SPRC UNSW Social Policy Research Centre

Impact Evaluation of the Integrated Carer Support Service (Carer Gateway): Final Report

Prepared for: Department of Social Services

March 2024

Authors: Ilan Katz, Trish Hill, Bruce Bradbury, Kylie Brosnan, Massimiliano Tani, Cathy Thomson, Elizabeth Adamson

UNSW SYDNEY

Acknowledgements

This project is supported by the Aboriginal and Torres Strait Islander Advisory Group, and we acknowledge their contribution to the project. Specifically, we would like to acknowledge Anne Campbell, Vanessa Davis, Eliziah Wasaga, and Roland Wilson.

We also acknowledge the Department of Social Services and Services Australia colleagues who supported this project. We would also like to acknowledge and thank all the carers and participants who have given their time for this evaluation.

Disclosure of interest statement

Known possible/perceived conflicts of interest:

UNSW Sydney researchers Catherine Thomson, Trish Hill and Ilan Katz have relationships with one service provider for Carer Gateway (Carers NSW) through the Carers and Knowledge Exchange Advisory Group, and previous projects. All interviews with service providers for this evaluation were conducted by a researcher with no potential/perceived conflict of interest.

One of the Aboriginal and Torres Strait Islander Advisory group members (Eliziah Wasaga) works for Qld Health, and may refer clients to Selectability Ltd, who is a consortium partner for a Carer Gateway service provider in Qld.

Research Team

Social Policy Research Centre, UNSW Sydney: Ilan Katz (Chief Investigator), Trish Hill (Project Manager), Bruce Bradbury, Elizabeth Adamson, Cathy Thomson

UNSW Canberra: Massimiliano Tani

Social Research Centre: Kylie Brosnan, Stevie McMillan, Alison Eglentals, Anna Lethborg, Nikki Honey.

Ipsos Aboriginal and Torres Strait Islander Research Unit: Sharon Barnes, Michael Barnes

For further information:
Ilan Katz +61 2 9385 7810

ilan.katz@unsw.edu.au

Social Policy Research Centre

UNSW Sydney NSW 2052 Australia

T +61 2 9385 7800
F +61 2 9385 7838
E sprc@unsw.edu.au
W unsw.edu.au/sprc

The Social Policy Research Centre is based in the Faculty of Arts, Design and Architecture at UNSW Sydney. This report is an output of the Integrated Carer Support Service Impact Evaluation research project, funded by DSS.

Suggested citation: Katz, I. Hill, T., Bradbury B., Brosnan, K., Tani, M, Thomson, C, and Adamson, E. (2024) *Impact Evaluation of the Integrated Carer Support Service (Carer Gateway): Final report,* Sydney, UNSW Social Policy Research Centre.

Contents

Key messages ix
1 Summary xi
  1.1 The evaluation xii
  1.2 Appropriateness xii
  1.3 Effectiveness xiv
  1.4 Efficiency xvii
  1.5 Aboriginal and Torres Strait Islander Carers xviii
  1.6 Conclusions xviii
2 Introduction 1
  2.1 Policy context 1
  2.2 Program background 2
  2.3 Objective of the impact evaluation 4
  2.4 Status of the report 5
3 Approach 6
  3.1 Summary of data sources 6
  3.2 Limitations 7
  3.3 Ethics 8
Part A: Appropriateness 9
4 Question 1: Appropriateness of design 10
  4.1 Carers’ needs for support 10
  4.2 Services to meet carers’ needs 11
  4.3 Stakeholder perspectives 14
  4.4 Non-Indigenous carer perspectives 17
  4.5 Aboriginal and Torres Strait Islander carer perspectives 20
  4.6 Summary 20
5 Question 1a: Most appropriate supports for carers 21
  5.1 Overall satisfaction with Carer Gateway 21
  5.2 Measuring satisfaction in the Carer Wellbeing Survey (CWS) 21
  5.3 Measuring satisfaction in DEX for performance monitoring reports 22
  5.4 Satisfaction with aspects of Carer Gateway services 23
  5.5 Satisfaction with types of Carer Gateway services 24
  5.6 Stakeholder perspectives 26
  5.7 Aboriginal and Torres Strait Islander carer perspectives 30
  5.8 Non-Indigenous carer perspectives 32
  5.9 Summary 34
6 Question 1b: Use of Carers StarTM assessment 35
  6.1 Surveys: Satisfaction with assessment and planning 35
  6.2 Stakeholder perspectives 36
  6.3 Aboriginal and Torres Strait Islander carer perspectives 41
  6.4 Non-Indigenous carer perspectives 42
  6.5 Summary 43
7 Question 1c: Early intervention and high levels of need 44
  7.1 Emergency respite use 44
  7.2 Carers of people with high needs for assistance 44
  7.3 Stakeholder perspectives 44
  7.4 Summary 45
8 Question 2: Interaction with the NDIS and other policies 46
  8.1 Eligibility, referrals and access 46
  8.2 Stakeholder perspectives 46
  8.3 Aboriginal and Torres Strait Islander carer perspectives 48
  8.4 Non-Indigenous carer perspectives 48
  8.5 Summary 49

