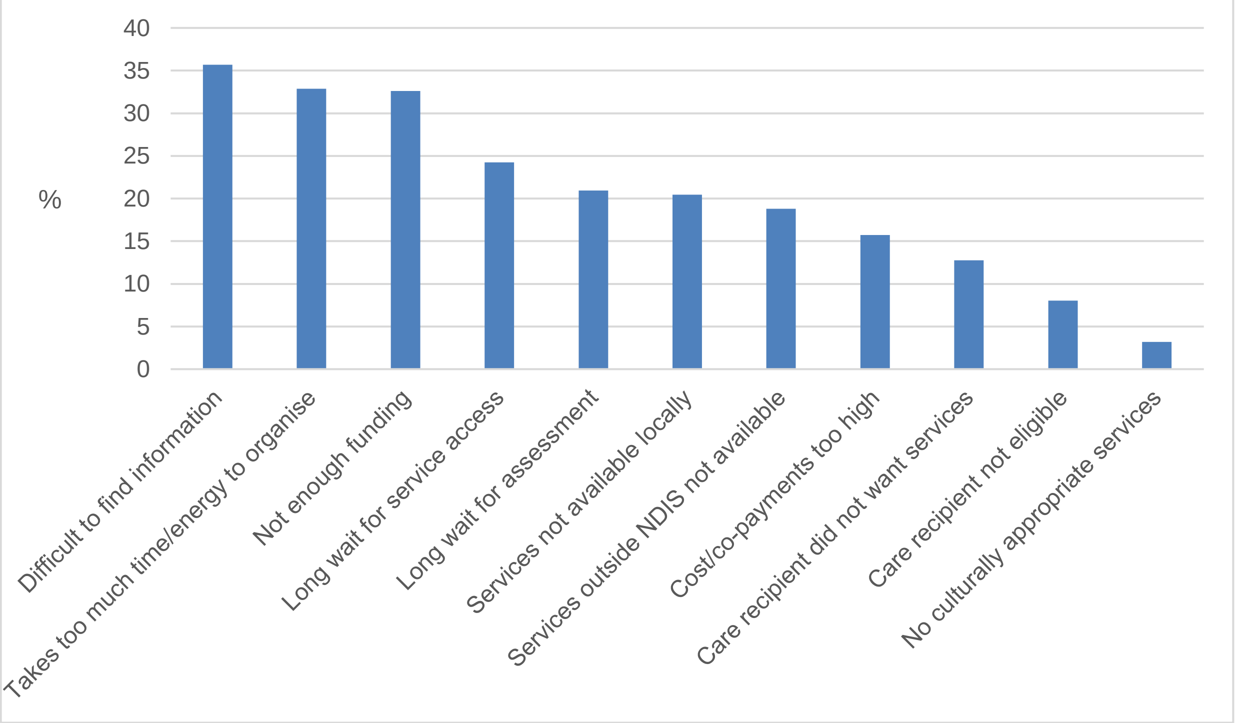

Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

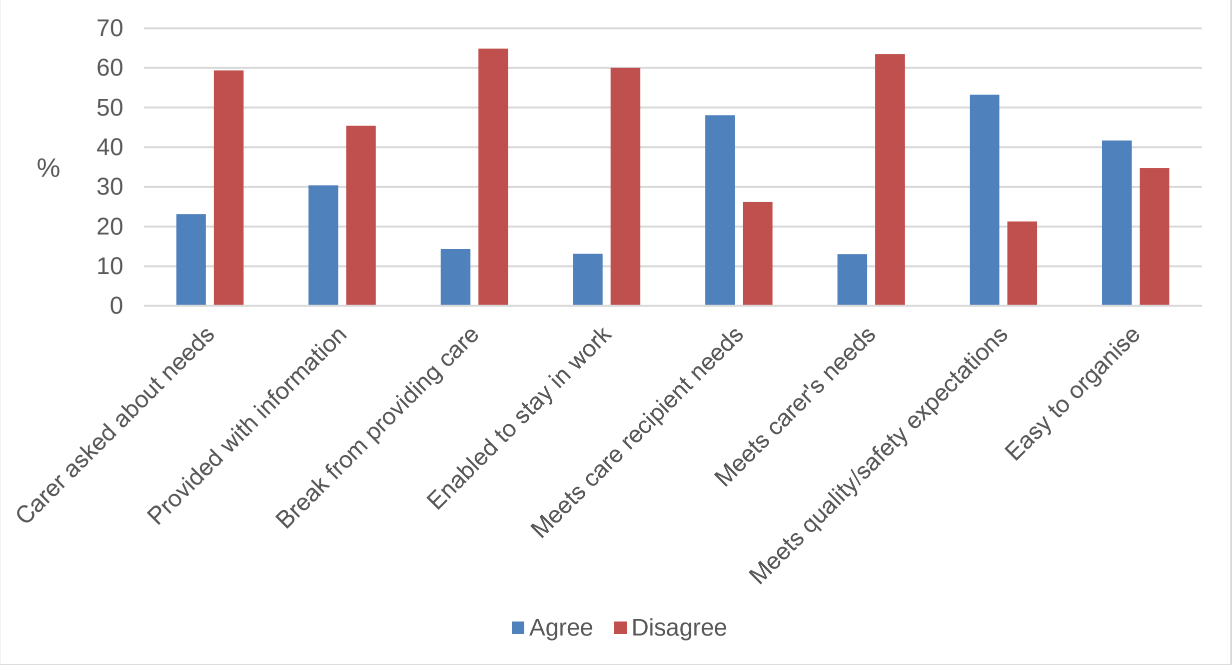

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Figure 8: Challenges with accessing mental health services

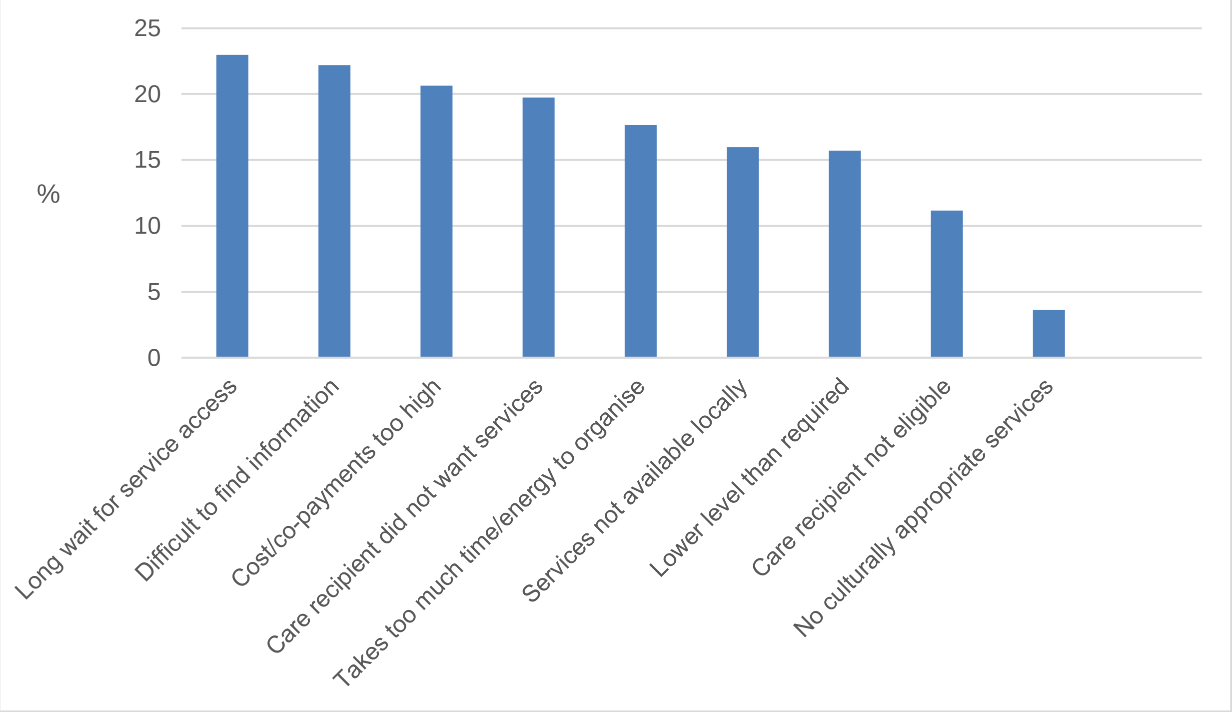

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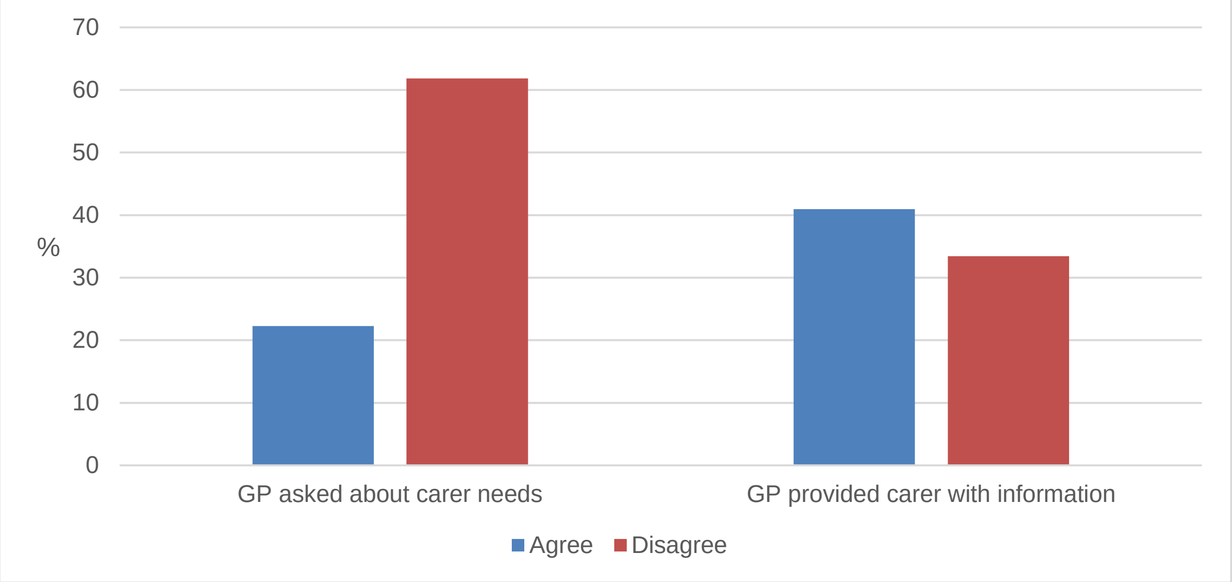
Figure 9: Carer inclusion and support by general practitioners (GPs)



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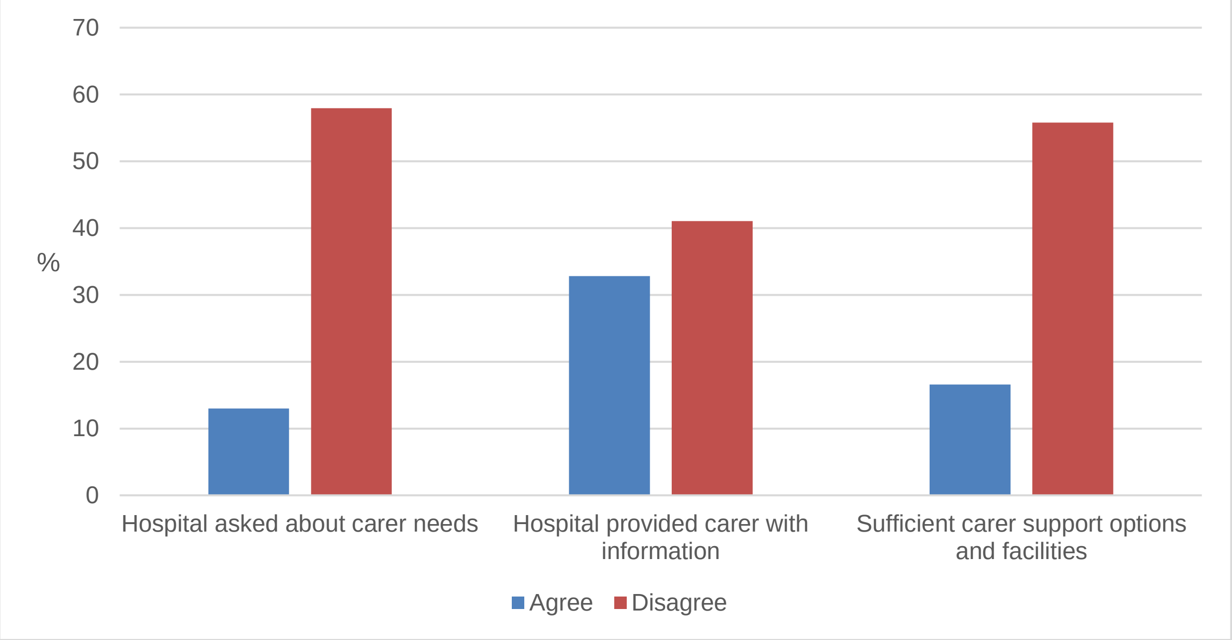

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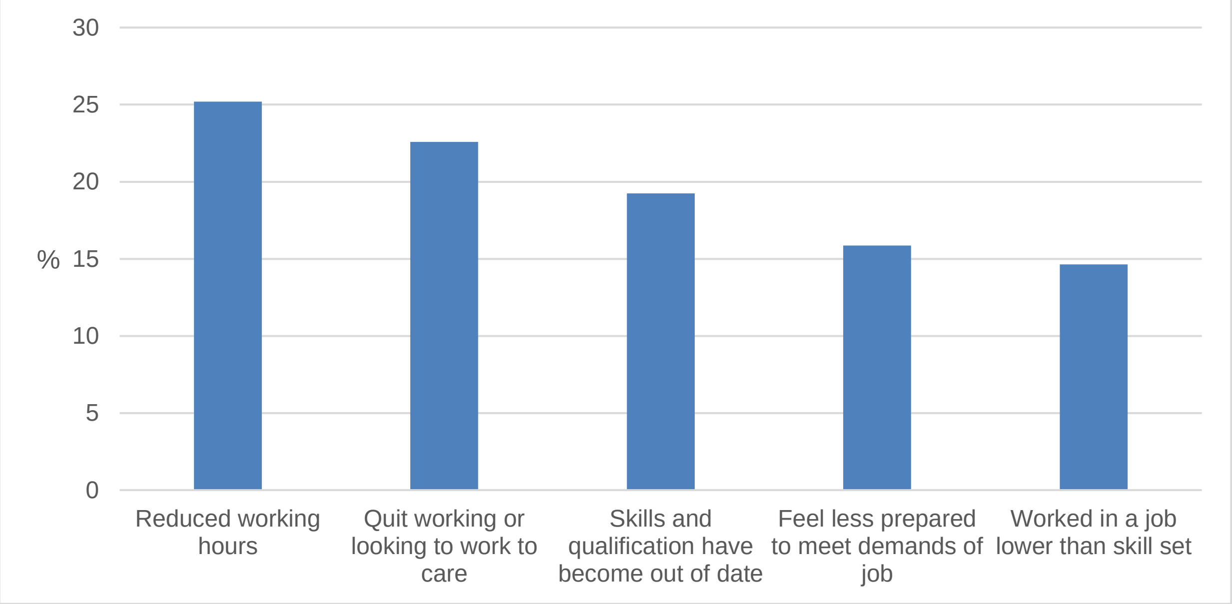


Northern Territory (NT) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in the NT.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

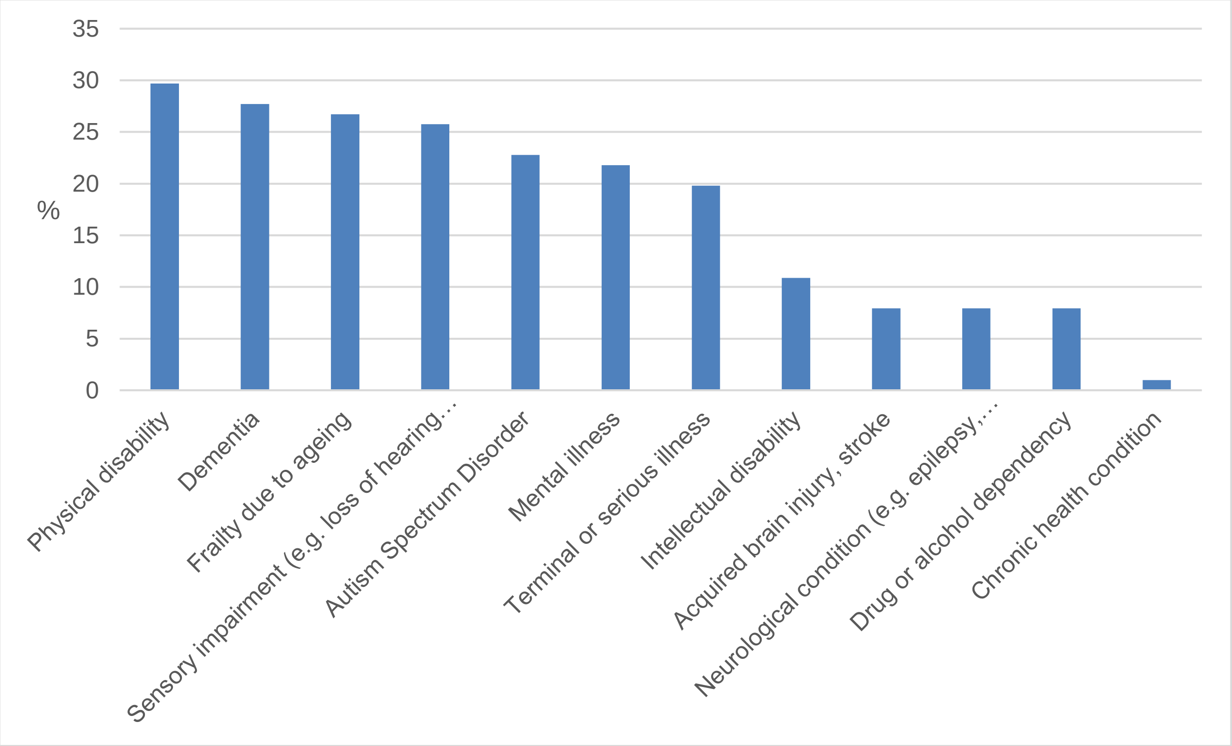


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in the NT and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