9 Question 3: Governance and funding processes 50
  9.1 Stakeholder perspectives...50
  9.2 Summary 51
10 Question 4: Implementation of prior recommendations...52
  10.1 Raise awareness of the model...52
  10.2 Improve capability to collect and use Carers Star^{TM} data.............................53
  10.3 Increase monitoring Carers Star^{TM} completion rates....................................53
  10.4 Continue COVID-19 ‘fast-track’ intake for carers with extreme need............53
  10.5 Integrate online, telephone, and face-to-face components 53
  10.6 Review respite processes in greater detail 53
  10.7 Re-incorporate social connection for carers 54
  10.8 Summary – Appropriateness 54
Part B: Effectiveness 56
11 Question 5: Program reach...57
  11.1 Program reach...57
  11.2 Program reach: Carer Allowance recipients 59
  11.3 Awareness and access of Carer Gateway..61
  11.4 Accessing Carer Gateway website and online services 65
  11.5 Summary 70
12 Question 6: Impact on the services system..71
  12.1 Stakeholder perspectives...71
  12.2 Carer perspectives 73
  12.3 Summary 73
13 Question 6a: Impact on respite services 74
  13.1 Need for more access to respite 74
  13.2 Use of respite 75
  13.3 Barriers to respite use 79
  13.4 Satisfaction with respite 81
  13.5 Summary 81
14 Question 7: Were intended outcomes achieved?..83
  14.1 Wellbeing...83
  14.2 Capacity for caring 89
  14.3 Social participation and loneliness...90
  14.4 Economic participation 92
  14.5 Resilience...94
  14.6 Stakeholder perspectives...97
  14.7 Aboriginal and Torres Strait Islander carer perspectives..............................99
  14.8 Non-Indigenous Carers 100
  14.9 Summary 102
15 Question 7a: Unintended outcomes 104
  15.1 Stakeholder perspectives...104
  15.2 Carer perspectives 104
  15.3 Summary 105
1 Question 7b: Factors affecting program outcomes 106
  15.4 Stakeholder perspectives...106
  15.5 Aboriginal and Torres Strait Islander carer perspectives............................109
  15.6 Non-Indigenous carer perspectives 110
  15.7 Summary 111
16 Question 7c: Carers who have benefited most 112
  16.1 Changes in Carers Star^{TM} scores by demographic group 112
  16.2 Summary 115
17 Question 7d: ICSS services contributing most to carer outcomes........................116
  17.1 Changes in Carers Star^{TM} scores by service types.....................................116
  17.2 Summary 118

Part C: Efficiency 119
18 Question 8: Interactions and Referral Pathways 120
18.1 DEX data on carer support programs 120
18.2 Stakeholder perspectives...120
18.3 Summary 122
19 Question 9: Cost-effectiveness of the program 123
19.1 Cost of Carer Gateway...123
19.2 Benefits of Carer Gateway 125
19.3 Estimating cost effectiveness..126
19.4 Summary 128
20 Question 9a: Cost-effectiveness of restructure 130
20.1 Effect of the restructured investment in carer support................................130
20.2 Summary 131
Part D: Aboriginal and Torres Strait Islander carers 132
21 Aboriginal and Torres Strait Islander carers 133
21.1 Introduction...133
21.2 Appropriateness 133
21.3 Effectiveness 136
21.4 Summary of implications for Aboriginal and Torres Strait Islander carers ..139
Part E: Discussion and implications 140
22 Discussion...141
23 Implications for priority groups..143
23.1 Aboriginal and Torres Strait Islander carers 143
23.2 Female carers 143
23.3 Carers with disability 143
23.4 Regional or remote carers...143
23.5 Young carers (aged under 25 years) 143
23.6 Older carers..144
23.7 Carers of older persons...144
23.8 Culturally and Linguistically Diverse carers 144
23.9 Mental health carers...144
23.10 Summary 144
24 Conclusion and implications 145
24.1 Conclusion..145
24.2 Implications 146
References 147
Appendix A Evaluation questions 150
A.1 Appropriateness questions...150
A.2 Effectiveness questions..150
A.3 Efficiency questions 151
Appendix B ICSS Outcomes Framework 152
Appendix C Data sources 154
C.1 Program data 154
C.2 Carer Gateway Data Exchange (DEX) data 154
C.3 Carer Wellbeing Survey 156
Appendix D Qualitative methods 159
D.1 Stakeholder interviews 159
D.2 Interviews with non-Indigenous Carer Gateway program clients 159
D.3 Interviews with Aboriginal and Torres Strait Islander ICSS program clients162
Appendix E Population surveys: Methods 164
E.1 Population survey – Life in Australia^{TM} 164
E.2 Population survey of Carer Payment and/or Carer Allowance recipients164
E.3 Survey of carers who have received emergency respite care................165

E.4 Survey weighting and demographic differences between surveys.........165
E.5 Analysis of survey data 165
E.6 Carer Gateway Pre-Post Survey 166
E.7 Limitations...166
Appendix F Administrative data analysis...167
F.1 Carer distress as proxied by use of antidepressant and benzodiazepine prescriptions 167
F.2 Continuing to care: detailed regression analysis 173
F.3 Changes in Carers Star™ scores by service types................................176
F.4 DEX data on carer support programs..178
Appendix G Cost-effectiveness methodology..181
G.1 Common approaches to estimating economic value of informal care 181
G.2 Approaches used to estimate cost-effectiveness of Carer Gateway 181
G.3 Approach used to estimate cost effectiveness of restructure.................186

Tables

Table 1 Supports which would assist carers in their role 2022 (% those who need more support) 11

Table 2 Satisfaction with aspects of Carer Gateway: Carer Wellbeing Survey 2021, 2022, 2023 .. 23

Table 3 Carer Wellbeing Survey 2021, 2022 and 2023: Satisfaction with services by service type (% high satisfaction, scoring 7–10 out of 10) ... 25

Table 4 High satisfaction with types of services of Carer Gateway (% Used Carer Gateway, combined surveys, 2022) ... 26

Table 5 Carer Gateway clients compared to potential carer population ... 58

Table 6 Carer allowance recipients receiving client DSS carer support services, by year and characteristics (% receiving services and number of Carer Allowance recipients) ... 60

Table 7 Awareness and access of Carer Services in 2020 ... 62

Table 8 Awareness and access of Carer Gateway 2022 (% combined survey respondents by subgroups) ... 64

Table 9 Carer Gateway: Website views and phone contacts ... 66

Table 10 Website analytics ... 66

Table 11 Use of Carer Gateway Online services 2020–2022 ... 67

Table 12 Use of online services 2022–2023 (% of carers in Carer Wellbeing Survey) ... 68

Table 13 Carer use of Carer Gateway services – DEX data 2020–2022 ... 69

Table 14 Types of Carer Gateway services accessed by carers (CWS 2022 and 2023) ... 70

Table 15 Number of individual client attendances for respite for DSS carer support services 2015–2022 ... 75

Table 16 Carer Wellbeing Survey 2022 and 2023: Use of respite services in the last 12 months by source (% of carers who had used services) ... 79

Table 17 Main reason never used respite care (% Carers never used respite care, time series) ... 80

Table 18 Carer Wellbeing Survey: Mean satisfaction score for respite services ... 81

Table 19 Carer psychological distress compared to general population (% all) ... 85

Table 20 Employment and the impact of caring on work (% All) ... 93

Table 21 Data on barriers to entry (Carer Gateway half yearly performance monitoring reports 2020–2022) ... 95

Table 22 Mean pre and post SCORES by demographic characteristics ... 114

Table 23 Increase in mental health, wellbeing and self-care score between first and last assessment: Clients who have received at least some of each service ... 116

Table 24 Change in mean mental health, wellbeing and self-care (circumstances) SCOREs for digital counselling clients 2020–2022 (DEX) 117

Table 25 Services in each period April 2020–December 2022 124

Table 26 Carers Star^{TM} score for All carers and Indigenous carers to December 2021 136

Table 27 Mean pre and post SCORES by Indigenous status characteristics 139

Table 28 DEX and Survey lists of services 156

Table 29 Carer Wellbeing Survey sample information 158

Table 30 Non-Indigenous Interviewee characteristics 161

Table 31 Key project statistics and mode of completion for surveys 164

Table 32 Logistic regression of use of antidepressants in 2022 among carers 170

Table 33 Logistic regression of use of anxiolytic benzodiazepines in 2022 among carers 171

Table 34 Logistic regression of use of hypnotic benzodiazepines in 2022 among carers 172

Table 35 Discrete time hazard model of exit from Carers Allowance 175

Table 36 First and second activity for carers as recorded in the following DEX programs 178

Table 37 Regression model predicting increase in mental health, wellbeing, and self-care score between first and last assessment 180

Table 38 The working sample used for economic evaluation – DEX data 182

Table 39 Low-cost and high-cost session attendance 182

Table 40 Cost of hospital admission by state based on hospital with lowest cost 185

Table 41 Effect of restructuring use of high-cost services 187

Table 42 Access to services pre and post Carer Gateway implementation for different demographics 189

Figures

Figure 1 Whether carers need more support or an improvement in situation to aid in role as a carer 2022 (% all) 11

Figure 2 Satisfaction with Carer Gateway (% used Carer Gateway, combined surveys) 12

Figure 3 Satisfaction with aspects of Carer Gateway (% all, post-survey) 13

Figure 4 Session numbers by year 52

Figure 5 Awareness and access of Carer Gateway 2022 (% all respondents) 62

Figure 6 Interest in Carer Gateway in future 2022 (% not heard of Carer Gateway) 65

Figure 7 Whether need more access to respite care to help care for the person currently providing the most care for (% Carers, time series) 74

Figure 8 Proportion of respite and emergency respite sessions 2020–2022 76

Figure 9 Whether ever used respite care to help care for the person currently providing the most care for (% Carers, time series) 77

Figure 10 Whether used respite care past 3 months to help care for the person currently providing the most care for (% Respite care ever used, time series) 78

Figure 11 Physical and emotional distress 2022 (% All) 86

Figure 12 Impact on Carer Sentiment 2020 and 2022 (ZBI – BURDEN, % All) 88

Figure 13 Desire for more contact with family or friends who do not live with them 2020 and 2022 (% All) 91