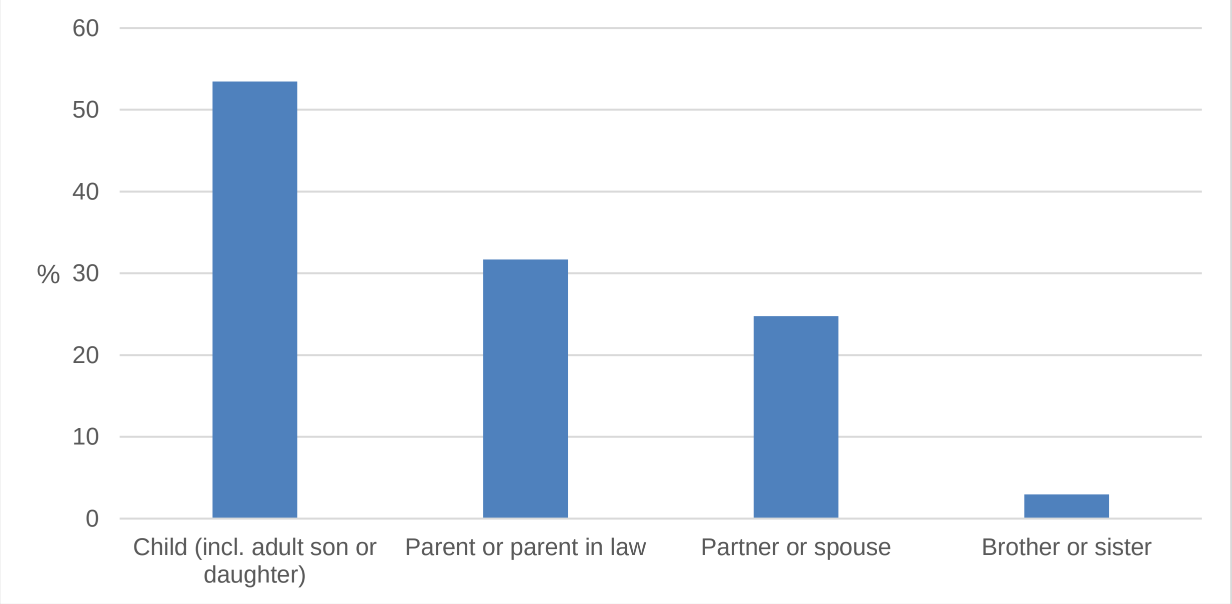


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

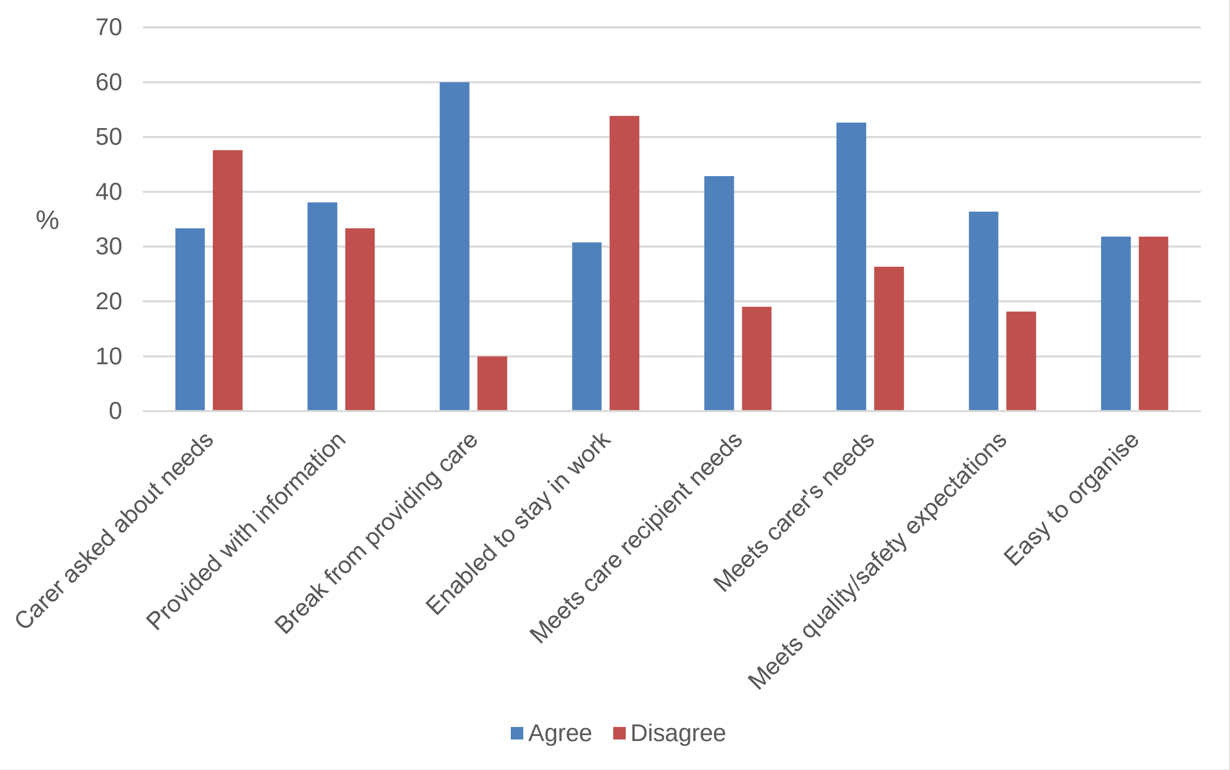


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

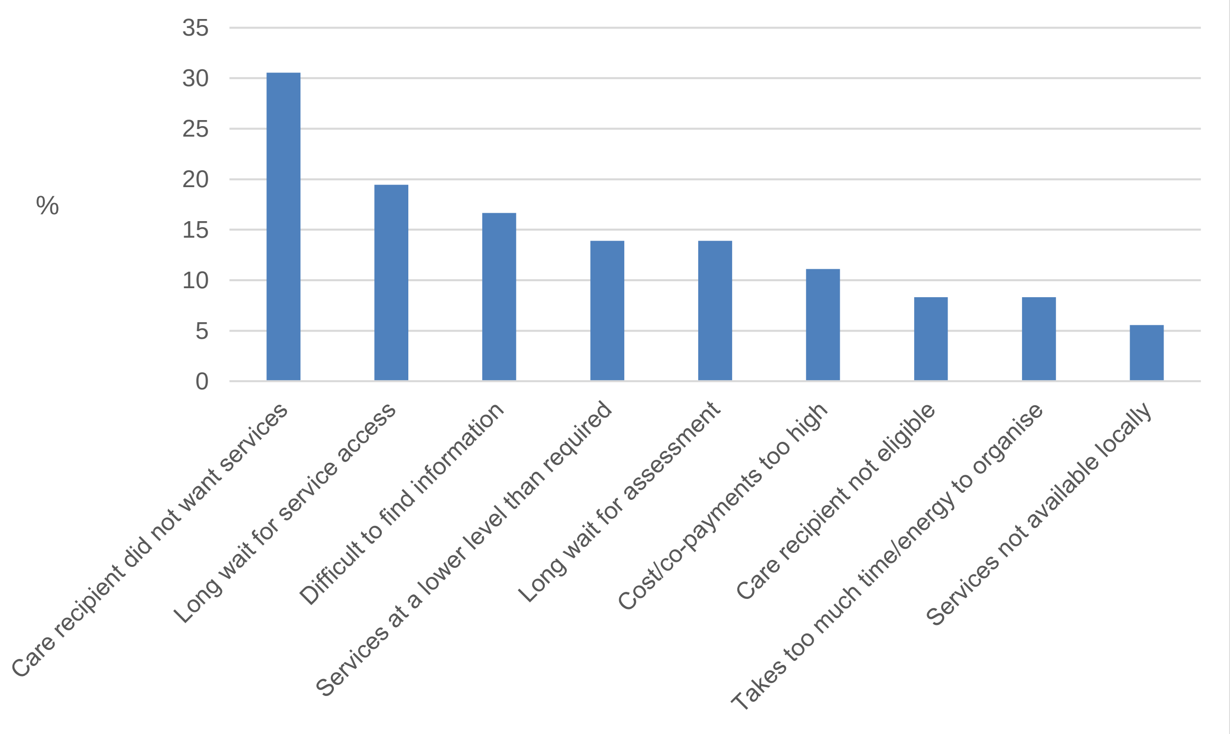


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

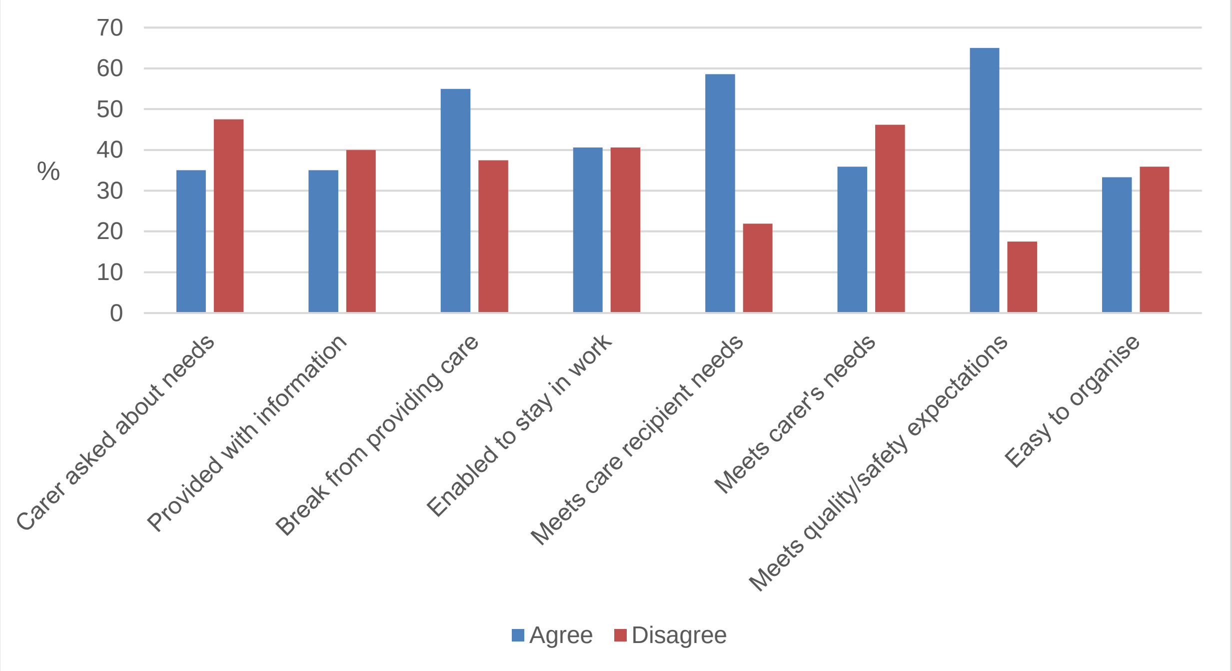


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

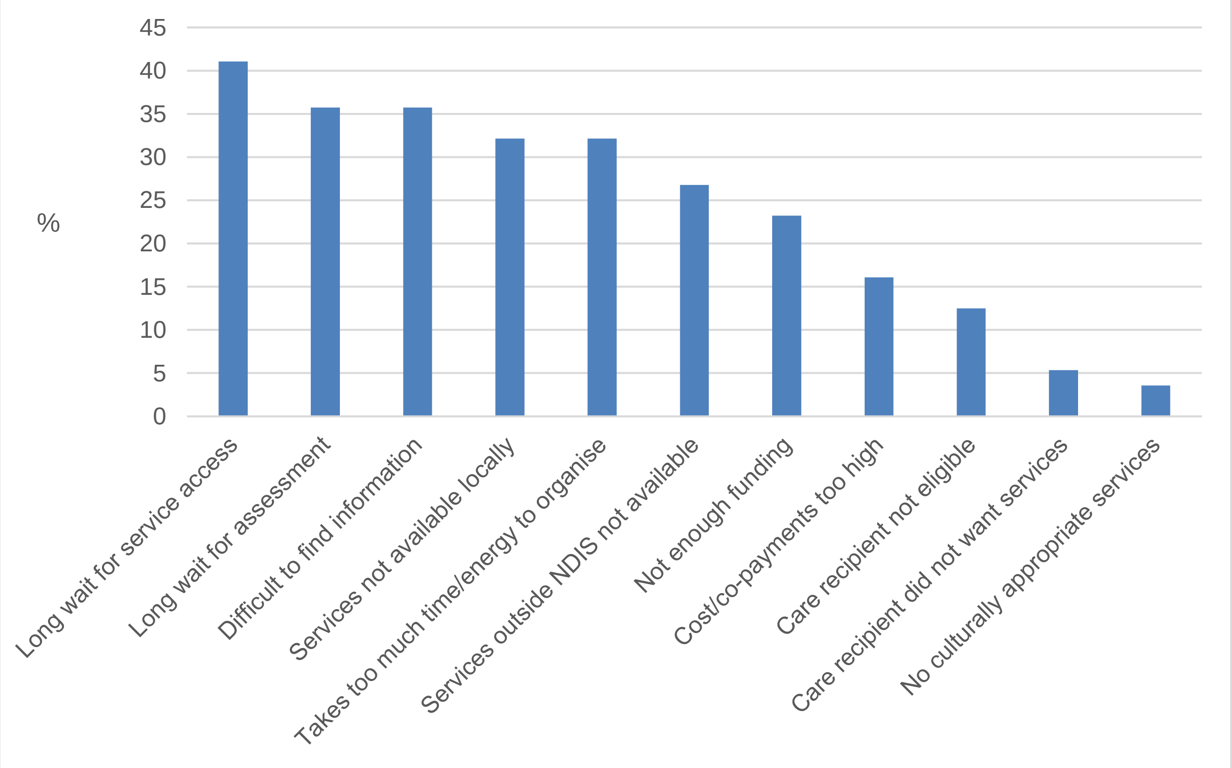


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

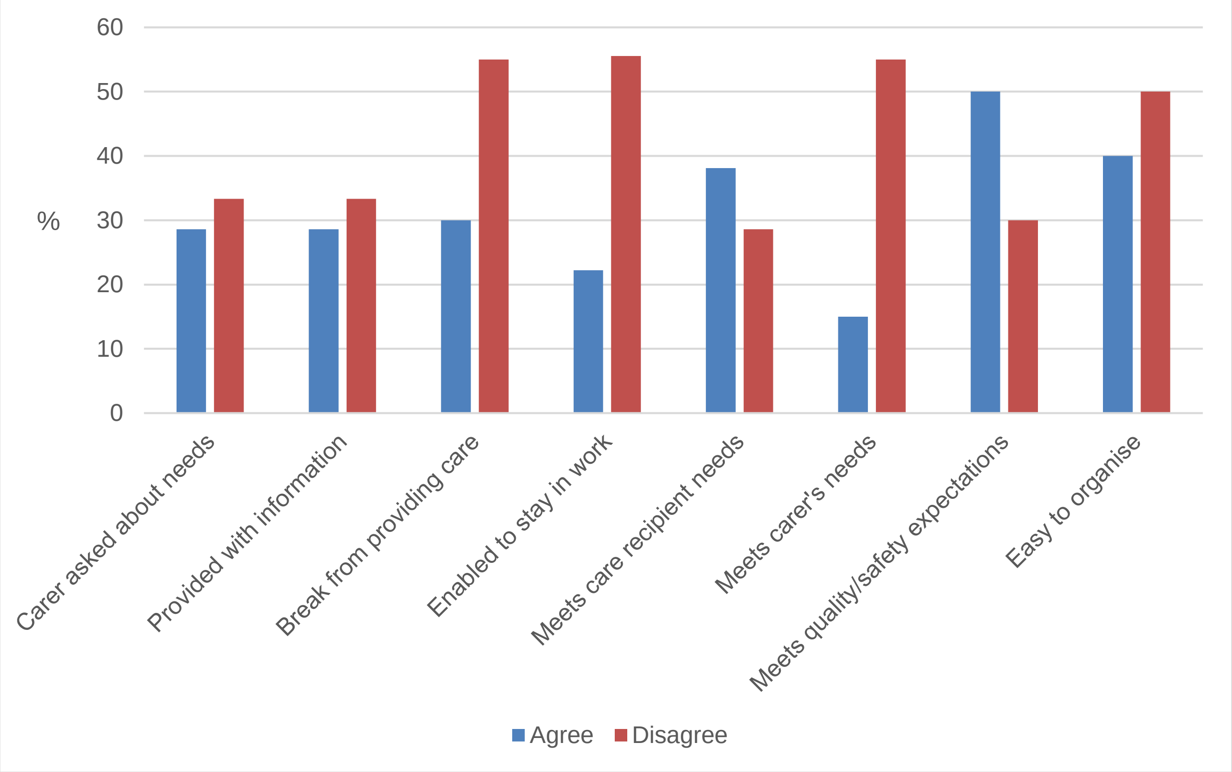


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

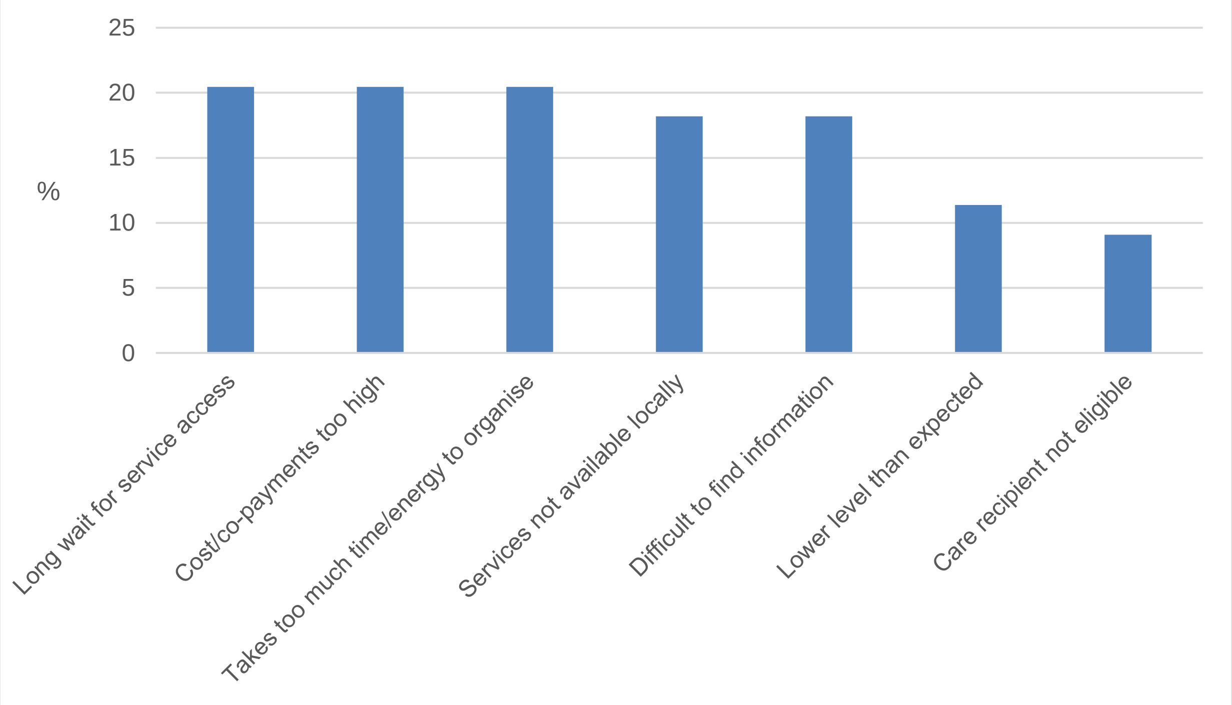


Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

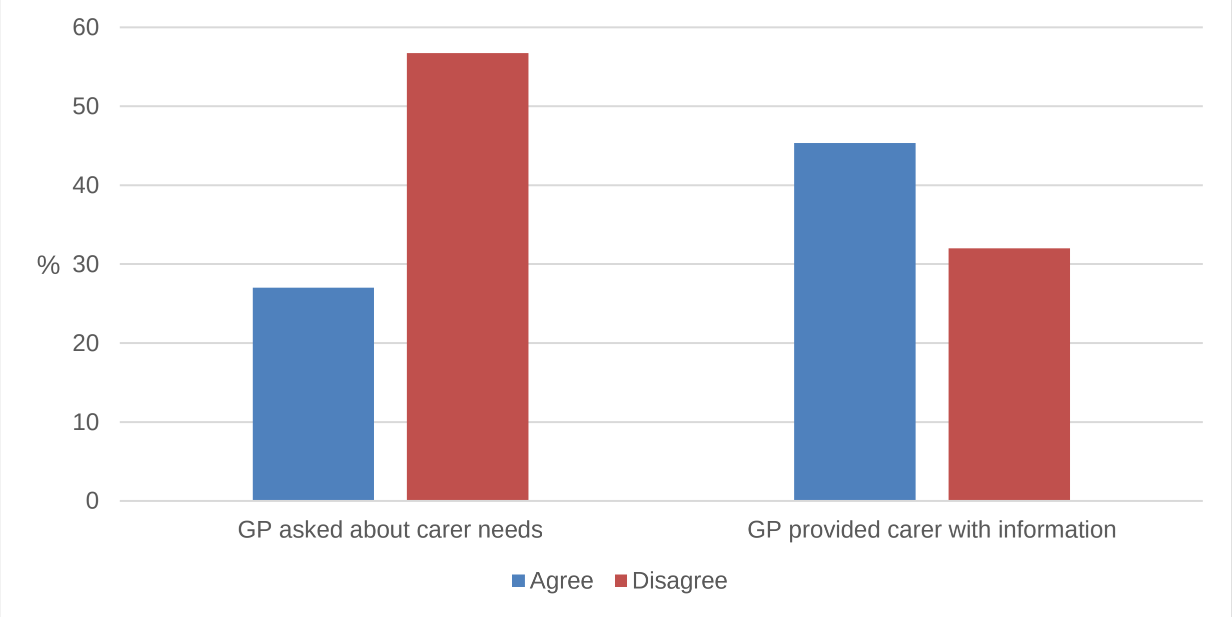


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

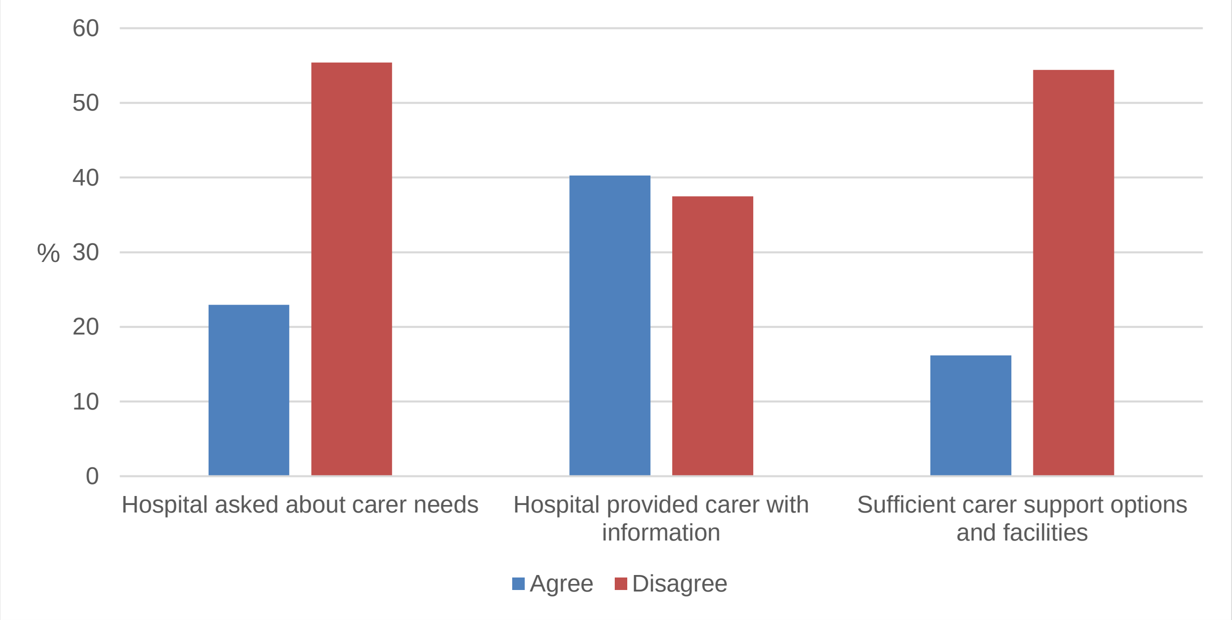
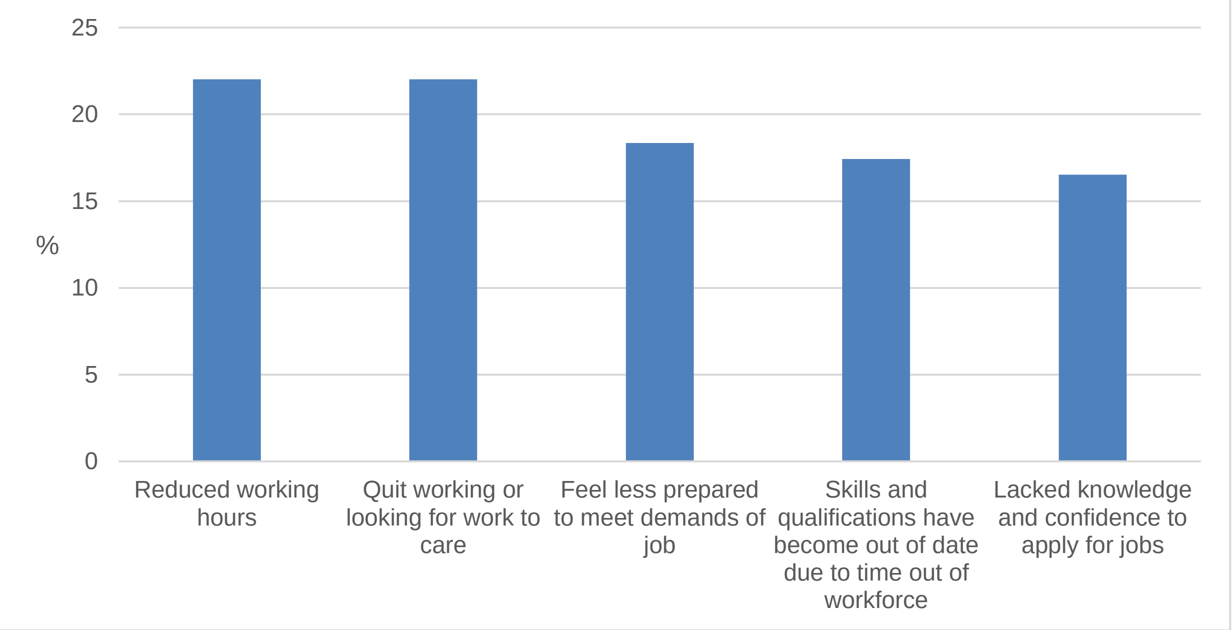


Figure 11 identifies the five most common impacts on career trajectory reported by carers in the NT.