Figure 14 Number of high- and low-cost services, 2020–2022 125

Figure 15 ICSS Outcomes framework 153

Glossary

ABS	Australian Bureau of Statistics
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
CGSP	Carer Gateway Service Provider
CPA	Carer Payment/Carer Allowance survey
CWS	Carer Wellbeing Survey
DASS-21	Depression Anxiety Stress Scale 21
DEX	Data Exchange
DOMINO	Data Over Multiple Individual Occurrences
DSS	Department of Social Services
ERC	Emergency Respite Care survey
ICSS	Integrated Carer Support Service
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
K10	The Kessler Psychological Distress Scale (10 item questionnaire)
MADIP	Multi-Agency Data Integration Project (note this is in the process of being renamed to the PLIDA)
NDIS	National Disability Insurance Scheme
PLIDA	Person Level Integrated Data Asset
PWI	Personal Wellbeing Index
RWS	Regional Wellbeing Survey
SCORE	Standard Client/Community Outcome Reporting
SDAC	Survey of Disability, Ageing and Carers
SEIFA	Socio-economic indexes for areas
SPRC	Social Policy Research Centre (UNSW Sydney)
SRC	Social Research Centre
TCVO	Tristate Carer Vocational Outcomes Pilot, known as Your Caring Way
YCBP	Young Carer Bursary Program
YCN	Young Carers Network
ZBI	Zarit Burden Inventory scale

Key messages

This report provides findings from the impact evaluation of the Carer Gateway component of the Integrated Carer Support Service (ICSS). The evaluation was conducted by the Social Policy Research Centre (SPRC) UNSW Sydney, UNSW Canberra, the Social Research Centre (SRC), and the Ipsos Aboriginal and Torres Strait Islander Research Unit.

Carer Gateway provides a range of ‘tailored supports and services to help carers manage their daily challenges, reduce stress and plan for the future’. Its objectives are to: (1) improve carer wellbeing, increase their capacity, and support their participation, socially and economically; (2) reinforce carer resilience through effective preventative support services; and (3) restructure investment in carer support to increase cost effectiveness.

The evaluation draws on a complex range of methods including analysis of program data, population surveys, client surveys; interviews with carers, service providers and stakeholders; and reviews of performance monitoring reports and other existing sources.

Findings indicate that the transition to Carer Gateway has been beneficial for most carers. Carers report satisfaction with services and stakeholders report that the streamlined structure is an improvement on the previous system.

Governance arrangements are key benefits of Carer Gateway, including routine outcome monitoring and close liaison between the Department of Social Services (DSS) and service providers. This has ensured that Carer Gateway services can be continuously adapted and improved.

A particular innovation of Carer Gateway was the introduction of the Carers Star^{TM} assessment. Carers Star^{TM} helps identify service needs, and where carers have completed assessments at more than one time point, provides crucial insights into how carers have benefitted from different services. However, assessments are reportedly still conducted inconsistently, and some stakeholders see Carers Star^{TM} to be inappropriate for some populations.

Carer Gateway has faced several challenges, including the delayed national communications campaign and the COVID-19 pandemic. The pandemic exacerbated care workforce challenges, disrupted service provision, and resulted in a lowering of wellbeing of carers in the population, potentially increasing the need for services. A challenge for Carer Gateway is the interaction with other services for carers and care recipients, particularly with National Disability Insurance Scheme (NDIS) services. Some carers continue to face structural barriers and service gaps, particularly in regional and remote areas.

All service types improved the wellbeing of carers. Respite was associated with the largest increase in wellbeing, although the differences in improvements between different services were small.

Outcomes for different populations of carers were similar. Carers with disability, mental health carers, and carers in remote areas had higher needs than other groups of carers.

There is still a high need for respite services and respite continues to constitute the majority of Carer Gateway services. However, respite and other high-cost services are reducing as a proportion of all services used. There are indications that carers are accessing respite from sources other than Carer Gateway.

Overall, despite the challenges faced by Carer Gateway, it has been a successful policy innovation. Carer Gateway is a cost-beneficial program; the benefits outweigh the costs, and the restructured investment is producing efficiencies in the service system for carers.

The implications of these findings are detailed in Section 24 of the report.

1 Summary

This is the Final Report for the evaluation of the Integrated Carer Support Service (ICSS) – publicly known as Carer Gateway.

Carer Gateway provides supports and services to help carers manage their daily challenges, reduce stress and plan for the future. The Australian Government's objectives for ICSS are to:

- improve carer wellbeing, increase their capacity, and support their participation, socially and economically[1]
- reinforce carer resilience through effective preventative support services, and
- restructure investment in carer support to increase cost effectiveness.

Components of Carer Gateway include:

- Carer Gateway Website and 1800 Phoneline
- National communications and social media content
- Carer Gateway website digital services:
    - Peer support (online)
    - Coaching (self-guided)
    - Online skills courses
    - Counselling (phone)
- Carer Gateway Service Providers (CGSPs[2]) providing the following services:
    - Information and advice
    - Counselling (in-person)
    - Peer support (in-person)
    - Coaching (in-person)
    - Tailored support packages (services and support specific to carer needs, such as education supplies, planned respite, or cooking and cleaning services)
    - Emergency respite.

An assessment of carers' needs is conducted using the Carers Star™ following a client's registration and as part of a service review. The Carers Star™ identifies the carer's needs and is important to successfully completing the support planning.

---

[1] See https://www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model (accessed 10 March 2023).

[2] Service providers includes sub-contractors.