Figure 11: Most common impacts of caring on career trajectory



Queensland (QLD) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in Queensland.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

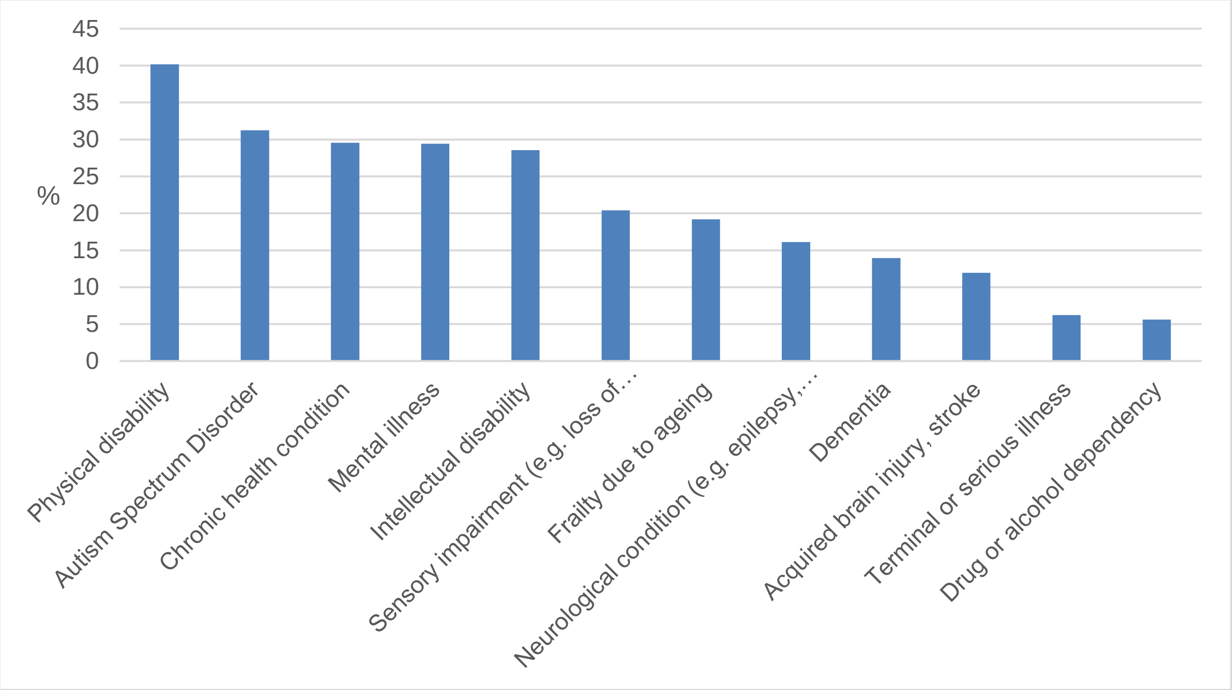


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in Queensland and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

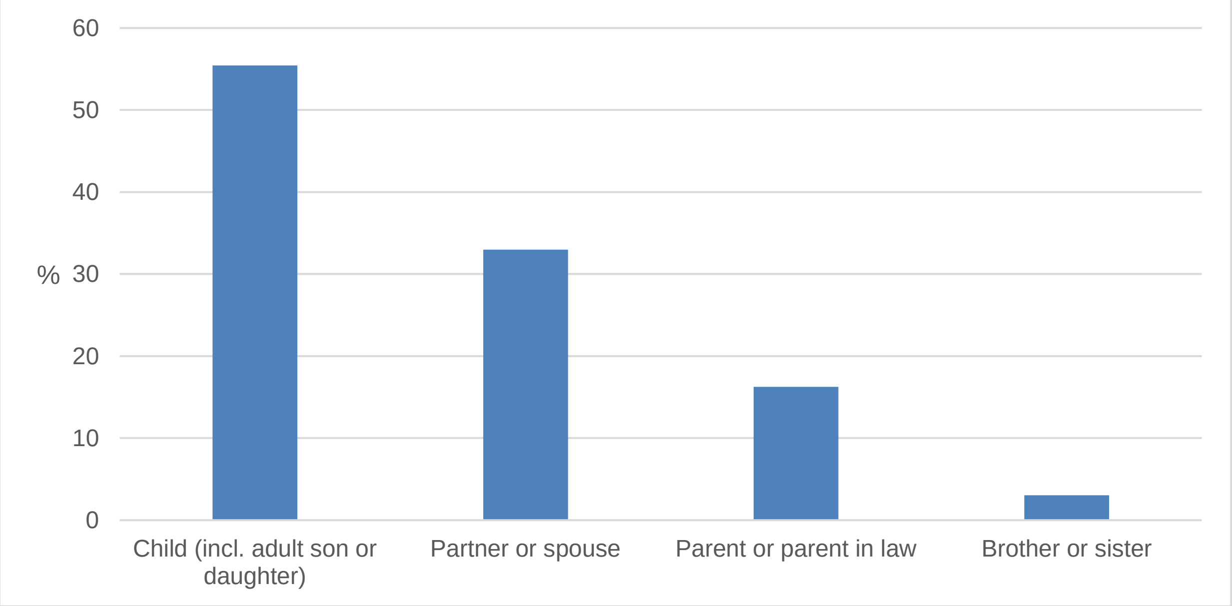


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

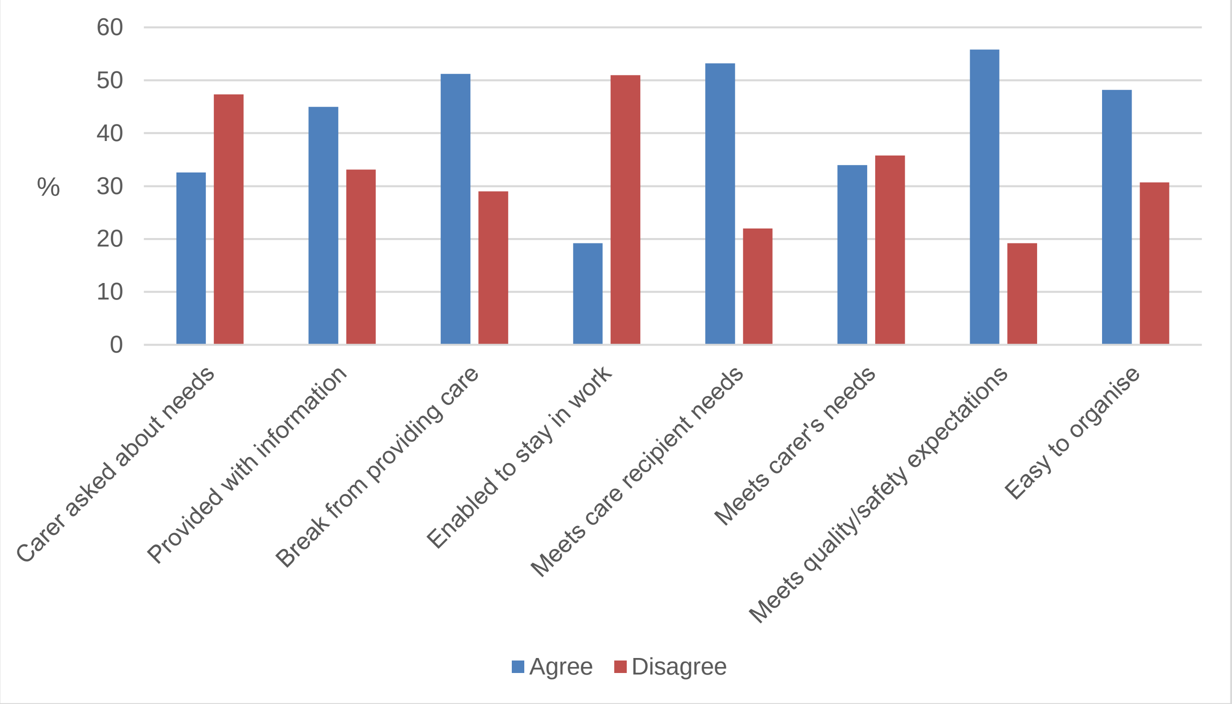


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

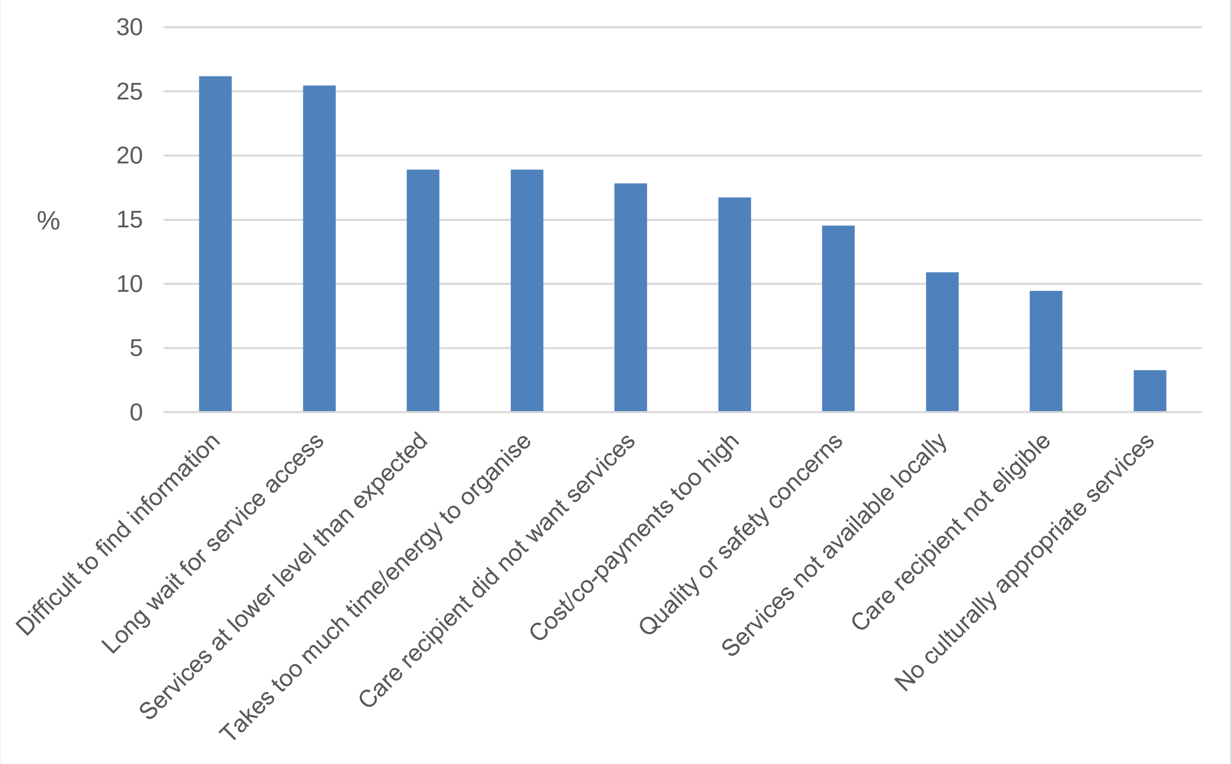


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

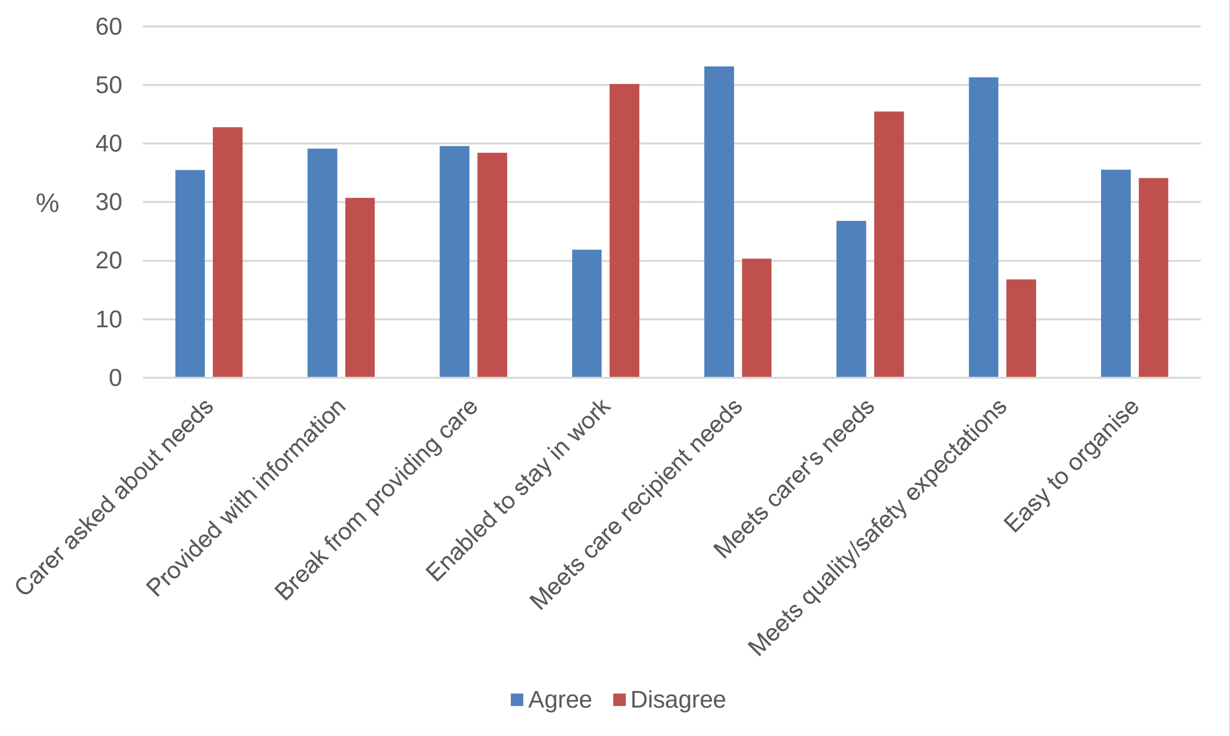


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

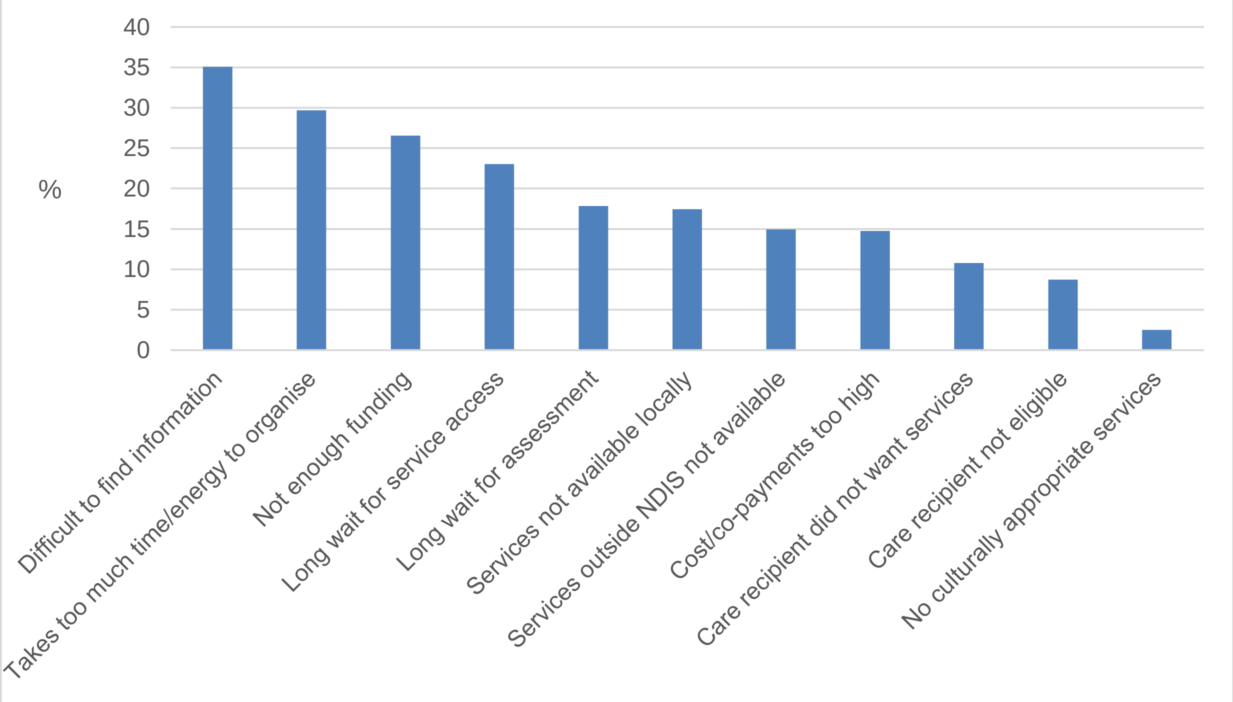


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

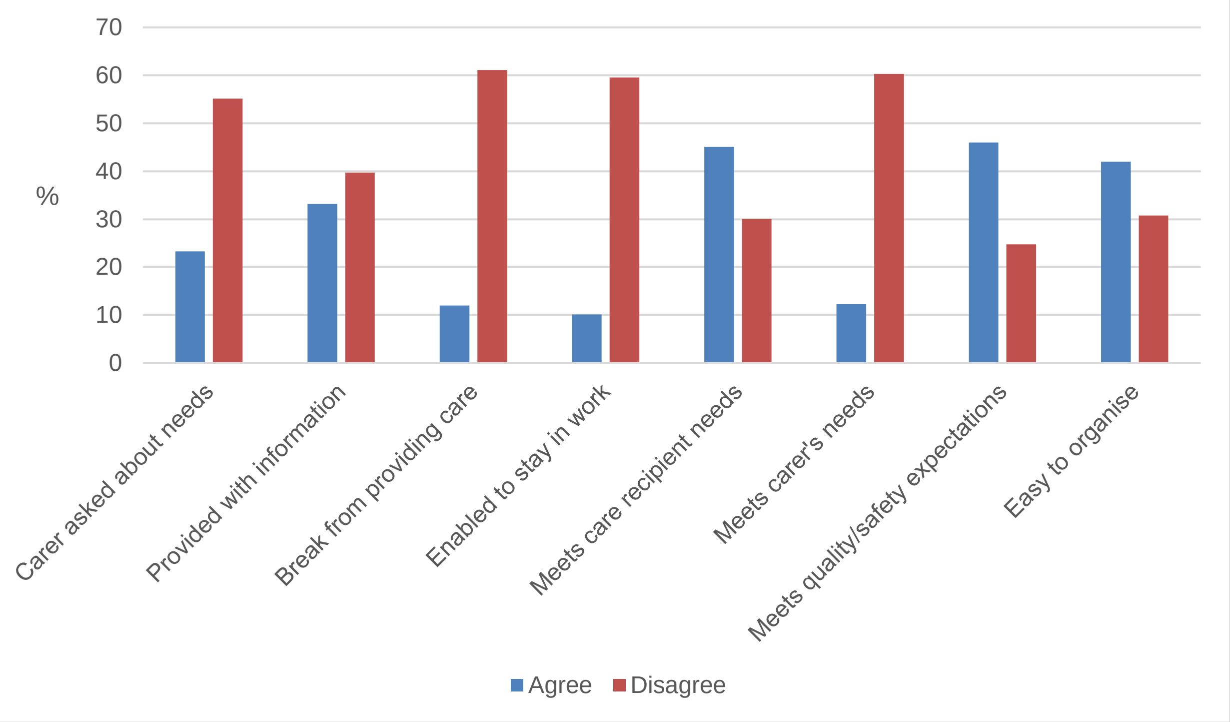


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

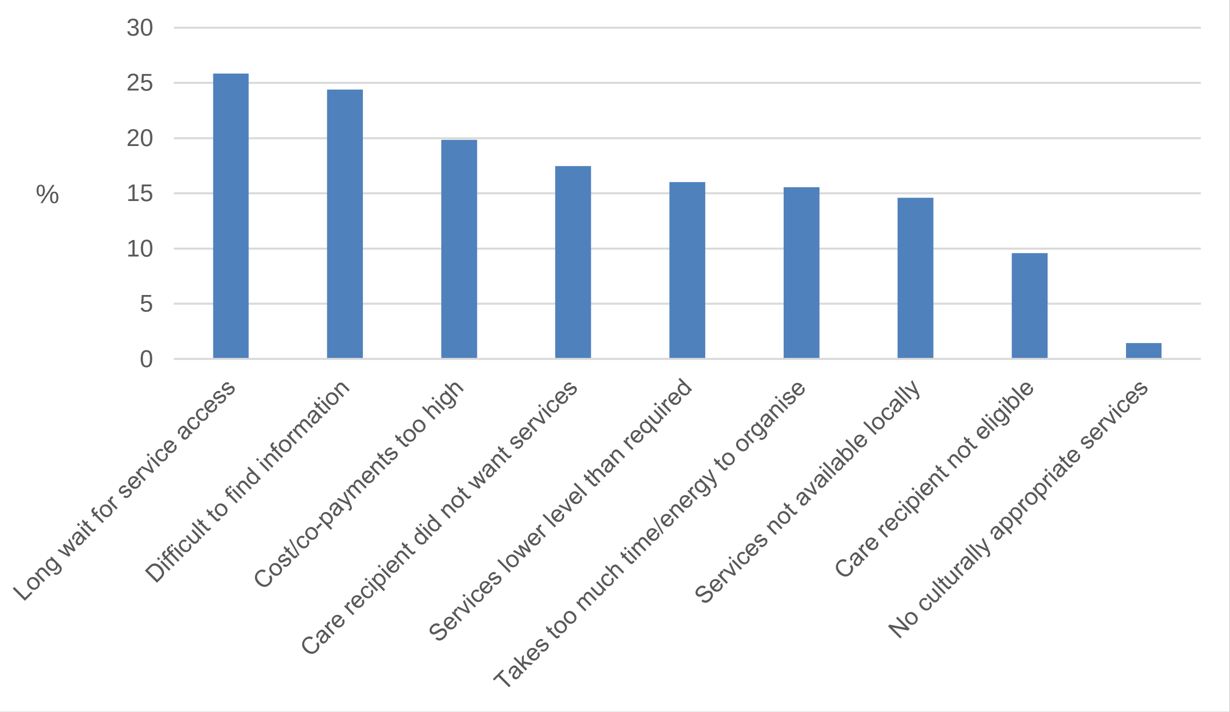


Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

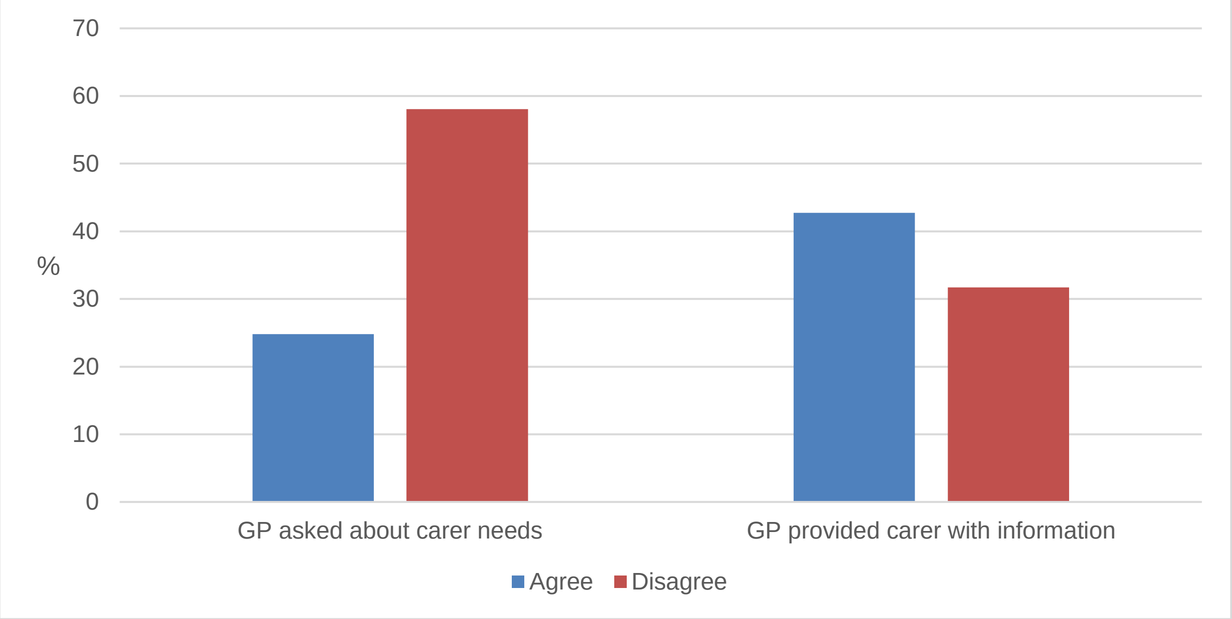


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

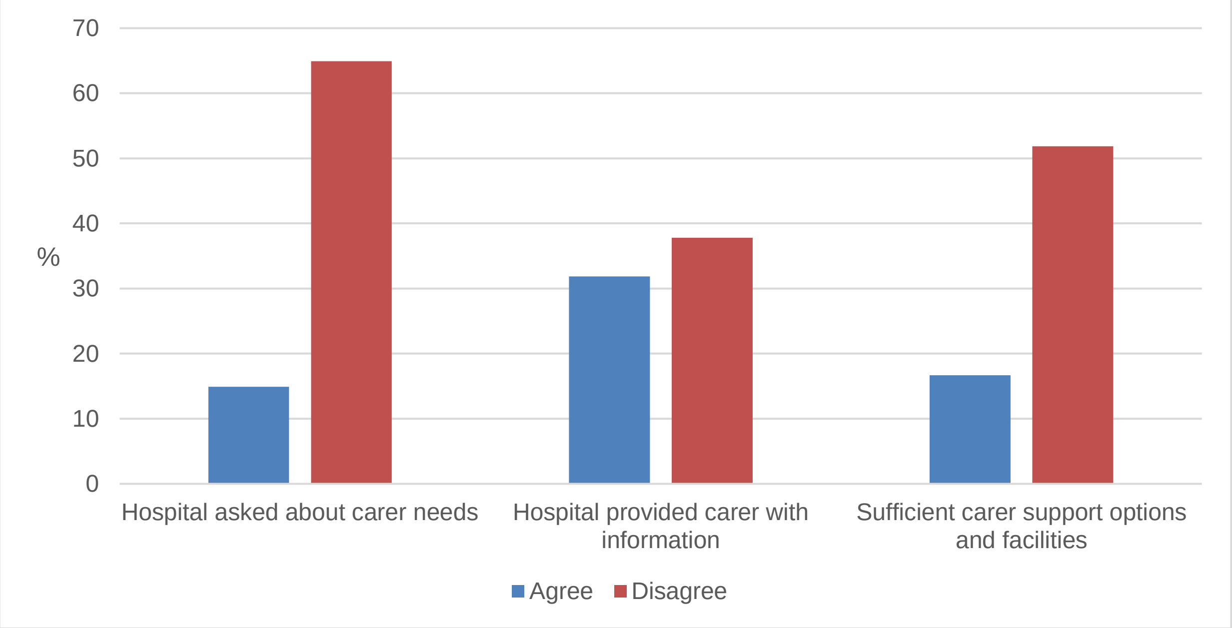
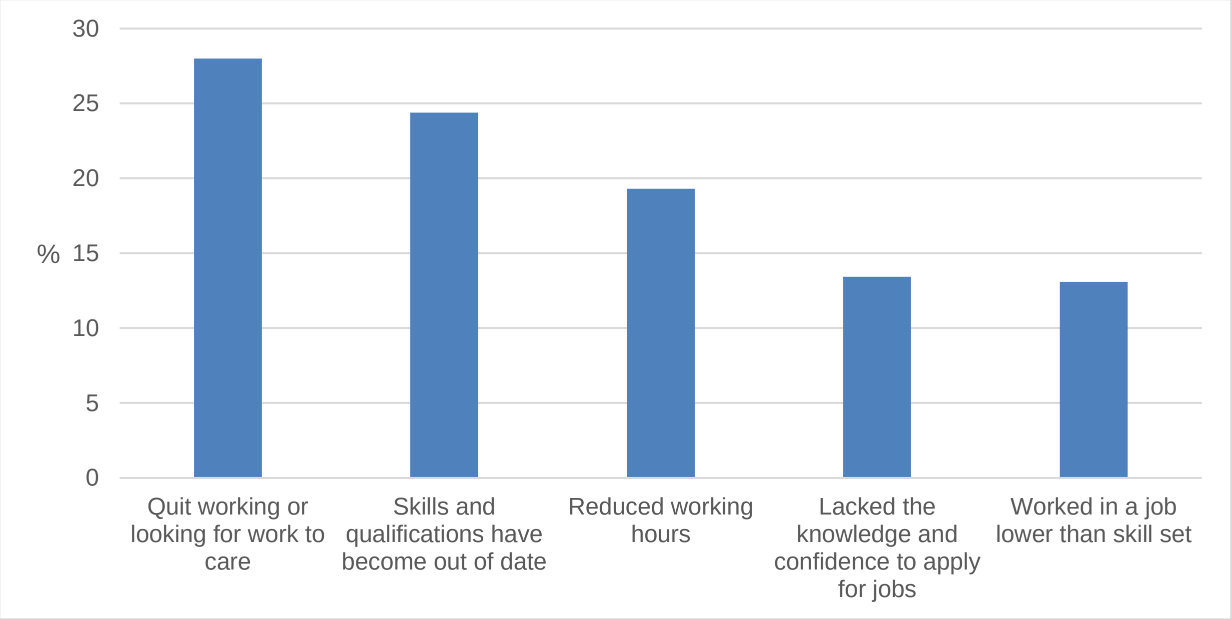


Figure 11 identifies the five most common impacts on career trajectory reported by carers in Queensland.

Figure 11: Most common impacts of caring on career trajectory



South Australia (SA) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in South Australia.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

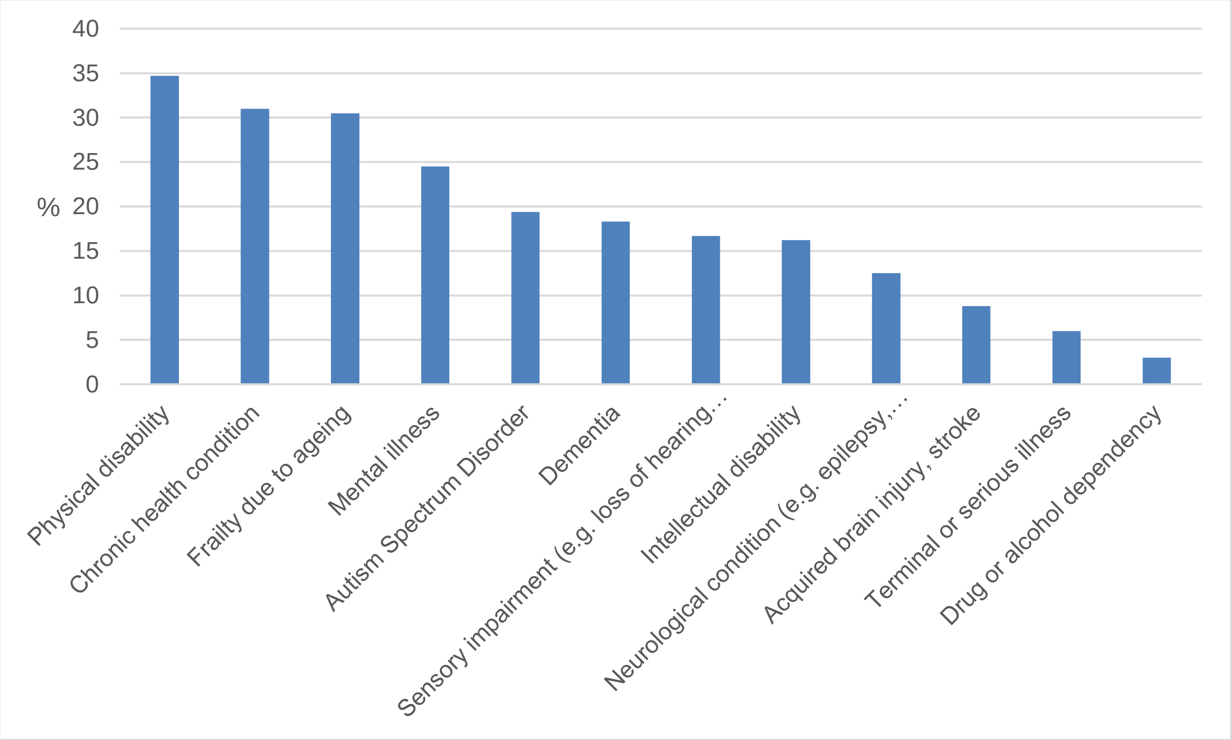


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in South Australia and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

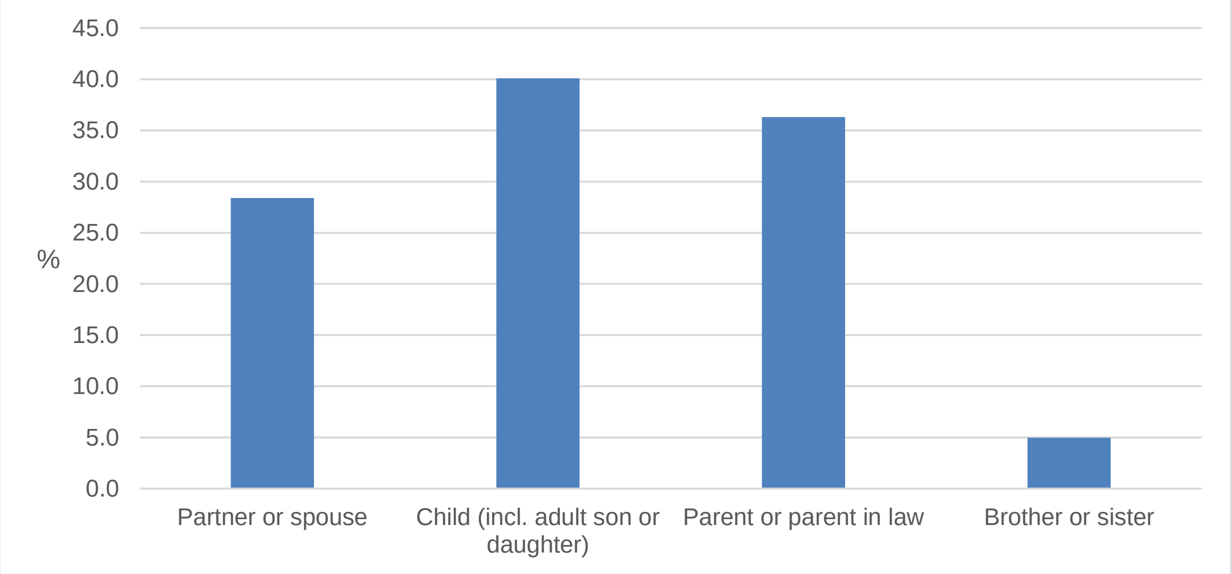


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

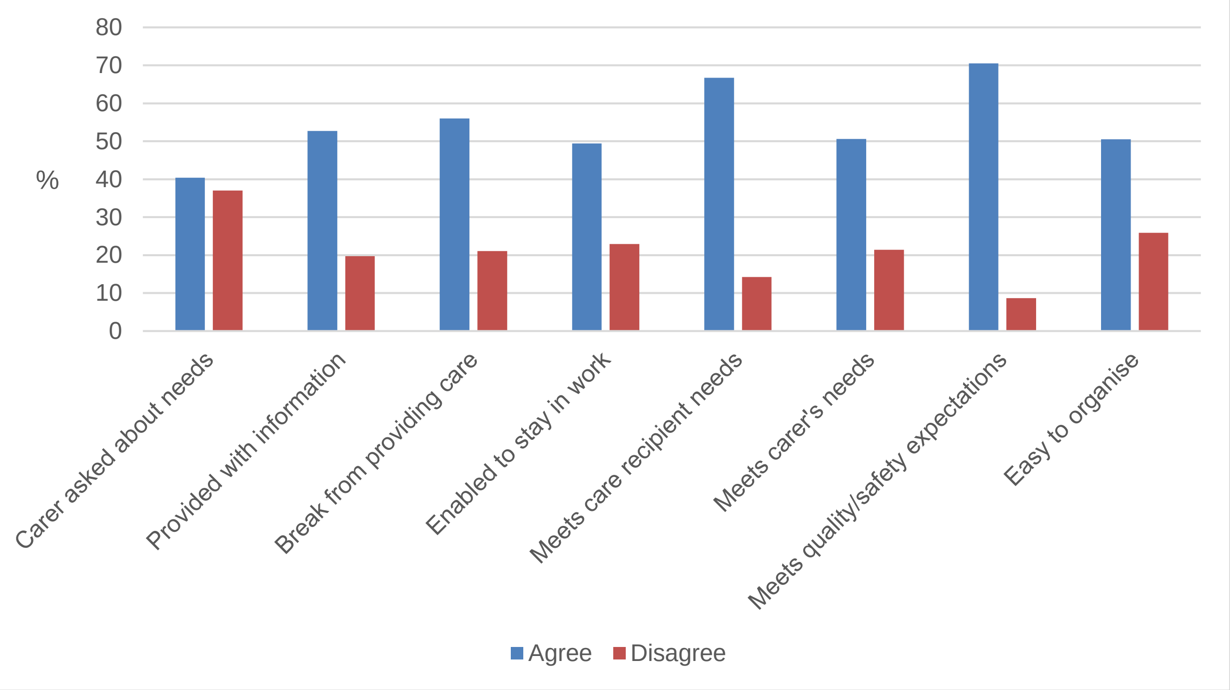


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

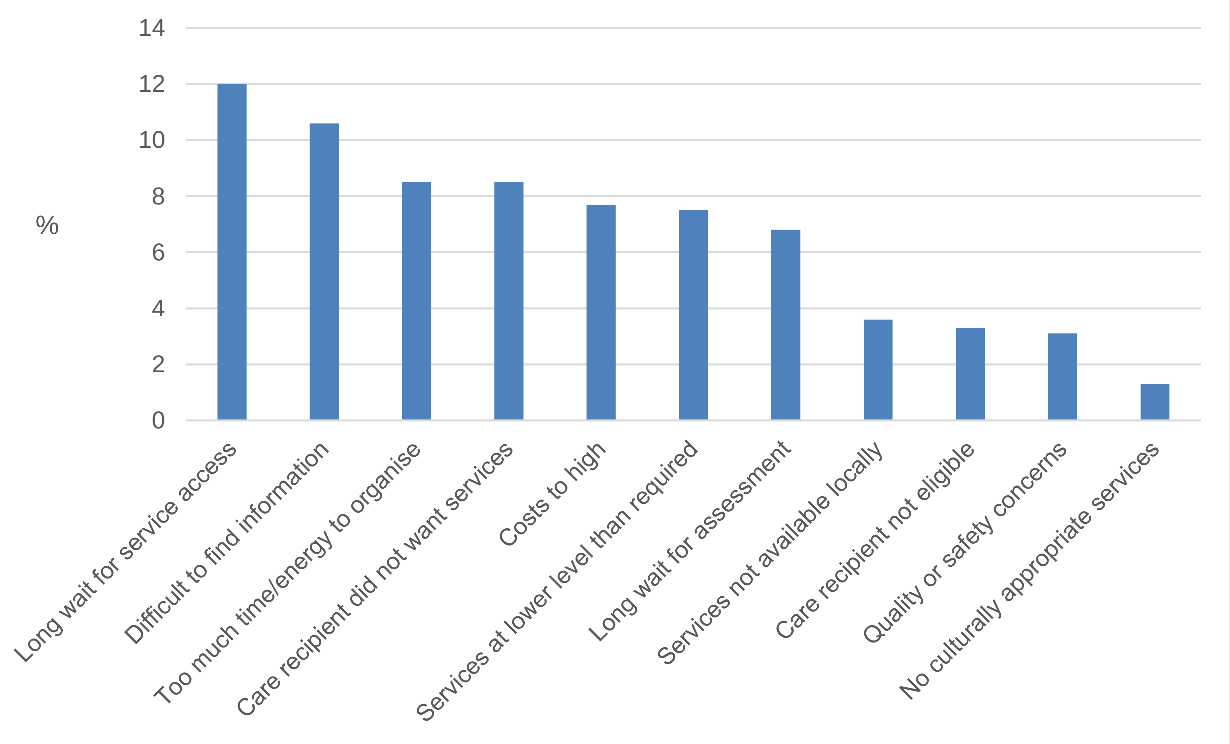


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

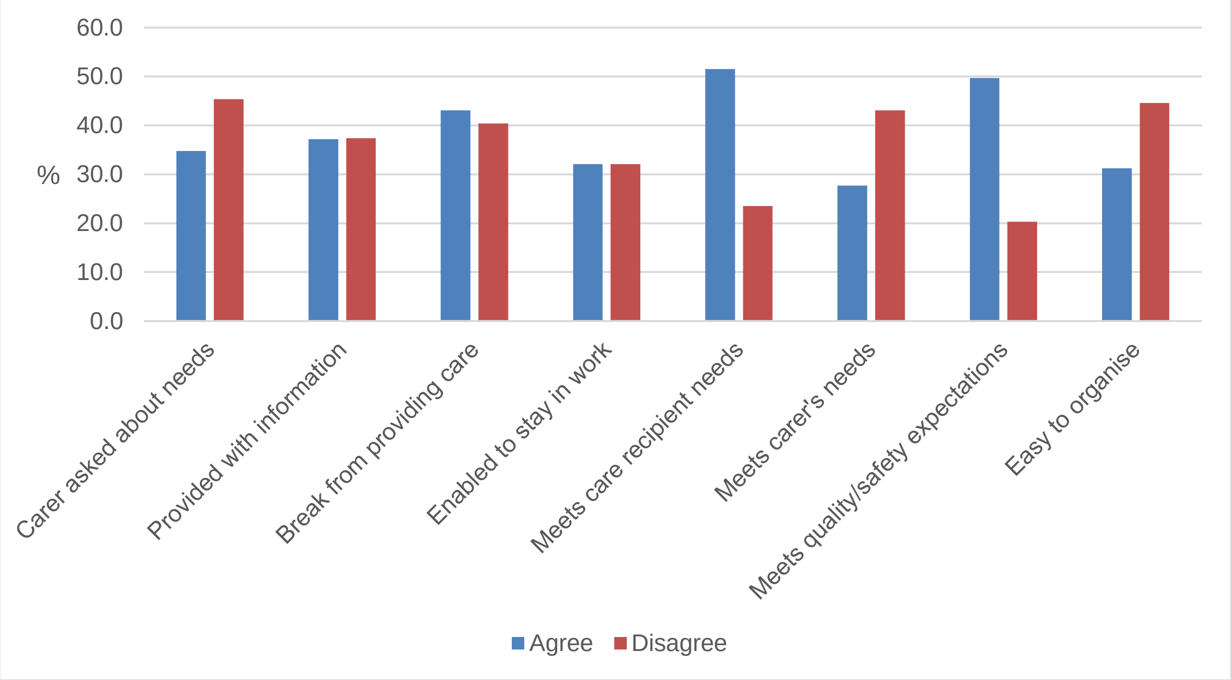


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

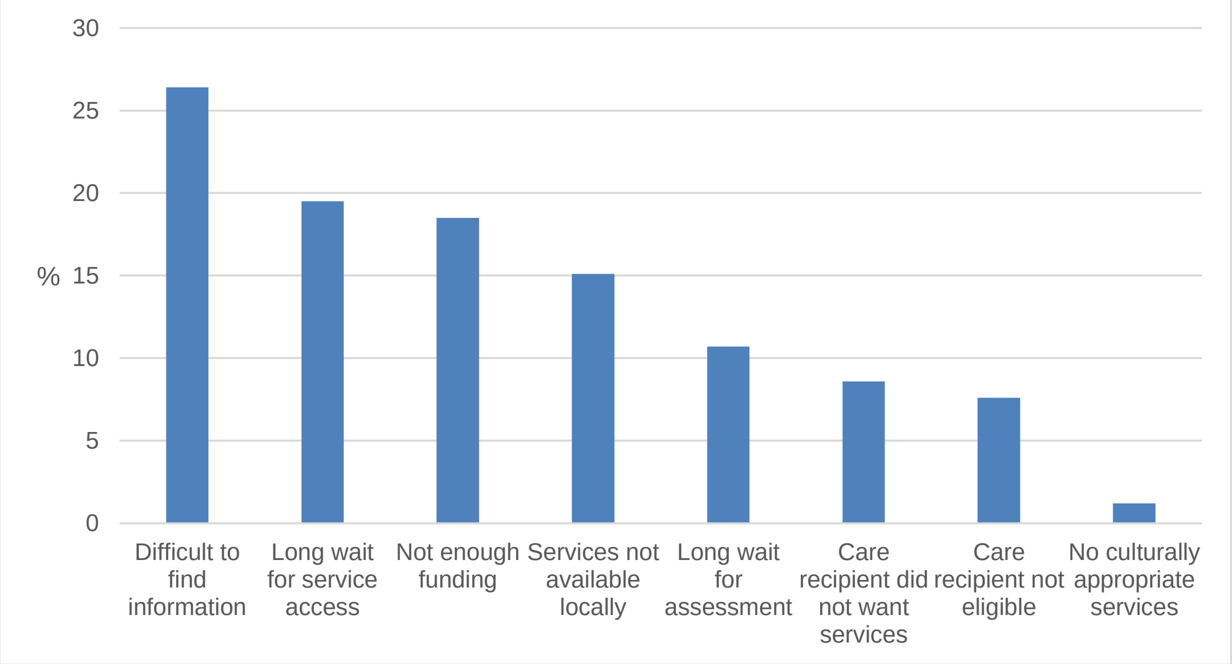


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

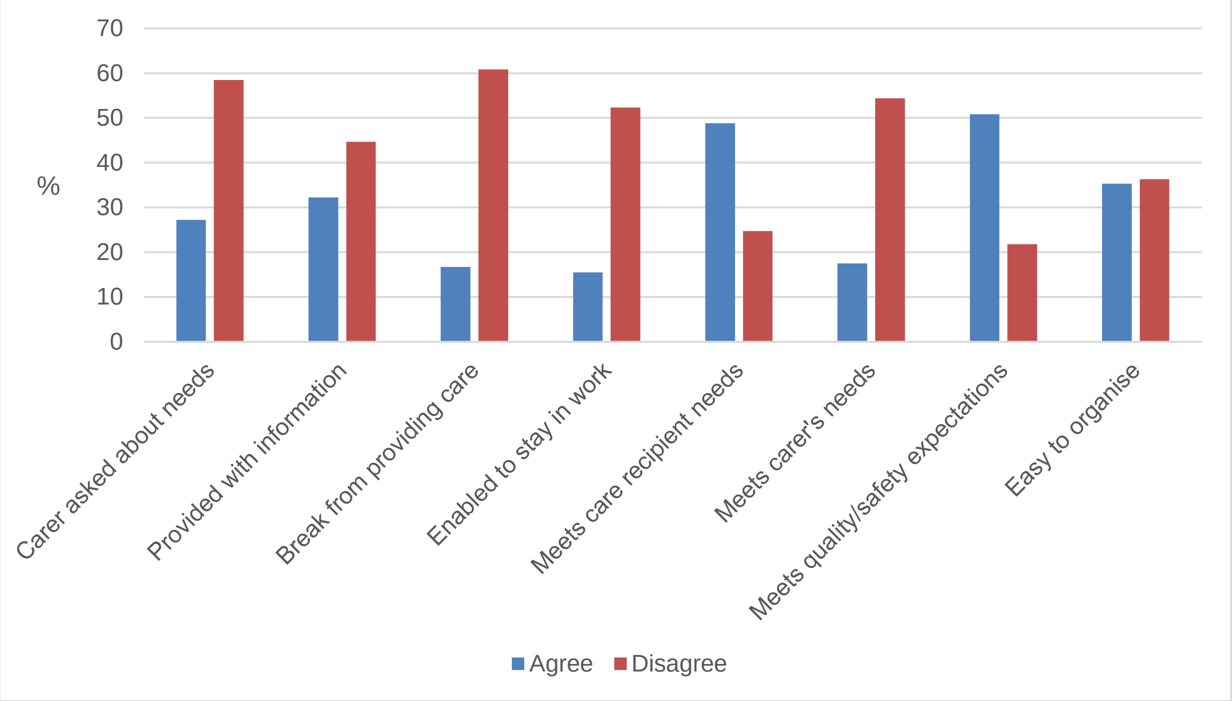


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

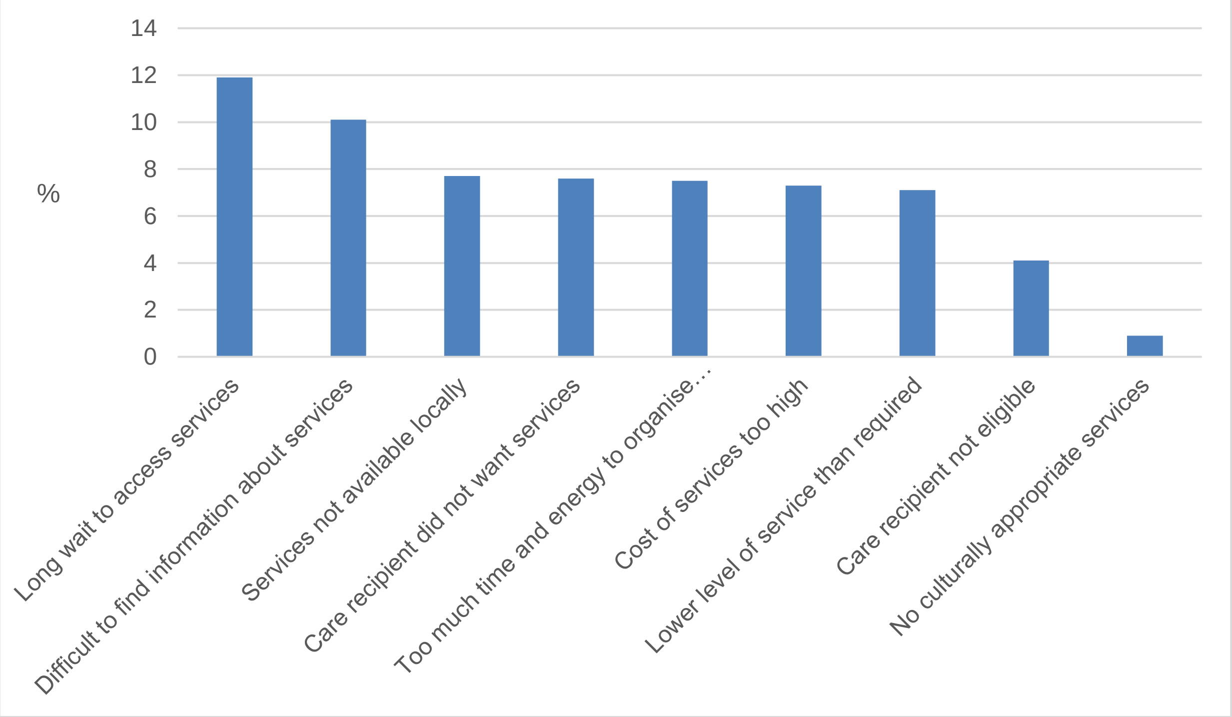


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Figure 9: Carer inclusion and support by general practitioners (GPs)