1.1 The evaluation

The impact evaluation assesses program appropriateness, effectiveness, and efficiency. The evaluation draws on a range of methods including:

- surveys of carers in the Australian population (Carer Payment and/or Carer Allowance recipients; carers who accessed Emergency Respite through Carer Gateway; and carers recruited through services such as the Carer Gateway client pre-post-survey) and the Carer Wellbeing Survey (CWS)[3]
- analysis of the DEX (Data Exchange) data which provides information about the services used by carers and the Standard Client/Community Outcome Reporting (SCORE) data from the Carers Star™
- interviews with Aboriginal and Torres Strait Islander carers and non-Indigenous carers
- interviews with CGSPs and other stakeholders
- reviews of half yearly Performance Monitoring Reports
- reviews of the CWS reports
- analysis of program data sources (e.g. web analytics and telephony data)
- analysis of DEX-DOMINO (Data Over Multiple Individual Occurrences) and DEX-PLIDA (Person Level Integrated Data Asset) datasets including data updated to December 2022.

There are a number of limitations to the methodology:

- Some surveys had low participant numbers and response rates.
- Not all services or client groups are represented in the client interview sample.
- Limitations in the DEX-DOMINO and DEX-PLIDA dataset linkage which limit the comprehensiveness of the population analysed.
- Unit cost data relating to Carer Gateway services was not available.

1.2 Appropriateness

Evaluation questions about program appropriateness focus on the redesign of services to carers; streamlining carer services around preventive services such as counselling, mentoring and peer support; the introduction of routine assessment and review for clients; and the extent to which this redesign meets the needs of different groups of carers. The questions explored whether the overall program design met the needs of carers, in particular carers from priority groups; which services are most appropriate for carers; the appropriateness of the Carers Star™ assessment; the appropriateness of Carer Gateway as an early intervention and for high need carers; the

---

[3] A separate report of the population surveys has been produced by SRC for this report: see Brosnan et al. (2023).

governance arrangements and the interaction with other policies for carers and those being cared for; and the implementation of recommendations from previous evaluations.

The **program design** was found to be appropriate for meeting the needs of carers overall, However, **some priority groups** had challenges accessing services that met their needs, including young carers, CALD carers, mental health carers, and Aboriginal and Torres Strait Islander carers. Their experiences reflect a larger pattern; that carer experiences of Carer Gateway are variable and are dependent on factors such as the knowledge and understanding of the people they are dealing with, the appropriateness of the assessment process, and the availability of services that meet the specific needs of the carer at that time. Some Carer Gateway Service providers had developed specific services or approaches to engage with some of these groups – in particular, for young carers and Aboriginal and Torres Strait Islander carers.

All the services were found to be **appropriate for meeting carer needs.** Respite, in-person counselling, and in-person peer support had relatively high satisfaction ratings across the surveys. Respite, counselling, and, in particular, tailored support packages were also considered by stakeholders and carers to be the most appropriate services to meet carers' needs; however, other services were also valued when they met the needs of particular carers. Some services were considered by stakeholders to be less appropriate for particular groups of carers; for example, counselling and some other Carer Gateway services were considered less appropriate for Aboriginal and Torres Strait Islander carers. Access to Respite and Emergency Respite was limited in rural and remote areas due to workforce shortages and thin markets, and some Tailored Support Packages were not sufficient for carers in rural and remote areas because of higher costs.

Overall, there were **mixed views about the appropriateness and use of the Carers Star^{TM}**. The assessment process was generally viewed by both stakeholders and carers as a useful way for carers to discuss their situation and to provide a consistent way to assess progress and outcomes. However, Carers Star^{TM} was reportedly not appropriate for some Aboriginal and Torres Strait Islander carers or young carers and was not suitable to be conducted over the phone for either group. Some service providers adapted the assessment process to meet the needs of these carers or developed tools to support the assessment. There was inconsistency across providers in how the Carers Star^{TM} was used in crisis situations, and more clarity in this area would be helpful. The DEX entry for the Carers Star^{TM} is a summary of the seven domains of the assessment, and more granularity in DEX would reveal important differences in carers' trajectories in different aspects of their caring role.

Carer Gateway is an **early intervention service and also supports carers who have high support needs.** The CWS data indicate that carers who reported they were providing support for people with high needs were less satisfied than other carers with a number of aspects of Carer Gateway. Stakeholders were concerned that Carer Gateway packages were less flexible than previous offerings and that interventions were intended to be short-term, disadvantaging high needs carers and those who would benefit from ongoing support. Emergency respite sessions as a proportion of all Carer Gateway sessions declined between 2020 and 2022. This may be due to a combination of carers accessing preventive services, and the lack of available respite services especially in rural and remote areas. Among stakeholders, there was consensus that the shift to early intervention was a positive development, but also that this shift is a longer-term process.

Increasing awareness of Carer Gateway and the relatively good outcomes for counselling suggest there may be a shift towards early intervention services.

Carer Gateway **interacts with the NDIS and other policies** supporting carers and those being cared for. Some service providers facilitated this interaction through co-location with NDIS and/or My Aged Care services or by providing services for multiple programs. However, it appears the coordination between Carer Gateway and the NDIS was not working well for carers overall. There are gaps and overlaps between these programs and different funding rules, which carers found challenging to navigate. This was also reflected by stakeholders at the policy level, where there was reportedly limited engagement with the NDIA. The interactions with My Aged Care at both a service and policy level were reported to be much better. A challenge for the whole social care sector is the lack of trained workers, and in some cases competition between Carer Gateway and other services for the limited workforce. A whole of government approach is required to address this challenge, especially in regional and remote areas.