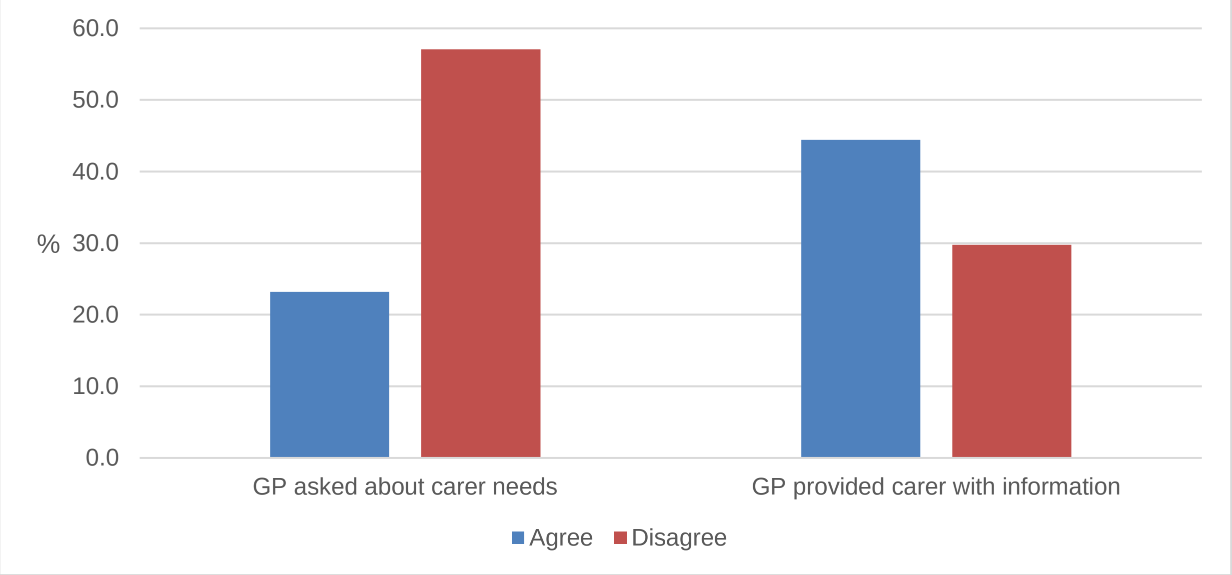


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

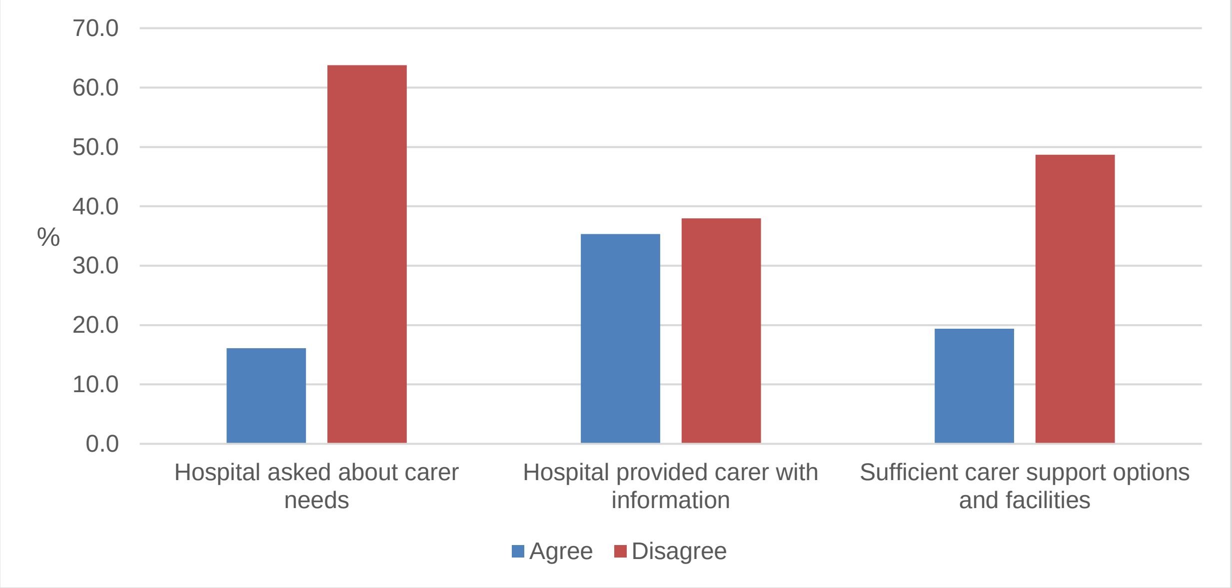
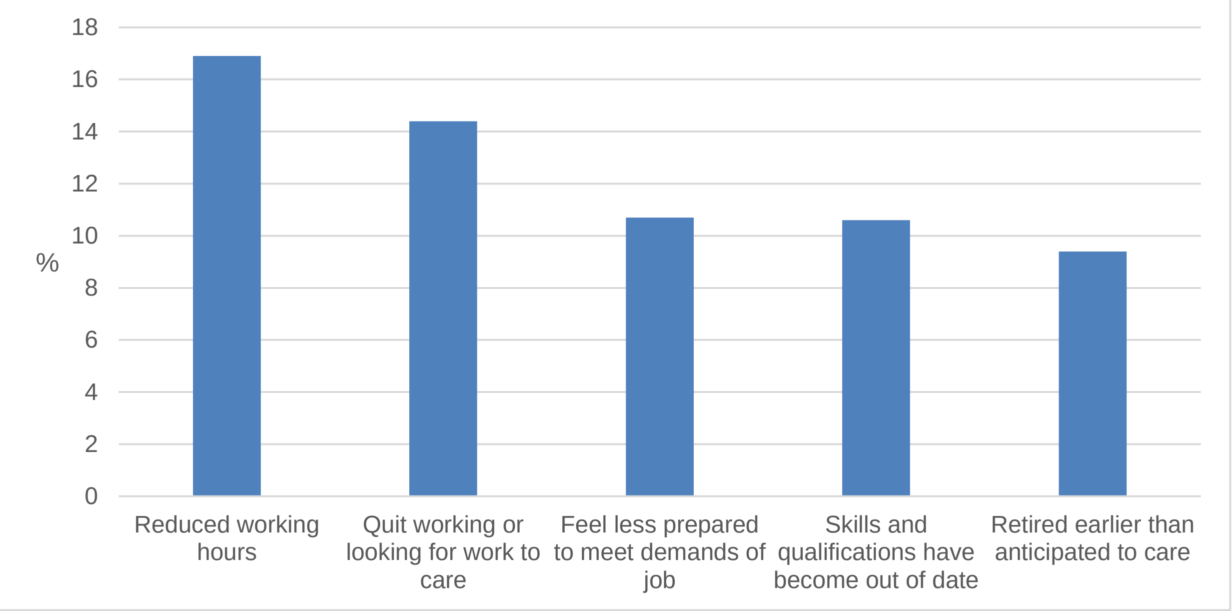


Figure 11 identifies the five most common impacts on career trajectory reported by carers in South Australia.

Figure 11: Most common impacts of caring on career trajectory



Tasmania (TAS) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in Tasmania.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

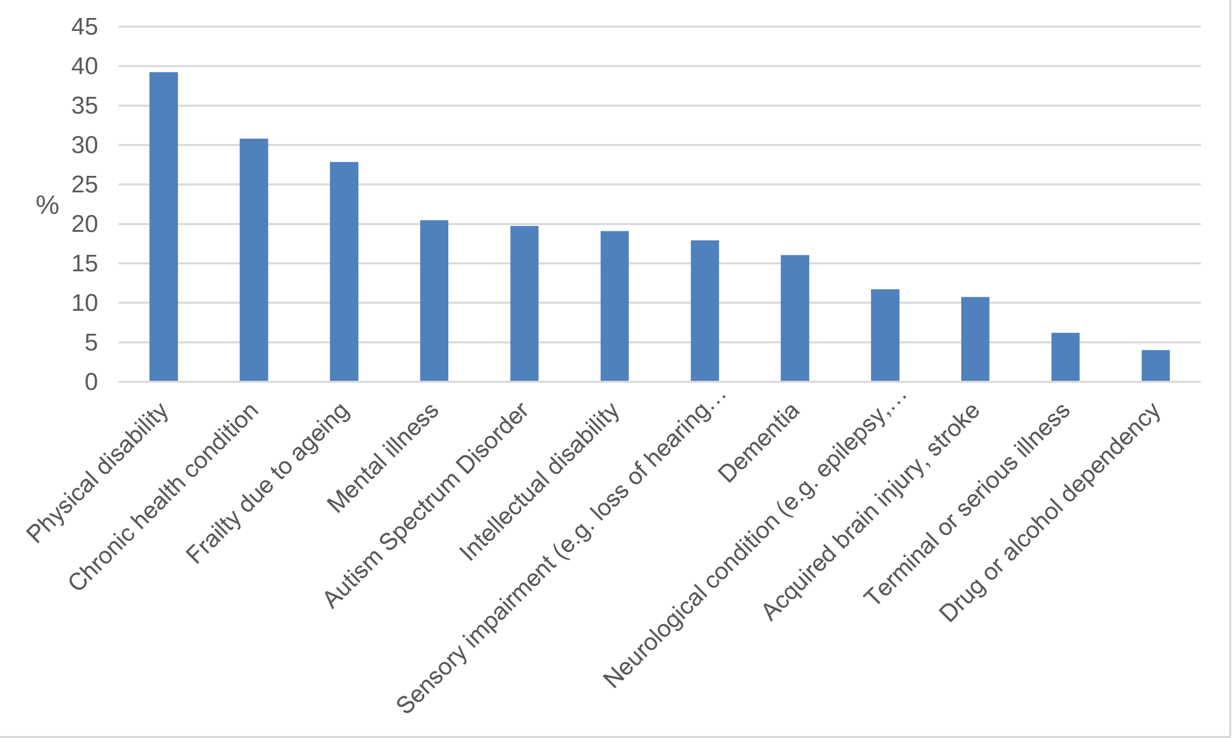


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in Tasmania and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