Governance and funding arrangements were considered to be effective by most stakeholders. Carer Gateway is in some ways a pioneering Commonwealth program because of its routine focus on outcomes, assessments and data dashboards to develop and manage the program. Stakeholders valued the close relationships and good communication between the Department of Social Services (DSS) and service providers. Nevertheless, there were some suggestions for how to improve governance such as including better resourcing to collect, use and report data, and more flexibility in the use of resources. Generally, providers felt the funding levels were adequate.

DSS has responded to, or is in the process of **responding to, all the recommendations of the previous evaluations**. The effectiveness of some of these responses – for example, the integration of online, telephone and face-to-face components – will need to be assessed in the future. This evaluation has shown that awareness of Carer Gateway has improved, and that completion of the Carers Star^{TM} has also risen and continues to rise. The national communications campaign has successfully increased awareness of Carer Gateway. Some recommendations, such as those relating to respite care, can only partly be addressed by Carer Gateway and progress has also been made in that respite is becoming a smaller proportion of all services, although this may be because of availability of respite services.

1.3 Effectiveness

The effectiveness questions report on access to services, which services are most effective and for which groups of carers, and whether Carer Gateway has achieved its intended outcomes; specifically, to ‘improve carer wellbeing, increase their capacity, and support their participation, socially and economically and reinforce carer. resilience. Only a small minority of carers (6% at June 2023) access Carer Gateway, so any population-level changes in wellbeing, participation and resilience in the carer population cannot be attributed to Carer Gateway.

In **terms of program reach**, the majority of carers in the population surveys in 2022 were either not aware of Carer Gateway, had not looked at the website, or had not accessed services. Among those who had not accessed services, around half would be interested in doing so, a quarter thought they did not need services, and a fifth thought they would not be eligible for services.

Carers with disability, young carers, and CALD carers were **underrepresented** in the cohort using Carer Gateway. There were also indications that regional and remote carers lacked access to a range of services, in particular respite care; however, there were relatively small numbers of carers in these areas. This calculation is based on broader population surveys that use different definitions of carers and different data collection methods which may affect these findings.

The proportion of Carer Allowance recipients who accessed DSS carer support services between 2016 and 2022 remained relatively stable – 4.8% in 2022. Groups of Carer Allowance recipients who had relatively *lower rates of access* are male carers, young carers, Aboriginal and Torres Strait Islander carers, and carers born in non-English speaking countries. Carer Allowance recipients who had the largest *increase* in rates of service use were those aged under 49 years; in contrast, Aboriginal and Torres Strait Islander carers and carers aged 50–64 years had the largest *decrease* in rates of service use.

Overall, the interview findings indicate Carer Gateway had a positive **impact on the service system**. Carer Gateway provides a more streamlined and accessible way for carers to enter the service system and provides carers access to a range of services based on a comprehensive assessment of their needs. Challenges related to the broader service system for carers and their recipients. Carers found the complex range of services difficult to navigate and negotiate, particularly when they also accessed the NDIS. Carers had different experiences of Carer Gateway, and some services appeared difficult to access – particularly in regional and remote areas. This was due mainly to workforce shortages, multiple requirements of this workforce (Carer Gateway, disability, and aged care), and challenges in recruiting and retaining workers, rather than the nature of Carer Gateway itself.

Satisfaction with respite services in the surveys was only available for the Carer Gateway period. The majority of carers who accessed Carer Gateway respite services were satisfied with the services they received, and satisfaction ratings remained fairly stable.

Access to respite, and particularly emergency respite, may have been restricted for some carers due to the lack of services. There was also inconsistency across providers in their perceptions of whether it was necessary to conduct a Carers Star™ assessment for carers seeking emergency respite. There was also evidence that carers were accessing respite from sources other than Carer Gateway.

The findings demonstrate that respite and emergency respite continued to be extremely important services for carers with high needs and at a time of crisis. However, some carers were concerned about the consistency and quality of staff providing respite, particularly for those with complex needs.

Overall, the program has **achieved the intended outcomes identified in the program logic:**

- improve carer wellbeing, increase their capacity, and support their participation socially and economically, and
- reinforce carer resilience through effective preventative support services.

In the general population carers scored lower on **wellbeing** measures than the non-carer population and some aspects of wellbeing (general health, carer burden) worsened between 2020 and 2022 for carers in the general population. Carers receiving Carer Payment or Carer Allowance or accessing Carer Gateway had lower wellbeing than carers generally, which may reflect these groups of carers having higher needs than those not accessing income support or services. Among carers who had used services, the majority of wellbeing outcomes remained the same.

Carers in the Carer Gateway pre-post surveys improved their scores on measures of competence and preparedness and therefore their **capacity for caring**. The CWS 2022 and 2023 analysis found that a number of Carer Gateway services were associated with improvements in carers' overall ability to care, their confidence in ability to be a good carer, and their ability to find out about and organise access to services for care recipients.

In terms of **social participation**, the majority of carers indicated they would like to have more contact with family or friends who do not live with them. A large proportion (85%) of carers who were accessing Carer Gateway reported wanting more contact. Loneliness was higher amongst Carer Payment/Carer Allowance recipients (63%) and carers accessing services (74% pre-survey and 69% post-survey) compared to the general carer population (44%). Among Carer Gateway pre-post survey respondents, most reported no change, 15% reported they were feeling increased loneliness, and 22% reported feeling less lonely.

The **impact of caring on employment** was similar in 2020 and 2022. Small changes may relate to the impact of COVID-19. Ninety per cent of respondents in the Carer Gateway pre-post surveys reported no change in their employment status.

Program data indicate that carers who received preventative services had a longer duration between emergency respite use episodes. Among Carer Allowance recipients, receiving respite care is associated with a lower rate of exit from Carer Allowance, which may be a proxy for being able to continue to care and therefore demonstrates **resilience**.

Overall, carers identified the benefits of support such as respite on reducing stress and improving wellbeing, although these outcomes could be short-term. Access to information and courses helped carers to continue to care and provided them with skills to assist in the caring role. Counselling and peer support contributed to positive outcomes in terms of wellbeing, resilience, and social participation. Carers were also supported financially by taking courses that helped them secure employment, and regular respite that enabled them to remain in part-time employment.

There were **very few unintended consequences –** positive or negative. The inconsistent use of Carers Star^{TM} assessments for emergency respite is potentially a negative unintended consequence, but this can also be considered a 'teething' issue. Most of the positive changes were intended as part of the program. For some carers it was unexpected to receive good information or advice when contacting Carer Gateway.

A range of **factors have been reported to affect outcomes**. In summary these include external factors, in particular COVID-19 and its impact on care services, as well as limited access to services for some groups of carers. The workforce challenges affecting the availability and timeliness of services were considerable barriers for many carers to improve their wellbeing. On the positive side, the more streamlined service, positive relationships, and good communication between DSS and service providers, and the use of the Carers Star^{TM} assessment, contributed to continuous improvement of service provision. Factors that facilitated Aboriginal and Torres Strait

Islander carers achieving outcomes included interactions with staff who treated them with respect, staff who actively listened to them, and being provided with or having access to information that met their needs. Non-Indigenous carers identified well trained staff who could help them to access appropriate support by streamlining their referral to high quality services.

All the demographic groups appear to have benefitted from Carer Gateway and there were few significant differences between them. However, there were lower increases in wellbeing for carers aged under 26 years, for carers over 65 years, for Aboriginal and Torres Strait Islander carers, for carers with disability, for carers living in remote and very remote regions, and for carers who reported their primary income source as government payments (though there were many carers who did not report their income status).

Carers were provided with services to meet their specific needs, and therefore**, the combination of these services influenced outcomes**. DEX data, indicate that carers who accessed respite had the largest increase in wellbeing. Some services were associated with *decreases* in mean score outcomes compared to those who received no services (training, advice, and mentoring/peer support), and other services were associated with no significant change (support and material goods). Digital counselling recorded positive changes for 70.9% of clients.

1.4 Efficiency

The third outcome of the Carer Gateway program logic is to restructure investment in carer support to increase cost effectiveness. The efficiency of Carer Gateway was assessed by examining the interaction with other ICSS programs, the overall cost-benefit of Carer Gateway and the changed funding priorities.

In terms of the **interactions between Carer Gateway, the Young Carer Bursary program YCBP)/Young Carers Network (YCN) program, and the Tristate Carer Vocational Outcomes Pilot (TCVO)** it is important to note that the YCBP/YCN and TCVO programs are much smaller than Carer Gateway. Thus, a low proportion of Carer Gateway clients had accessed these programs and they have had very limited overall impact on Carer Gateway outcomes. On the other hand, a high proportion of clients from both programs have accessed Carer Gateway. Stakeholders generally considered these interactions to be positive and that carers accessing YCBP and TCVO were provided with adequate Carer Gateway services when needed.

Three different effects were identified to calculate **the cost-benefits of Carer Gateway**. The results showed Carer Gateway is a cost-effective program. The three effects considered were:

- *Effect on the decision to provide care*: this analysis focuses on the extent to which carers receiving Carer Gateway support remained in employment or take up employment.
- *Effect on caring activity*: the prevention of, or reduction in, burnout and mental health issues among carers (estimated in the lower use of medication and associated health costs).
- *Indirect effect*: Preventing or delaying hospital admissions or avoiding outpatient services for the care recipient.

All three effects suggest that Carer Gateway provides greater benefits than costs, with a benefit-cost ratio (BCR) of 6.70 (actual expenditure).

The restructured investment **does appear to have increased cost-effectiveness** of carer services in that it helped shift service use away from high-cost services such as respite and specialist counselling, towards low-cost services such as information and peer support.

1.5 Aboriginal and Torres Strait Islander Carers

There are mixed findings in relation to Aboriginal and Torres Strait Islander carers. On the one hand, Aboriginal and Torres Strait Islander carers were accessing Carer Gateway in similar proportions to their representation in the carer population and their wellbeing had improved after accessing Carer Gateway. Most carers interviewed for this evaluation were satisfied overall with the services. On the other hand, Aboriginal and Torres Strait Islander carers had a lower increase in wellbeing than non-Indigenous carers.

Stakeholders and Aboriginal and Torres Strait Islander carers identified concerns about access, assessment and service delivery of Carer Gateway for some Aboriginal and Torres Strait Islander carers. Overall, it appears that practice is variable, with some services developing innovative methods for engaging and supporting Aboriginal and Torres Strait Islander carers, while others appear to fall short of culturally appropriate engagement, assessment and service provision. Aboriginal and Torres Strait Islander carers expressed concerns about the interface between Carer Gateway and the NDIS, indicating a lack of targeted information about how these schemes should work together.