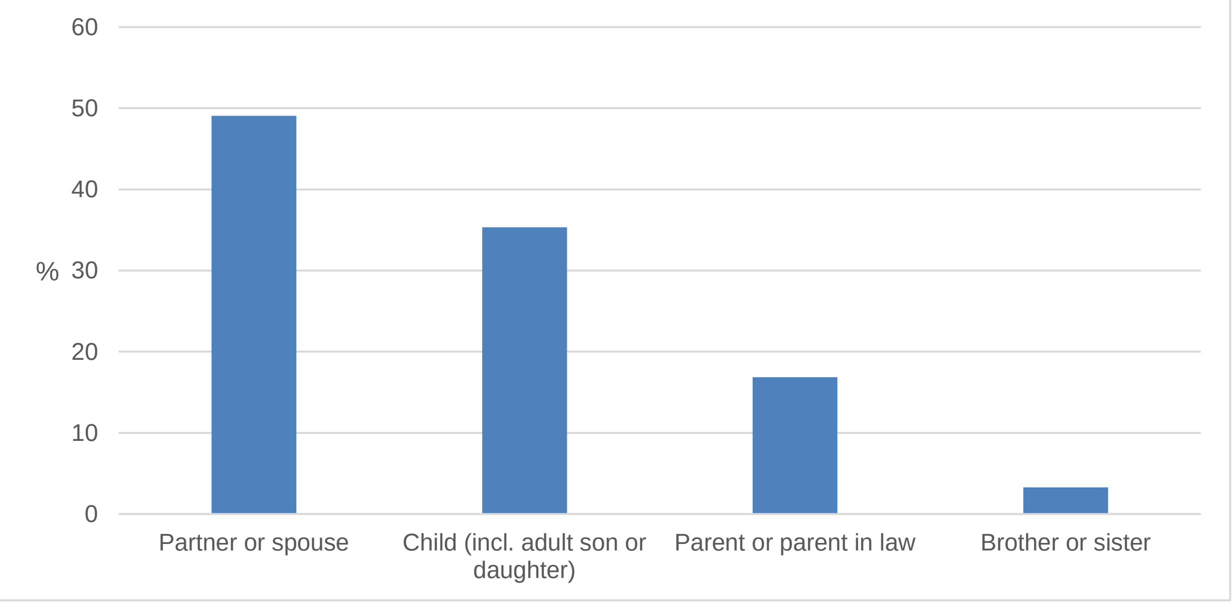


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

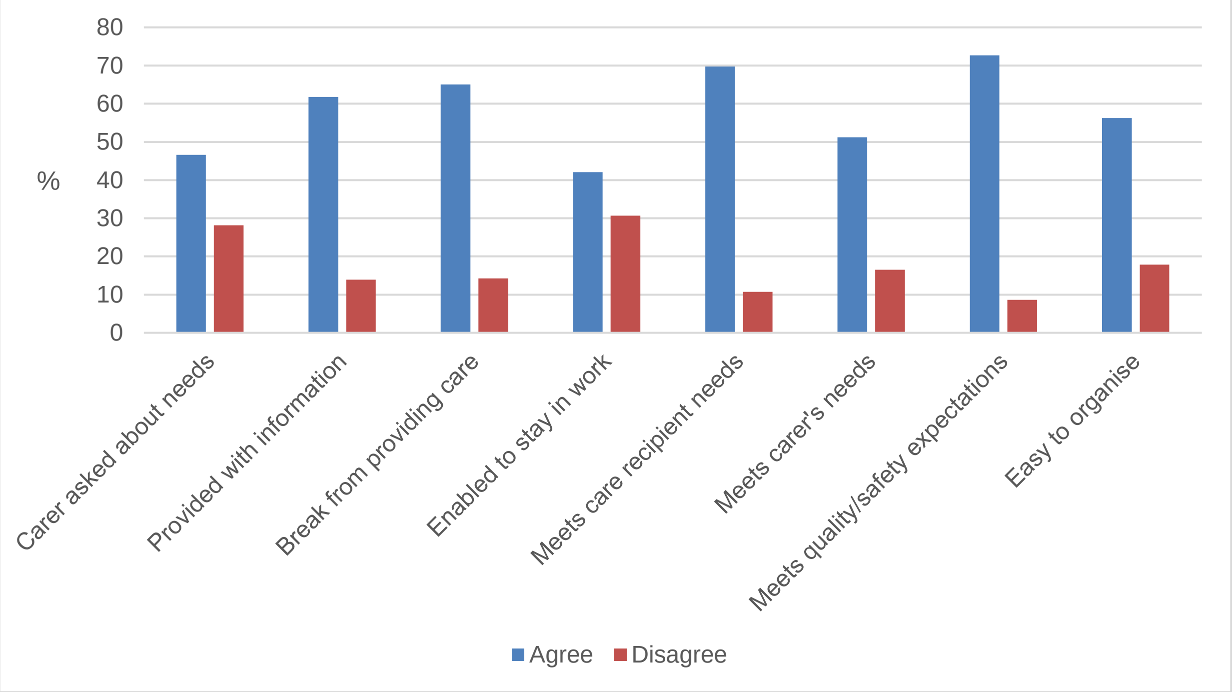


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

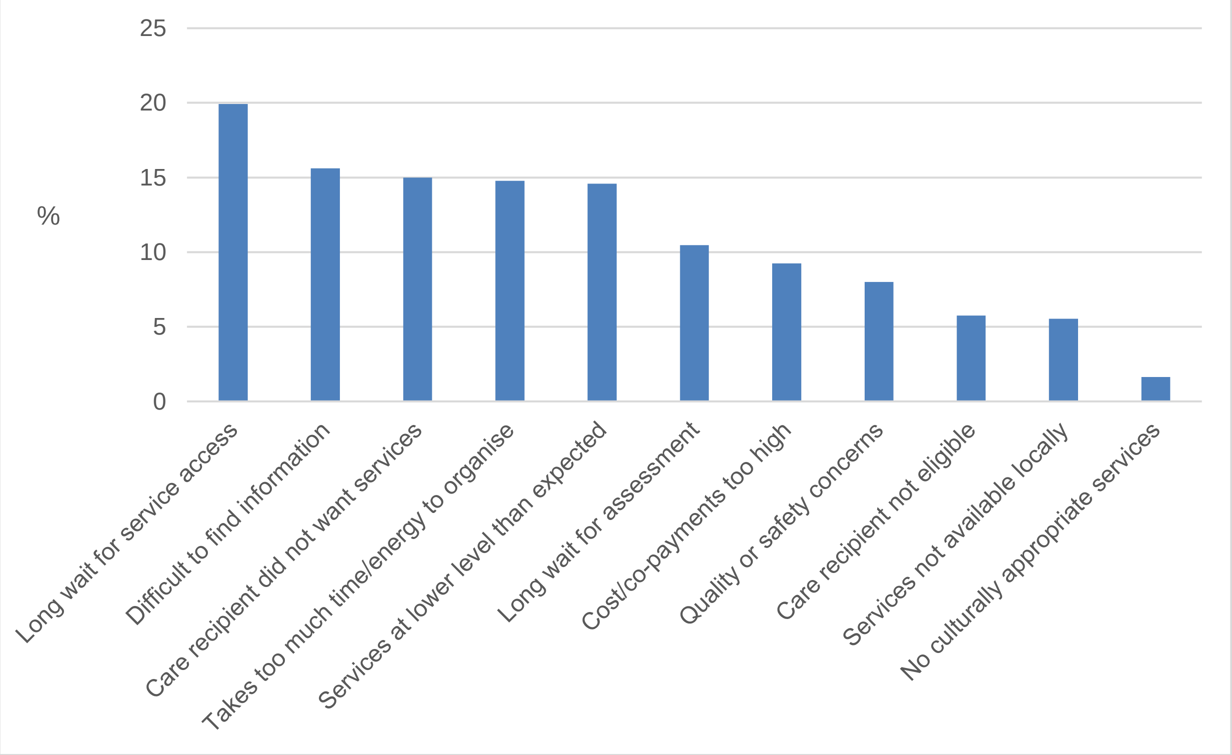


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

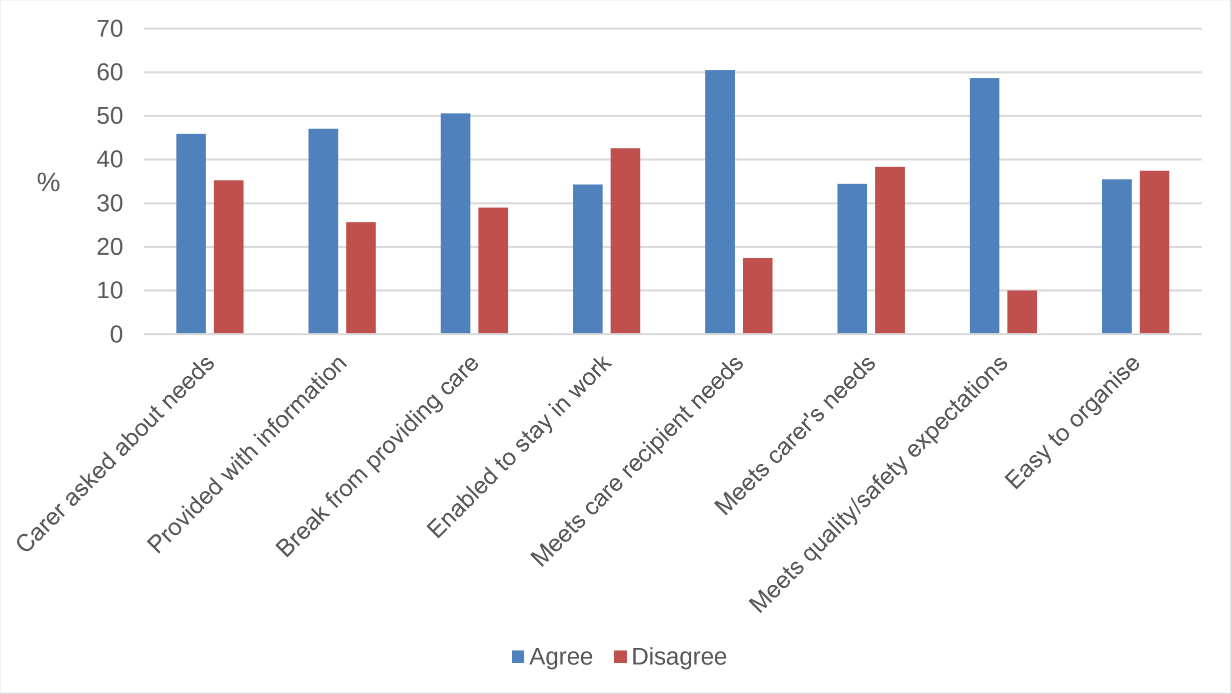


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

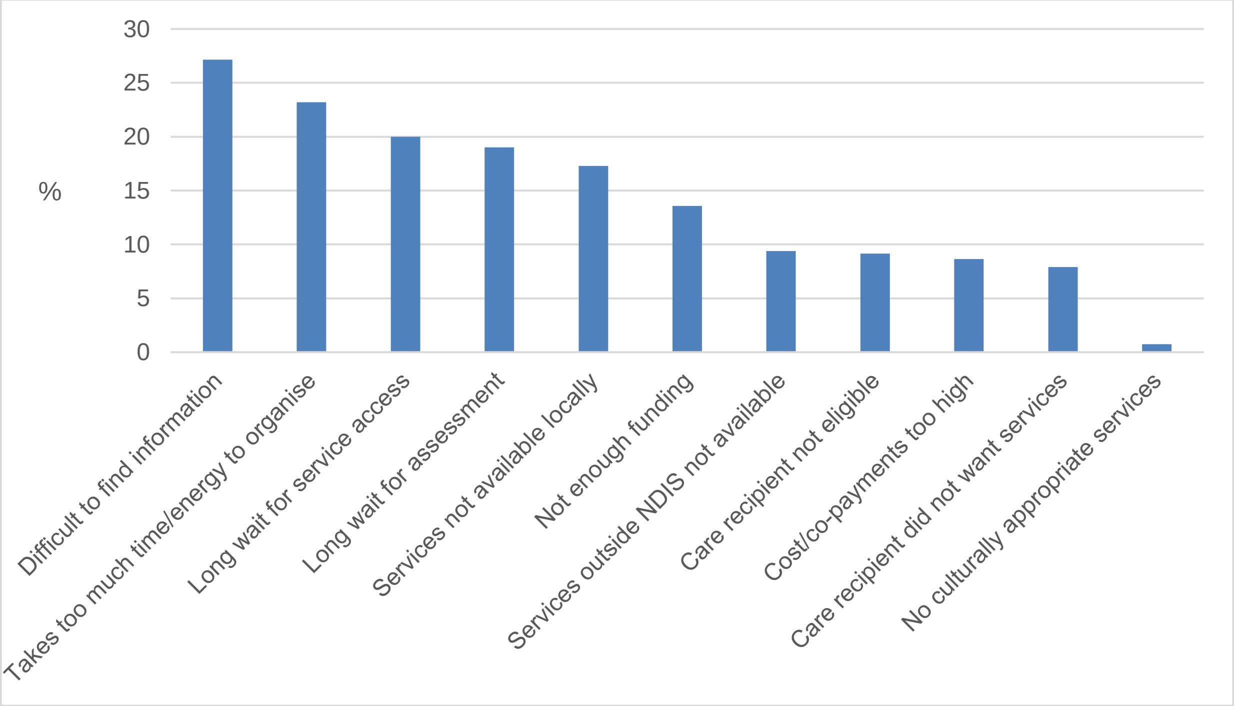


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

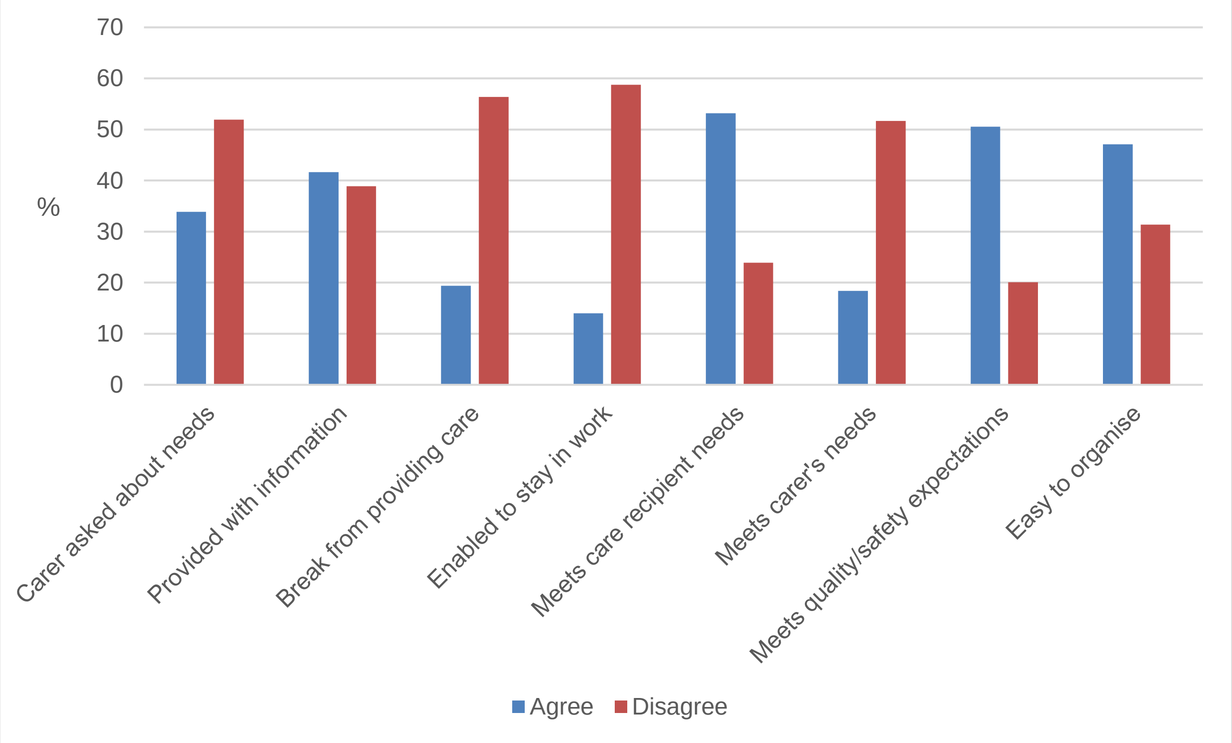


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

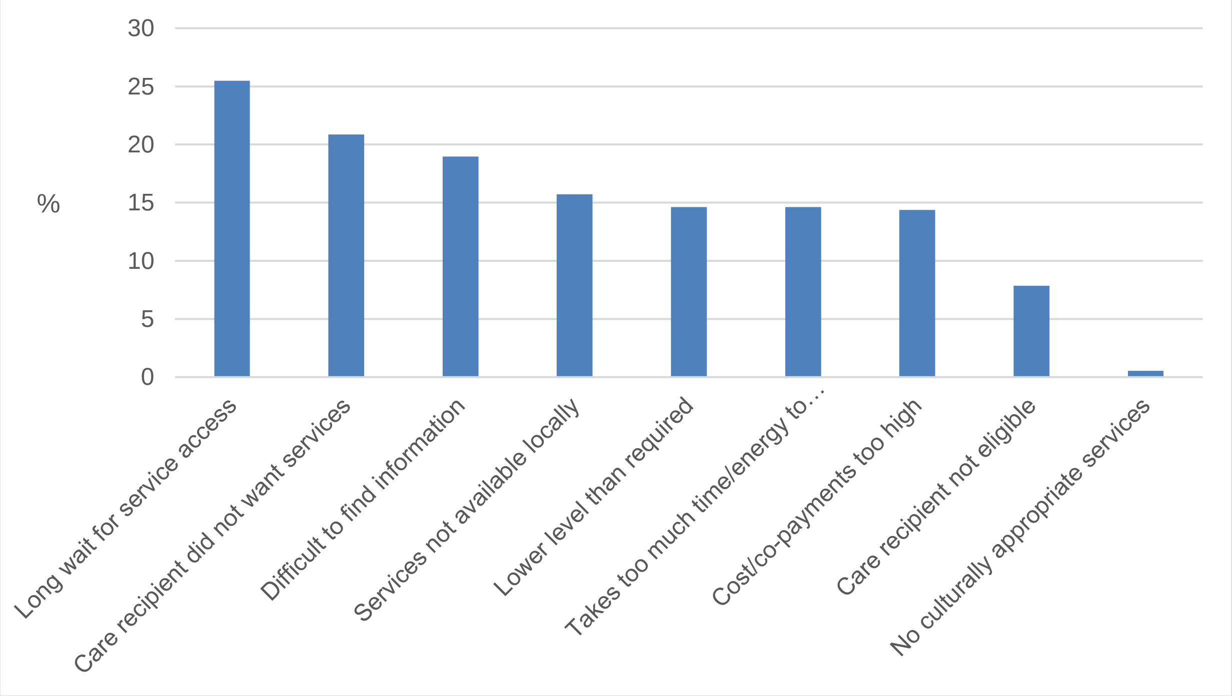


Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

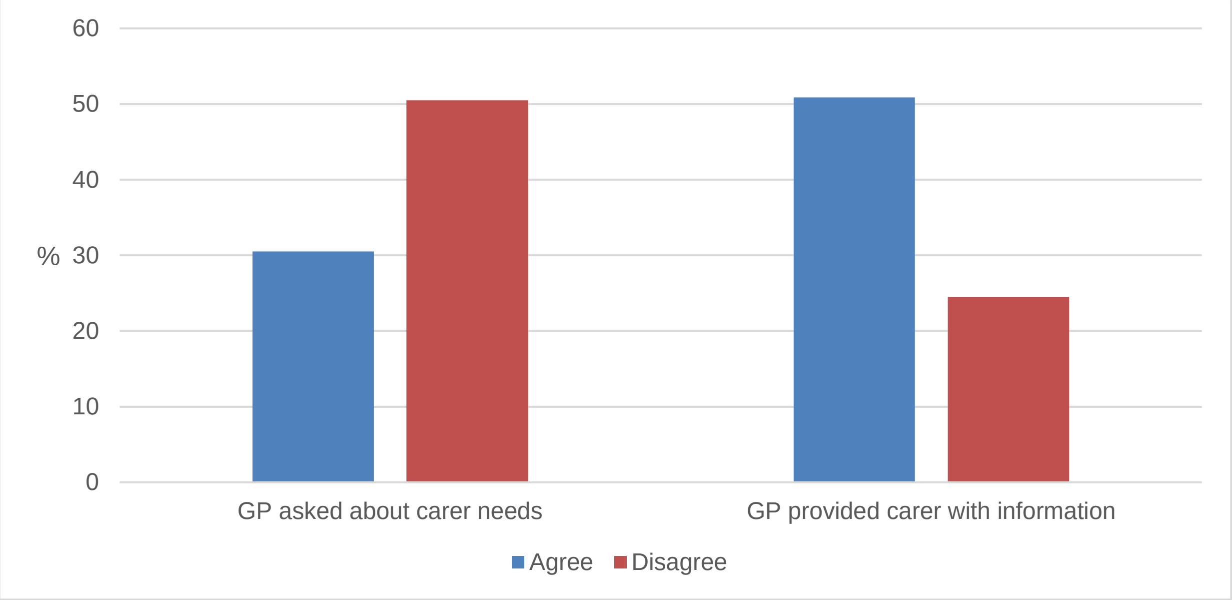


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

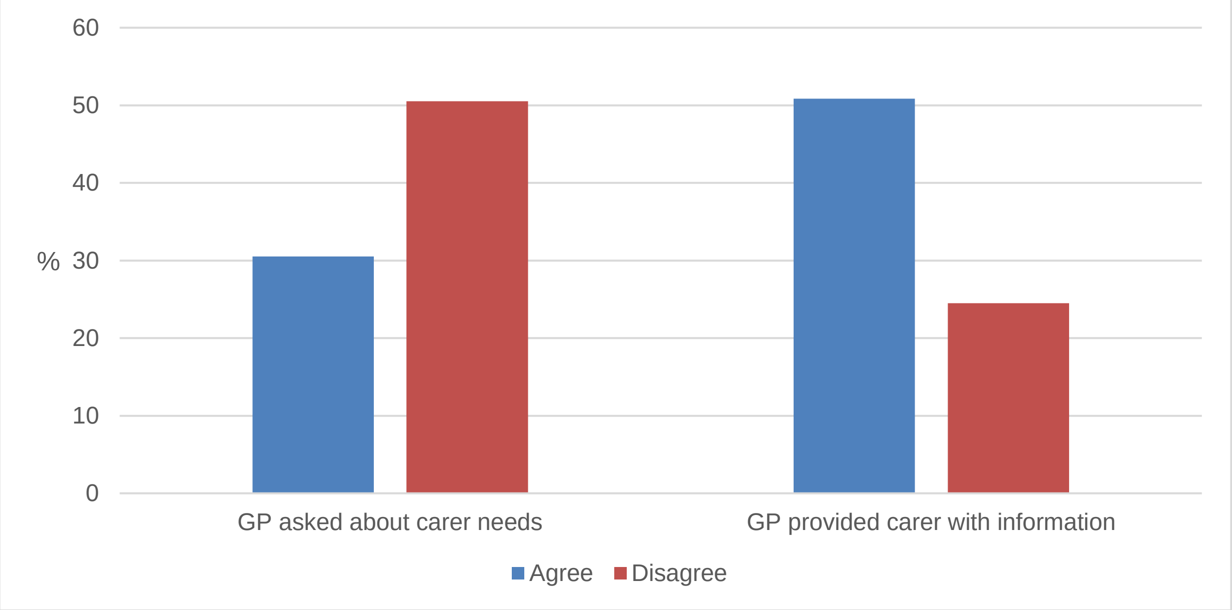
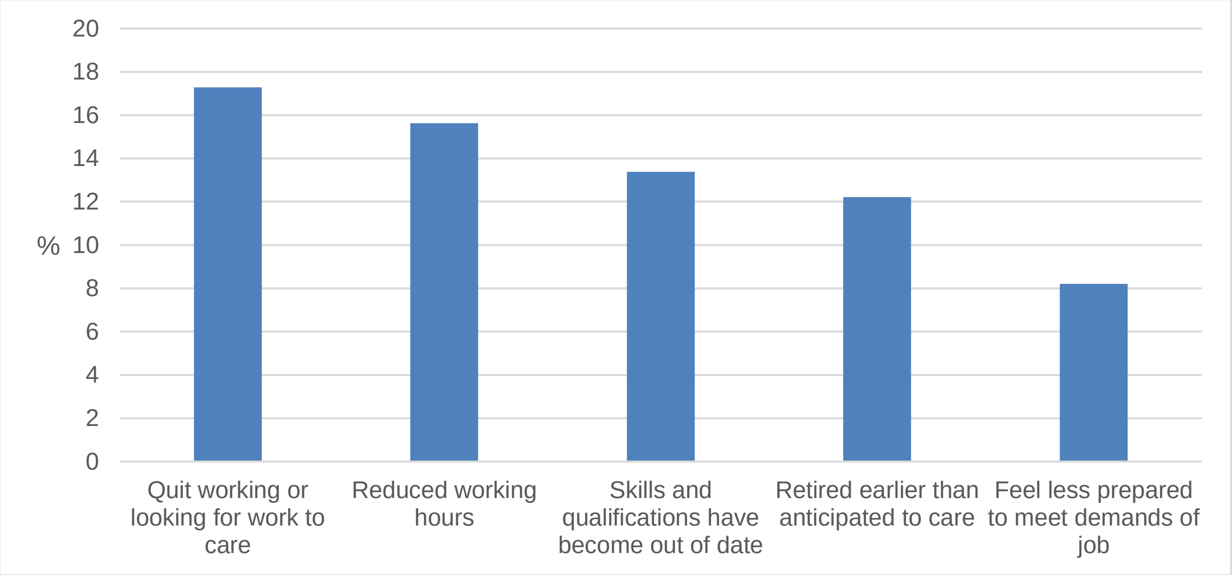


Figure 11 identifies the five most common impacts on career trajectory reported by carers in Tasmania.

Figure 11: Most common impacts of caring on career trajectory



Victorian (VIC) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in Victoria.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

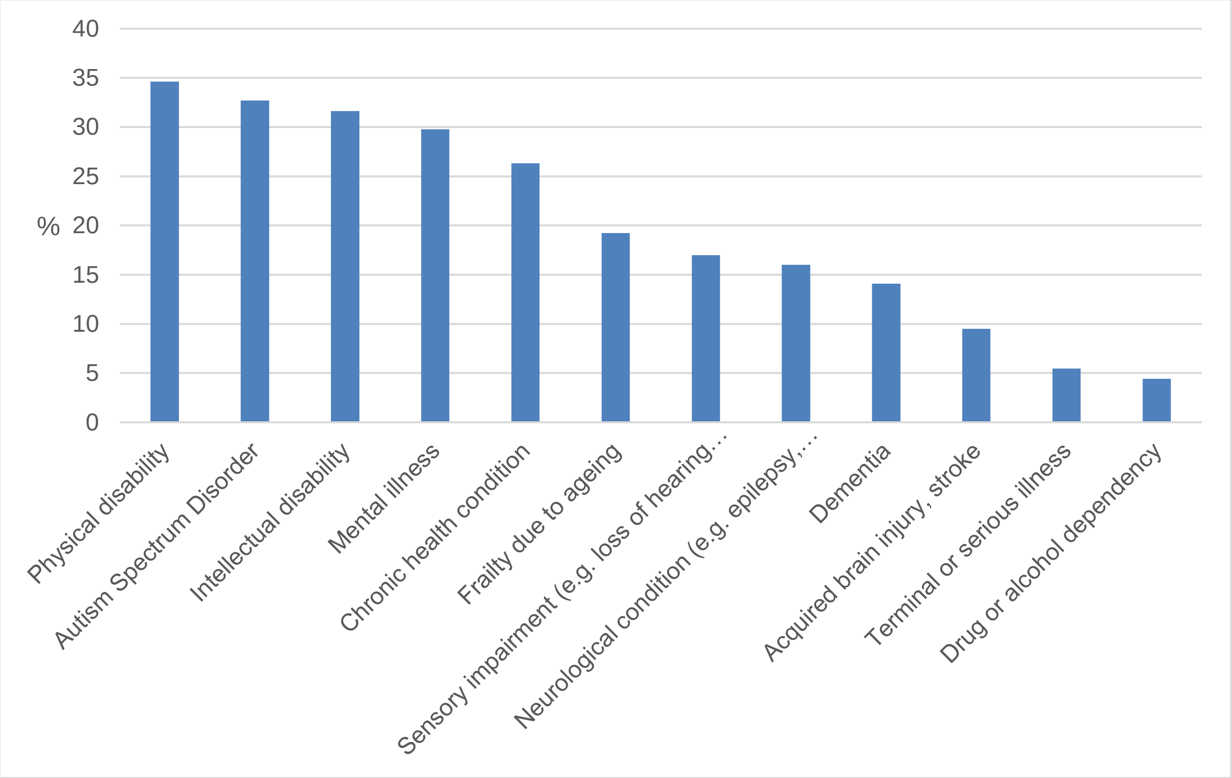


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in Victoria and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

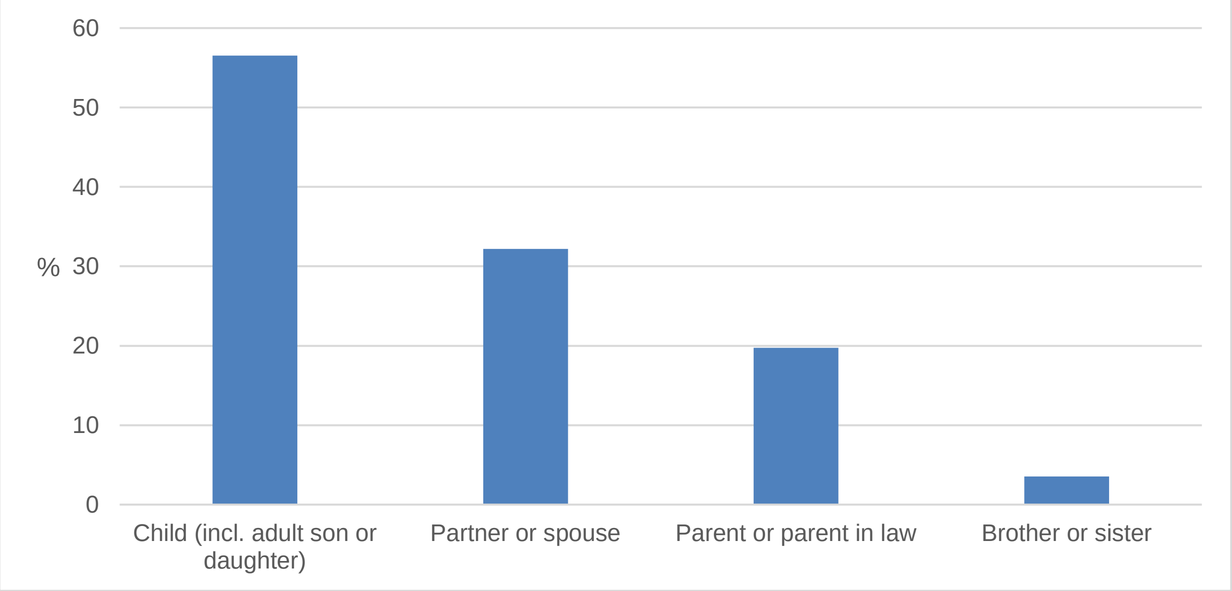


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

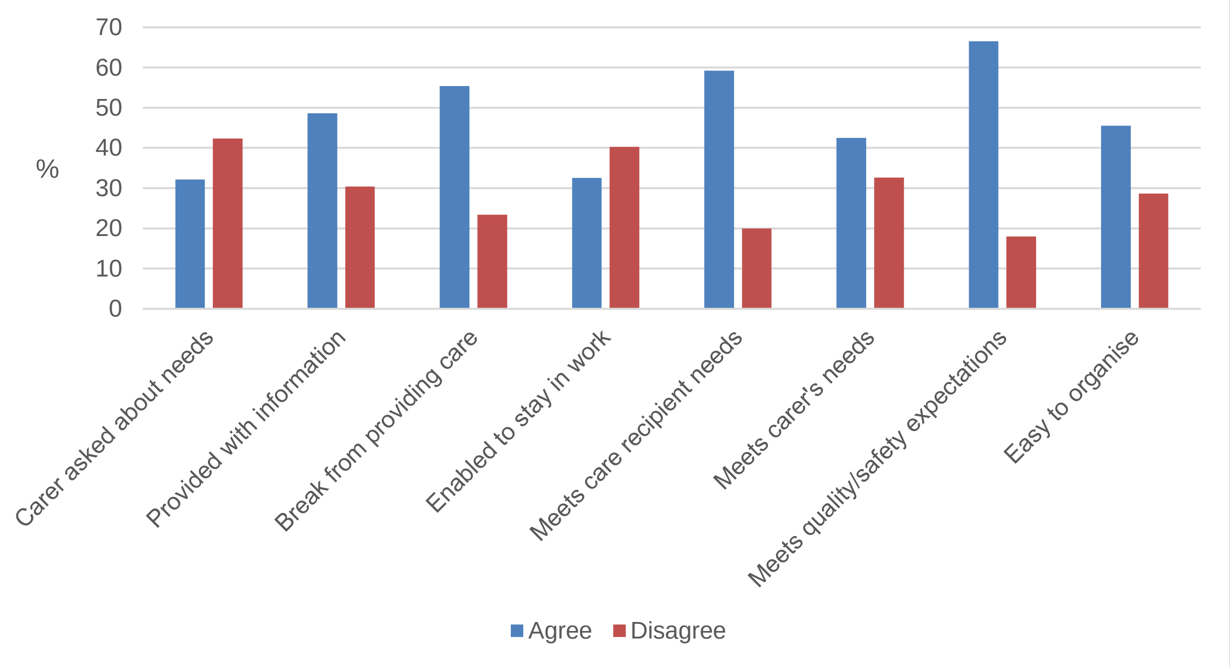


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

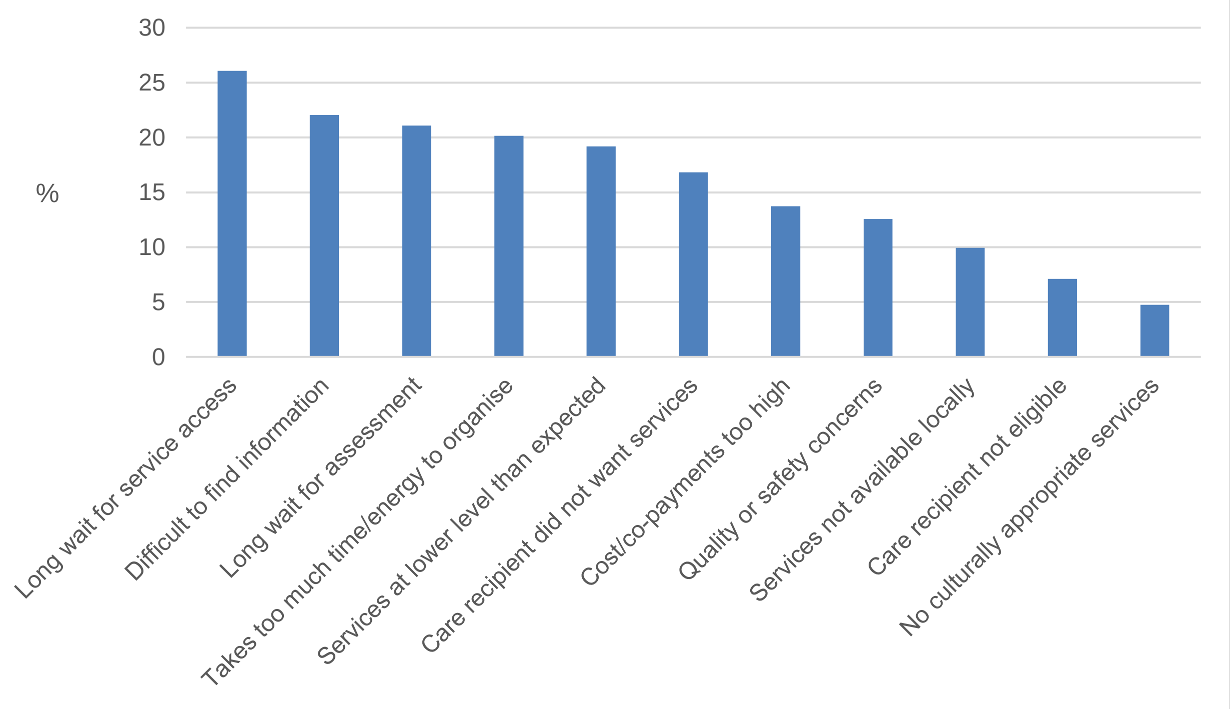


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

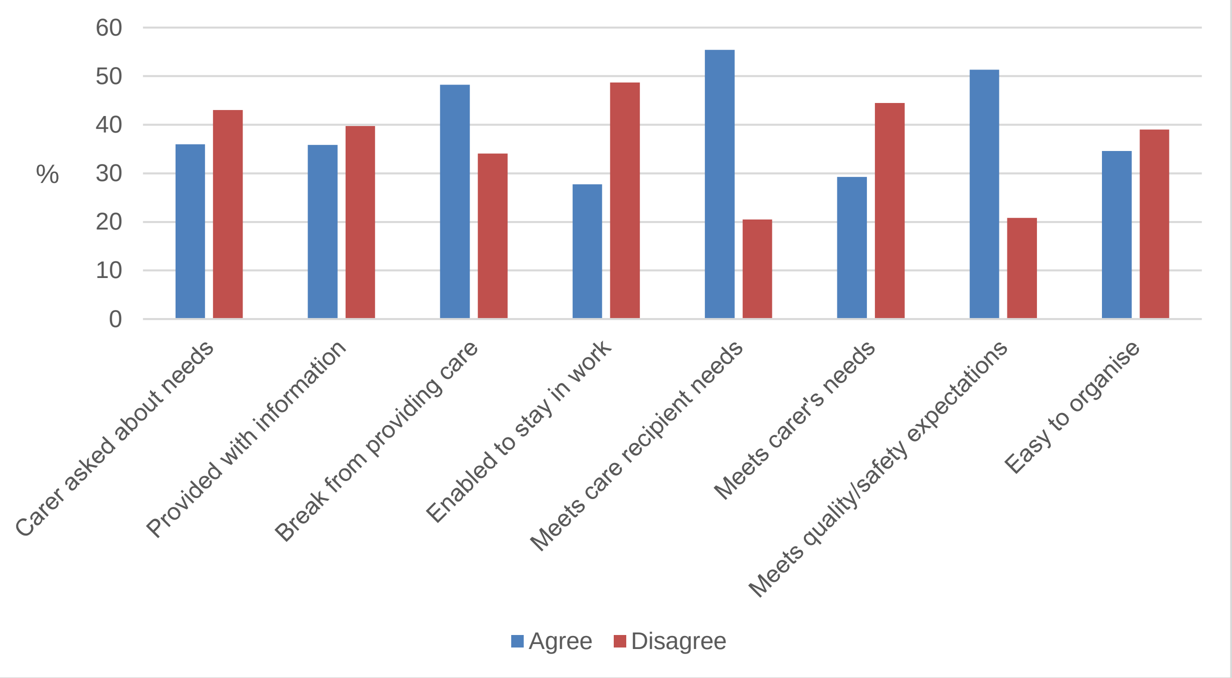


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

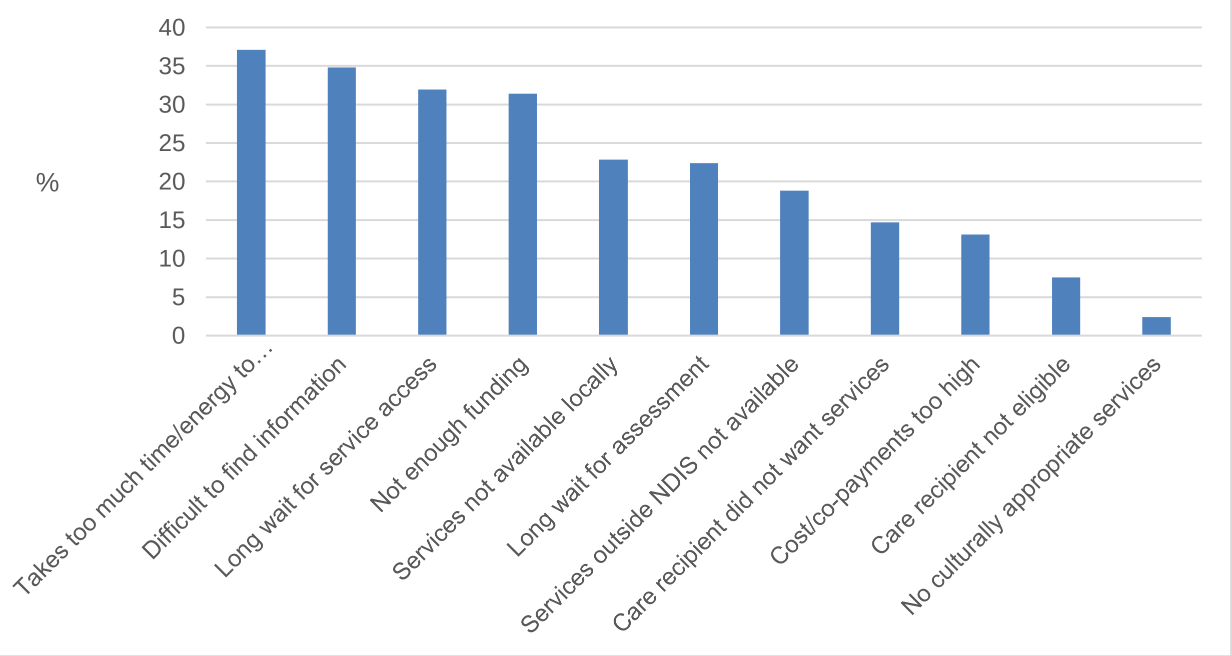


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

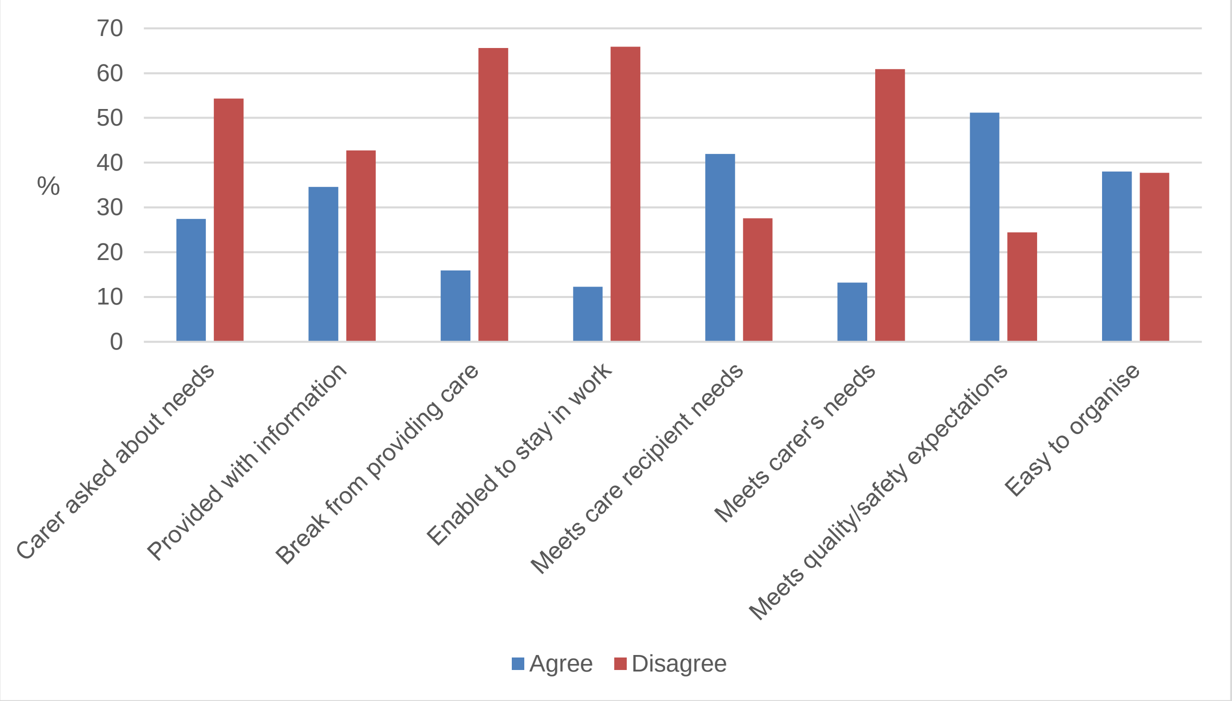


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

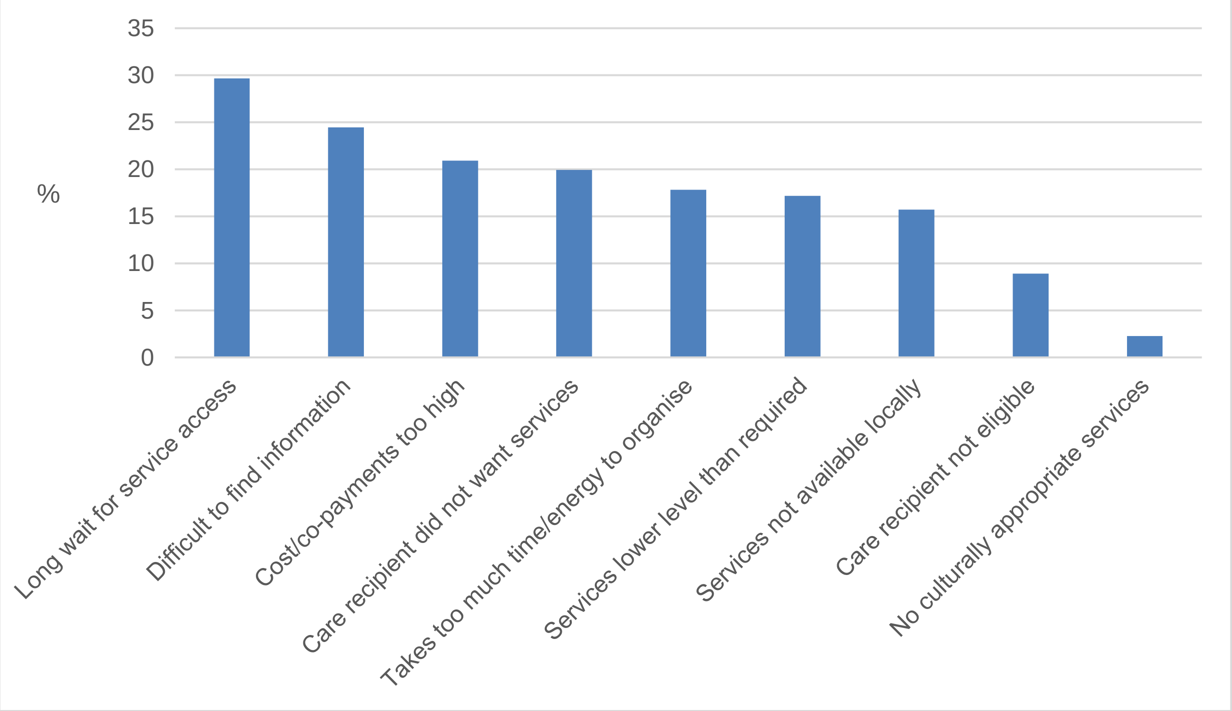


Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

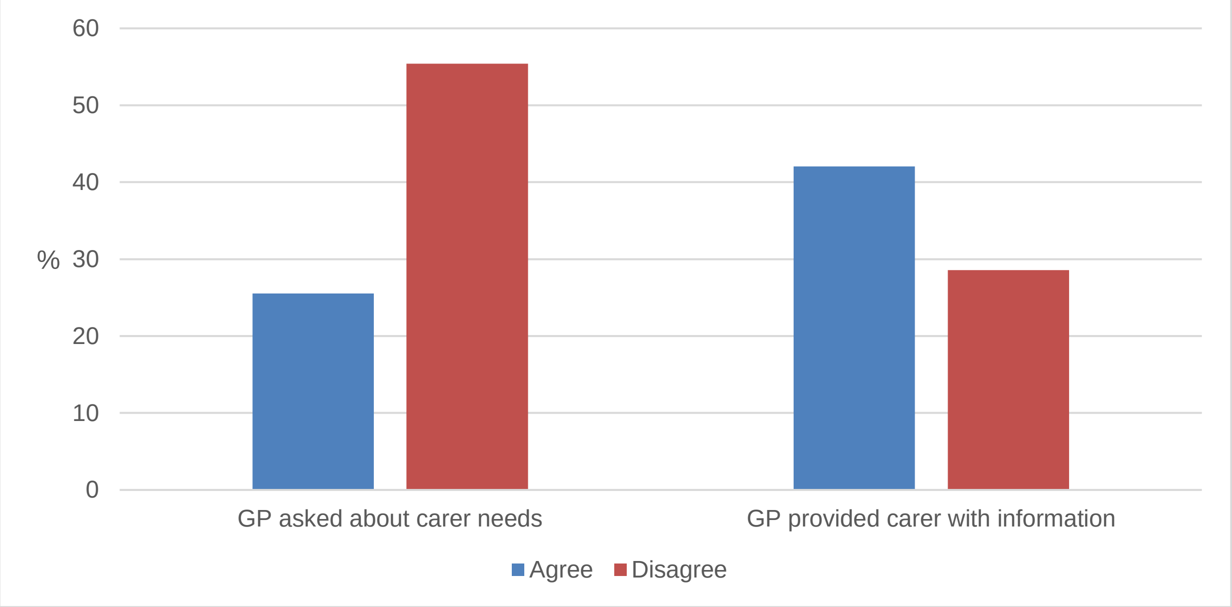


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

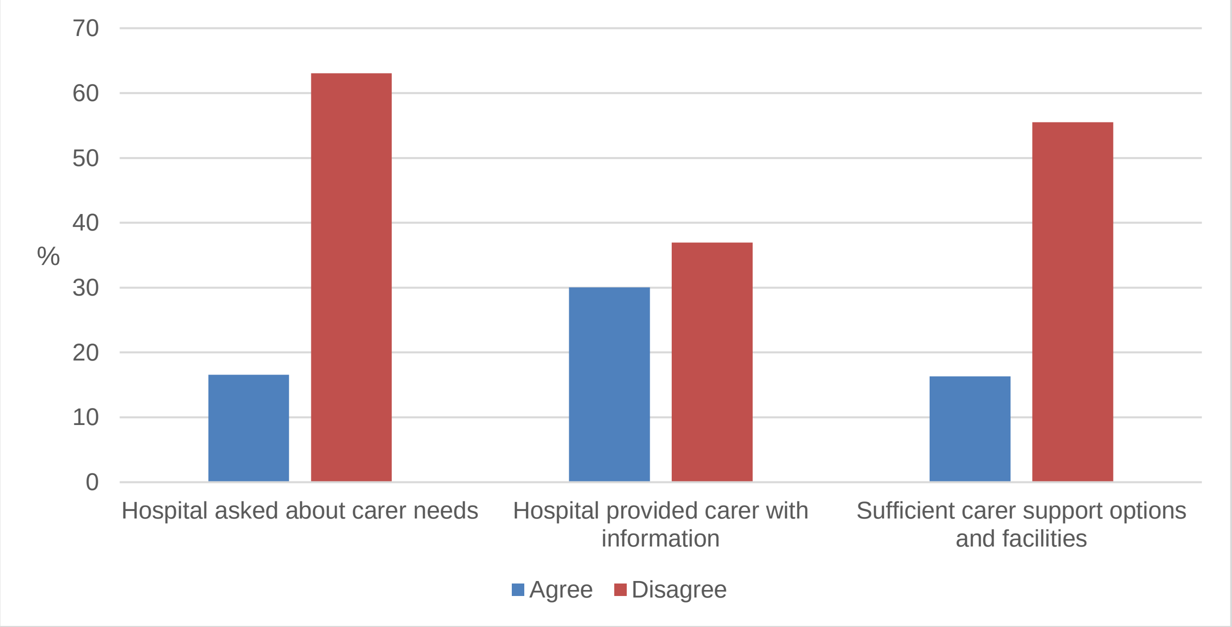
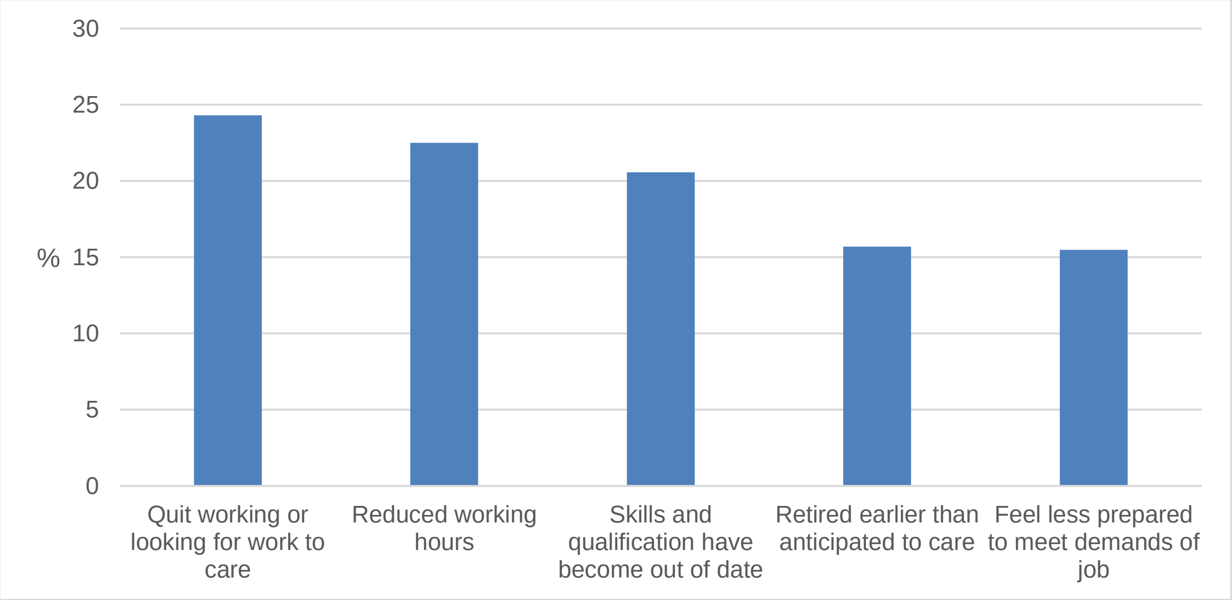


Figure 11 identifies the five most common impacts on career trajectory reported by carers in Victoria.

Figure 11: Most common impacts of caring on career trajectory



Western Australian (WA) respondents – Selected charts

Figure 1 breaks down the main conditions, illnesses or disabilities of person(s) being cared for by respondents to the 2020 National Carer Survey living in Western Australia.

Figure 1. Conditions, illnesses or disabilities of person(s) being cared for

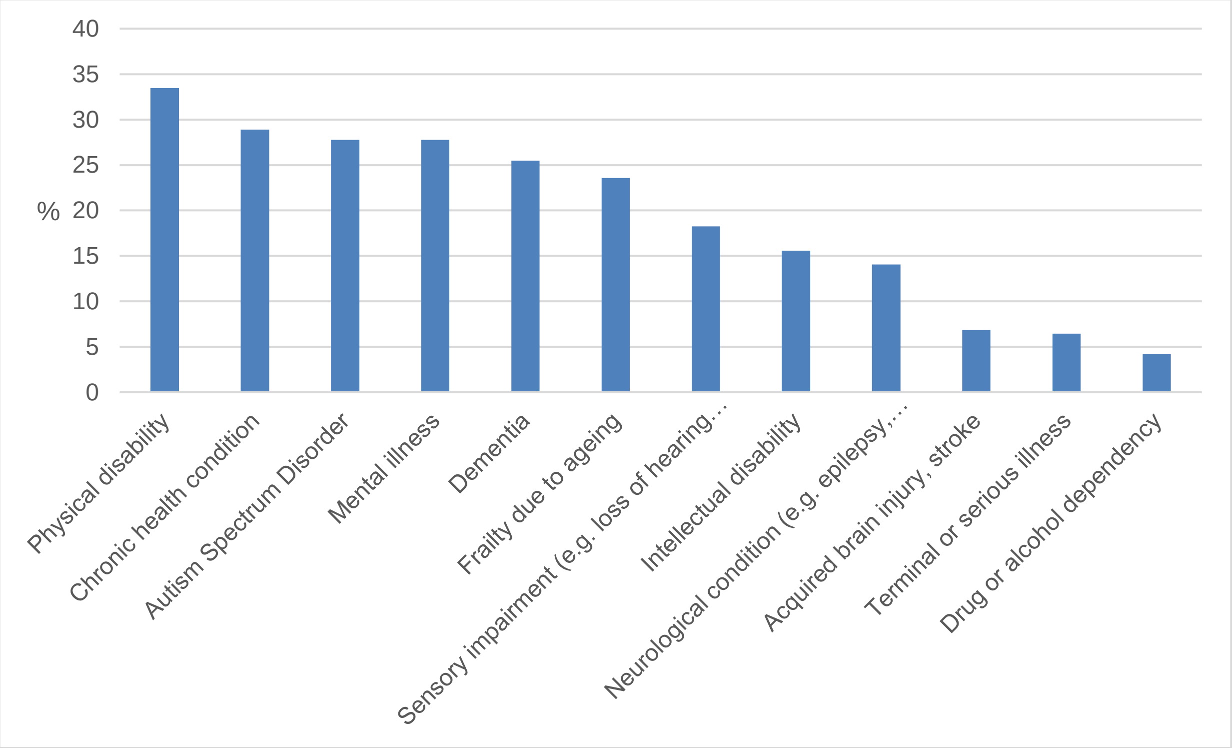


Figure 2 identifies the most common relationship between respondents to the 2020 National Carer Survey living in Western Australia and the person(s) they care for.

Figure 2. Relationships with person(s) being cared for

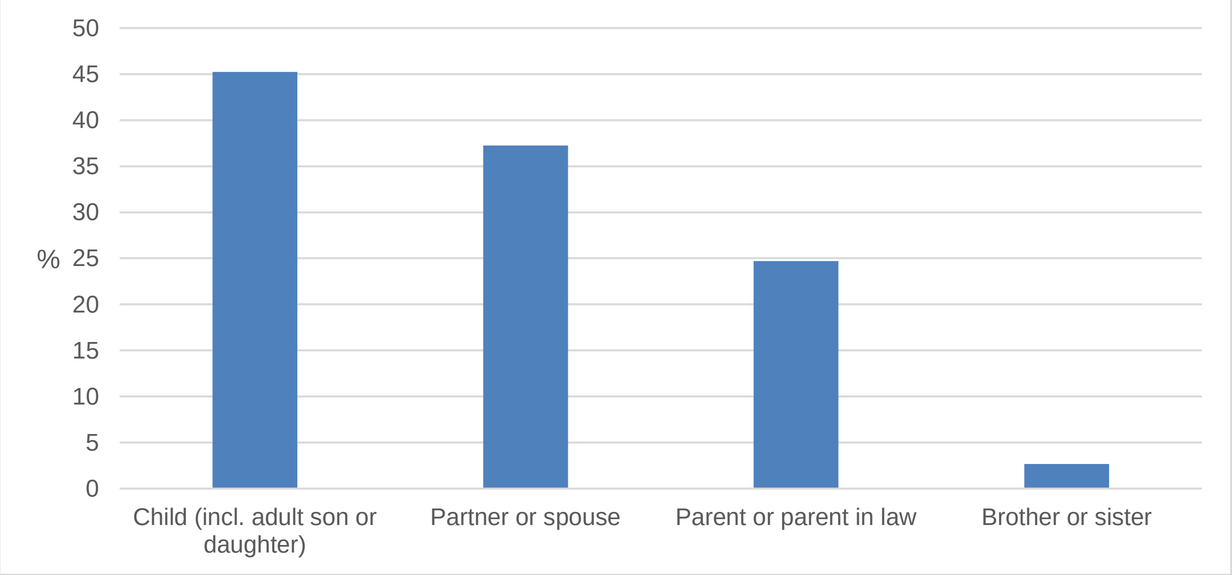


Figure 3 reports on carers' experiences with aged care services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 3: Carer inclusion and support in aged care services

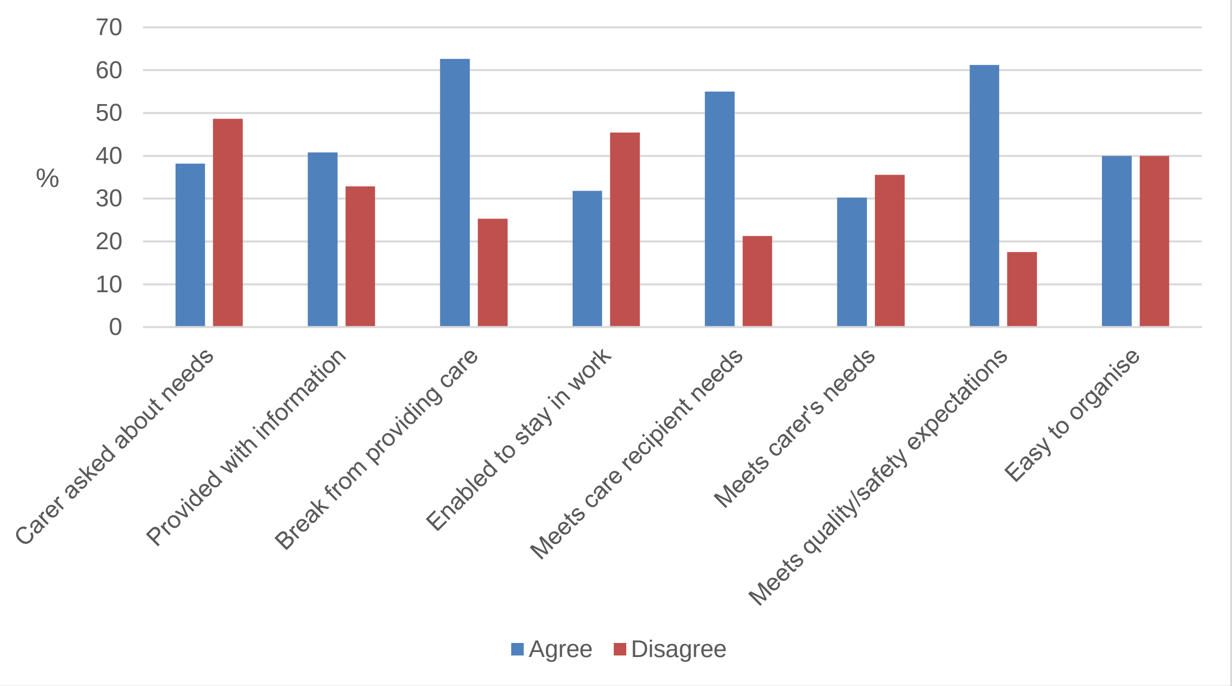


Figure 4 reflects how common a range of key challenges were among carers accessing aged care services with or on behalf of the person(s) they care for.

Figure 4: Challenges with accessing aged care services

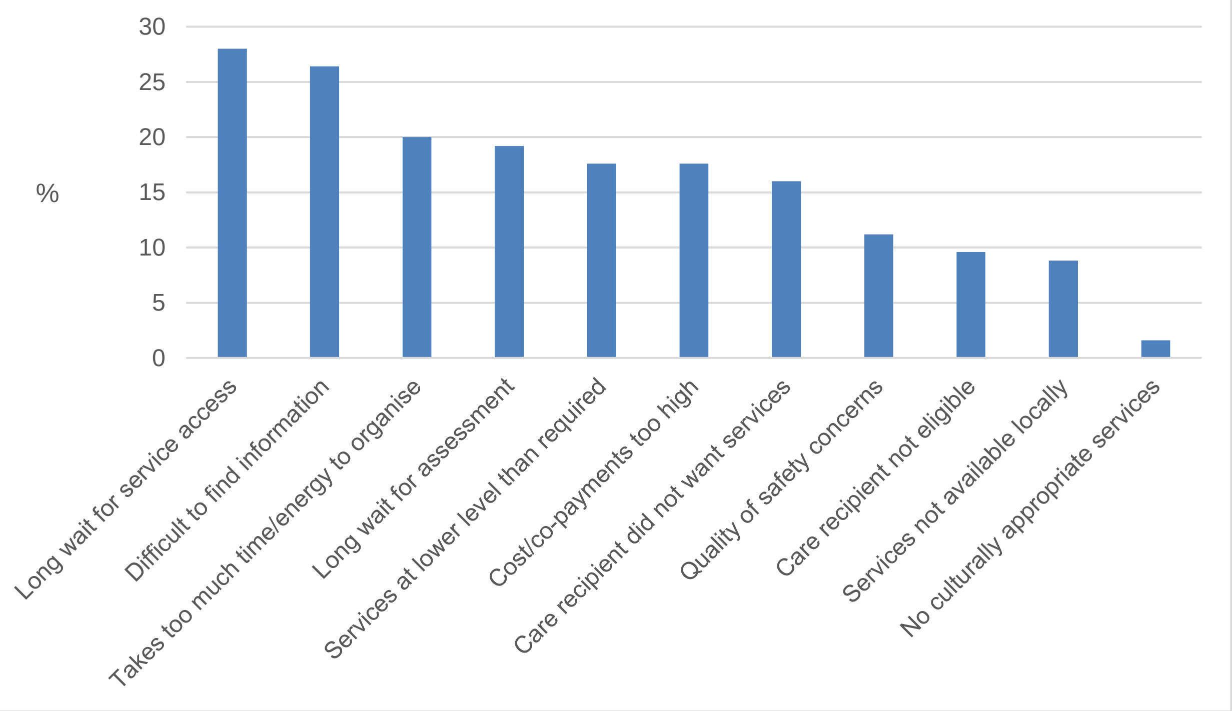


Figure 5 reports on carers' experiences with the NDIS, with a focus on carer inclusion and support.

Figure 5: Carer inclusion and support in the NDIS

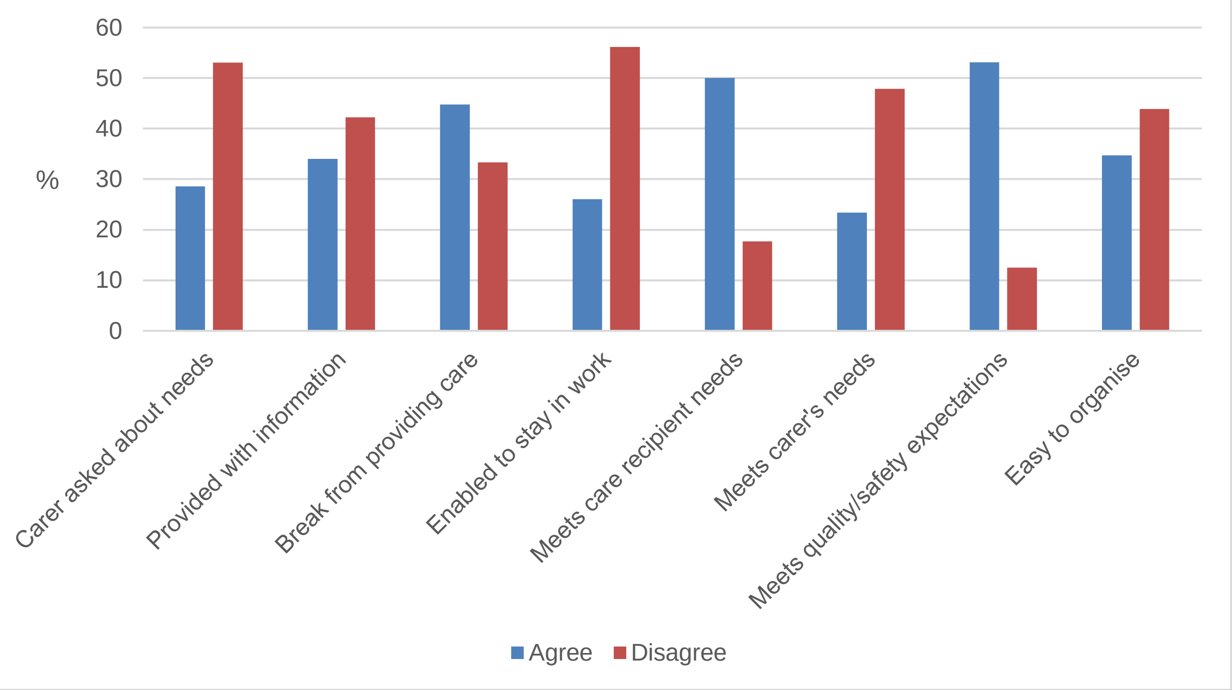


Figure 6 reflects how common a range of key challenges were among carers accessing disability services with or on behalf of the person(s) they care for.

Figure 6: Challenges with accessing disability services

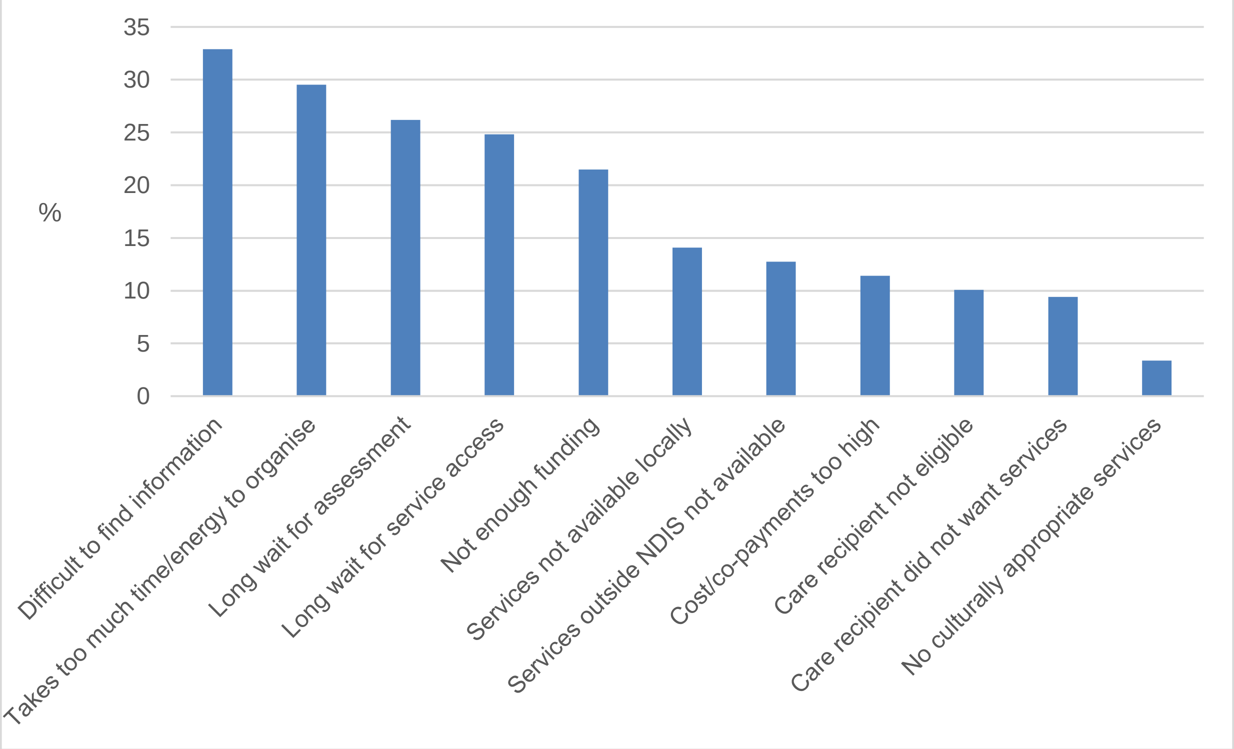


Figure 7 reports on carers' experiences with mental health services being accessed by or for the persons(s) they care for, with a focus on carer inclusion and support.

Figure 7: Carer inclusion and support in mental health services

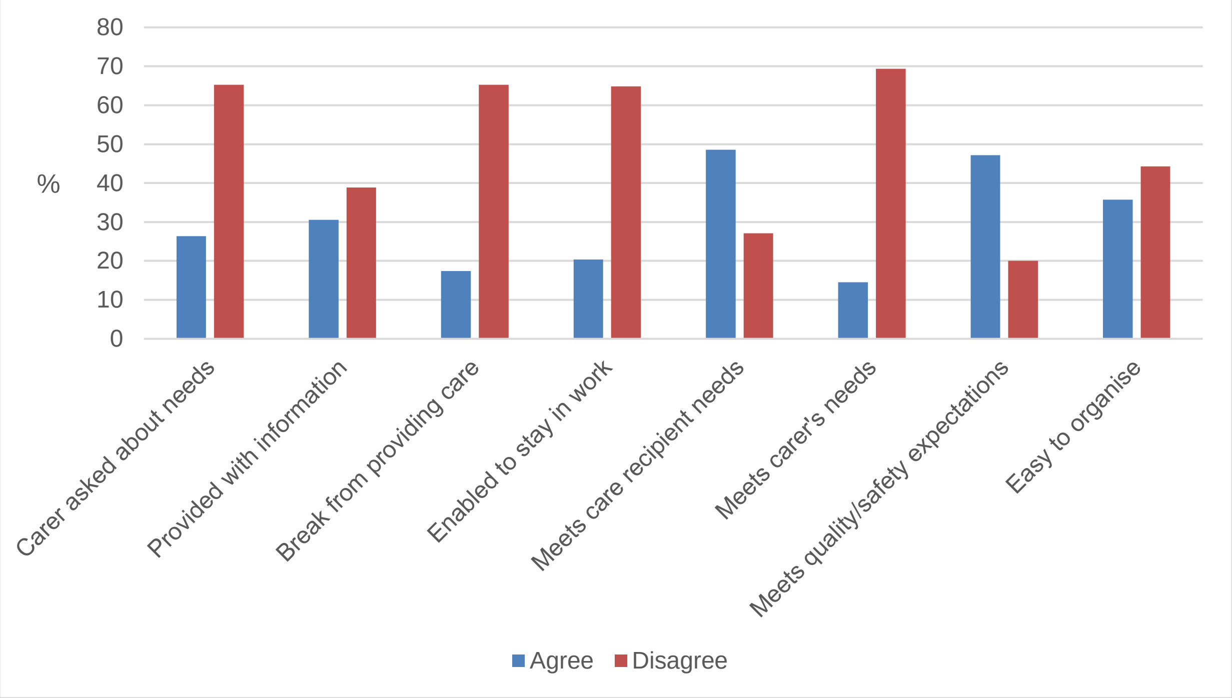


Figure 8 reflects how common a range of key challenges were among carers accessing mental health services with or on behalf of the person(s) they care for.

Figure 8: Challenges with accessing mental health services

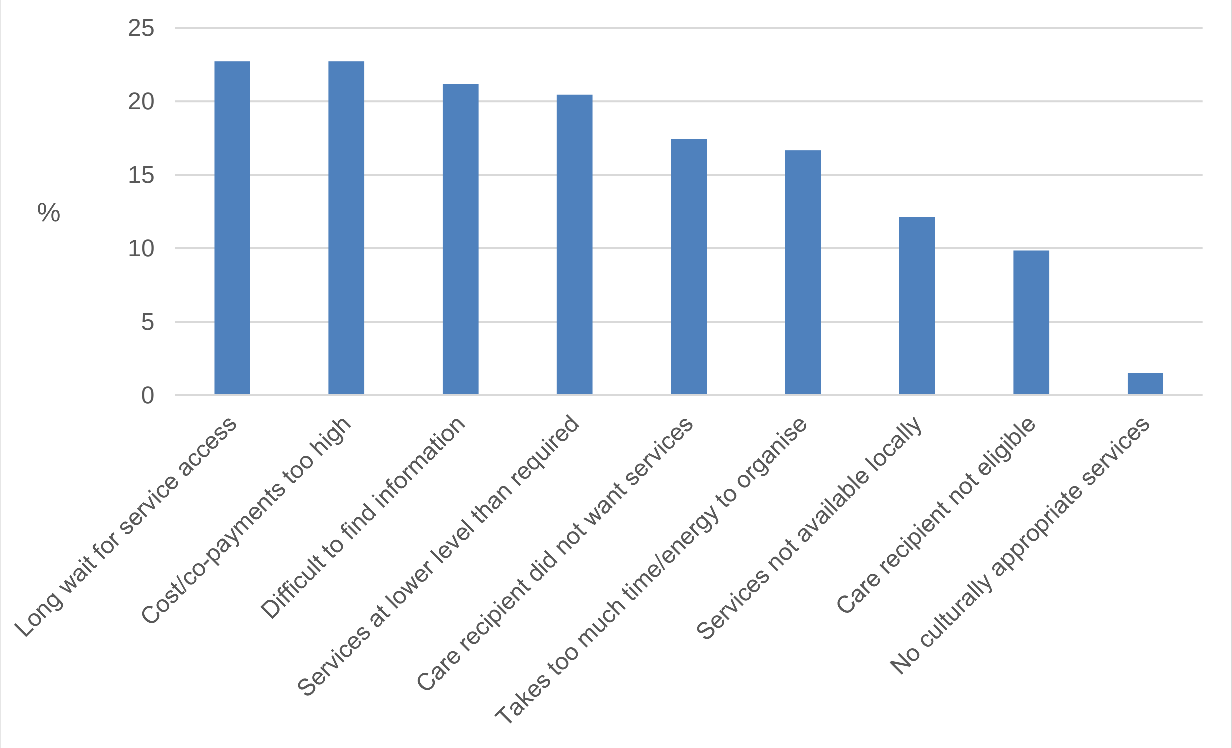


Figure 9 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a general practitioner (GP) or family doctor.

Figure 9: Carer inclusion and support by general practitioners (GPs)

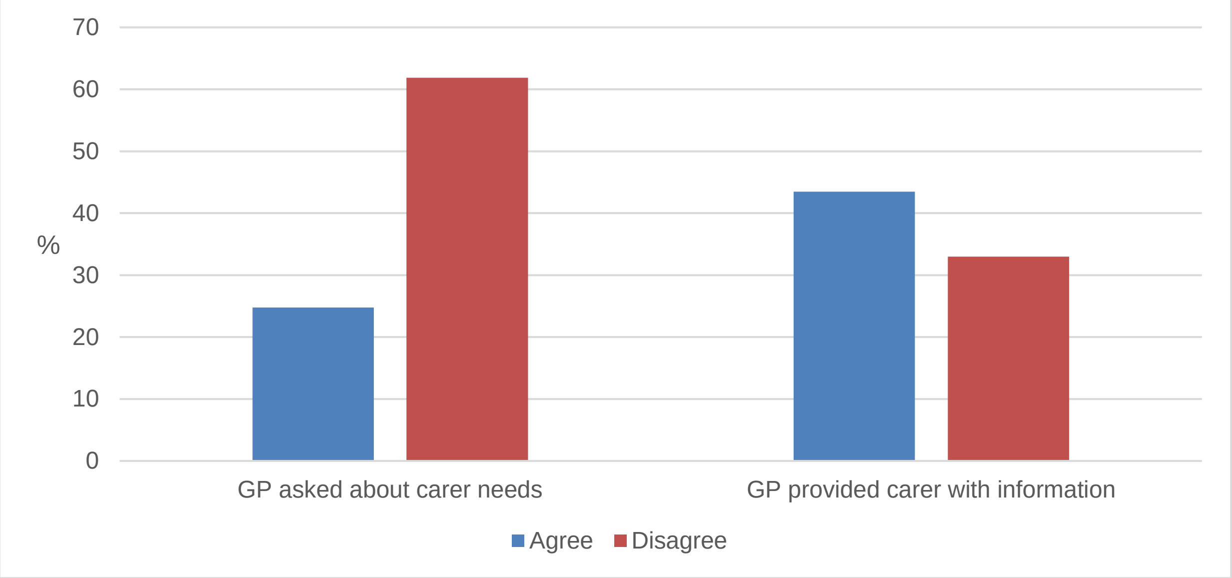


Figure 10 examines the extent of carer inclusion and support when carers accompany the person(s) they care for to a hospital or community health service.

Figure 10: Carer inclusion and support by hospital and community health services

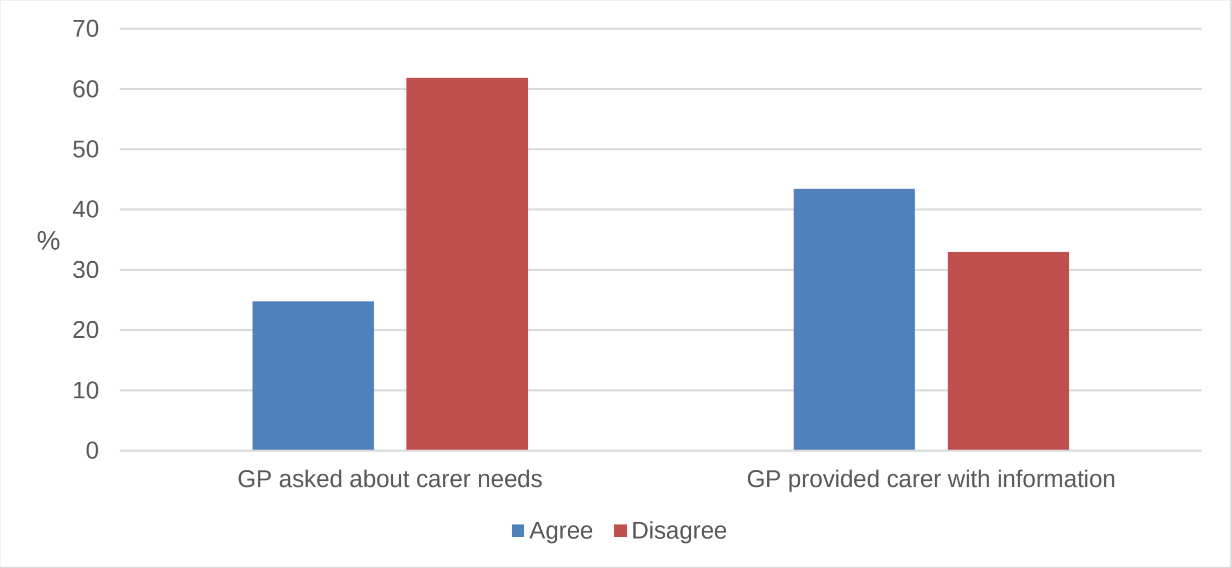


Figure 11 identifies the five most common impacts on career trajectory reported by carers in Western Australia.

Figure 11: Most common impacts of caring on career trajectory