1.6 Conclusions

Carer Gateway has been successfully implemented. Governance arrangements were perceived to be particularly effective. There were some concerns about the appropriateness of the Carers Star™ assessment and the availability and suitability of some Carer Gateway services for some groups of carers; in particular, Aboriginal and Torres Strait Islanders, CALD, and young carers. There are some gaps in service availability, due mainly to a lack of available trained staff for care services, particularly in regional and remote areas. Carer Gateway interactions with other service systems were considered to be good, except for the NDIS where there are challenges at the policy and practice levels.

Overall, all three objectives of Carer Gateway have been met. Carers were satisfied with the services they received and the wellbeing and participation increased for most carers. Carer Gateway is cost-effective, and the benefits outweigh the costs according to a range of different analyses. The shift to preventive services does appear to be making a difference and there are indications that engagement with these services increases the resilience of carers.

The conclusions and implications of these findings are detailed in Section 24 of the report.

2 Introduction

2.1 Policy context

The Integrated Carer Support Service (ICSS), known publicly as ‘Carer Gateway’, provides support for people who are defined as carers in the *Carer Recognition Act 2010 (Cth)*:

> A carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual: (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged (*Carer Recognition Act 2010* (*Cth),* Part 1-Preliminary, section 5).

The Act notes that individuals who provide care and support as part of employment, voluntary work, or as part of education and training, are not considered carers under this definition. In addition, people are not carers simply based on their relationship or co-residence with a person who requires care and support (*Carer Recognition Act 2010* (*Cth*), Part 1-Preliminary, section 5).

The 2018 Australian Bureau of Statistics (ABS) *Survey of Disability, Ageing and Carers* (SDAC) identified:

10.8% of Australians provided unpaid care to people with disability and older Australians

3.5% of all Australians aged 15 years and over were primary carers

around 1 in 11 carers were under the age of 25 (ABS 2019).

Women were more likely to be carers than men – 12.3% of all females are carers compared to 9.3% of all males (ABS 2019). In total, 2.65 million Australians were carers, including 861,600 primary carers and 235,300 young carers aged under 25 years. Carers make significant social and economic contributions; in 2020, the estimated replacement cost of unpaid care for people with disability and older people in Australia was $77.9b per year (Deloitte Access Economics and Carers Australia 2020).

While providing and/or receiving care is a central part of family life, carers provide care and support that is more regular and intensive than typical family caregiving. Becoming a carer can happen suddenly with the onset of illness or disability of a family member. Caring responsibilities can also gradually increase over time as the care recipient’s needs increase. Becoming a carer can happen at any age, and a significant body of research has explored the particular needs and challenges faced by young carers (Smyth and Hamilton 2021; Leu and Becker 2017).

The literature on caring acknowledges the advantages and disadvantages of providing care (Cass et al. 2009). Advantages include providing an opportunity to strengthen family bonds, enabling the care recipient to remain in the family home, and reducing the financial costs of procuring formal care. Conversely, providing care on a regular and/or long-term basis can have a significant impact on carers’ own social and economic participation. Providing care can be stressful and lead to carer burnout (Hill and Broady 2019). It can have a negative impact on individuals’ capacity to engage in paid work, study or training, and can reduce opportunities for social participation (Hill and Broady 2019; Australian Human Rights Commission 2013).

The Australian Government's policies for carers include providing income support for carers who are unable to participate in, or must reduce their hours in, paid employment due to their caring role. In June 2023, 305,330 carers received the Carer Payment, and 634,180 carers received the Carer Allowance (DSS 2023).

The Australian Government also funds programs to support carers in their caring role. The delivery of carer support services has undergone significant redesign in recent years to address the fragmentation of services across many different providers with differing eligibility requirements, and to address service gaps in some regional and rural locations. This extends to addressing variations in the approach taken regarding service allocation through the pre-ICSS service system which included: Consumer Directed Respite Care; Carer Information and Support Services; Commonwealth Respite and Carelink Centres; Counselling, Support Information and Advocacy; Dementia Education and Training for Carers; Mental Health Respite: Carer Support; and the National Carer Counselling Program. A key element of Carer Gateway is the way service areas are defined and are aligned to existing Government service delivery boundaries. Carer Gateway has 16 service areas and 10 service providers. The service areas align with Primary Health Network (PHN) regions (with some service areas containing more than one PHN), and lie within state and territory borders, reducing the challenges in providing services across service regions. This reduction in service areas and providers resulted in increased numbers of carers within each service area leading to economies of scale. Carer Gateway is designed to actively support carers earlier to build their capacity to remain caring and improve their longer term social and financial outcomes.

Much of the advocacy and literature on carers highlights the importance of supporting carers in their care-giving role and helping them recognise their own needs as carers. The three Australian Government funded carer support programs being evaluated are critical elements in supporting carers' social and emotional wellbeing and promoting and supporting their economic participation. The ICSS also aims to reinforce carer resilience through effective preventative support services and to increase the cost effectiveness of carer services.

2.2 Program background

ICSS, publicly known as Carer Gateway, provides a range of 'tailored supports and services to help carers manage their daily challenges, reduce stress, and plan for the future'. The Australian Government's objectives with the ICSS are to:

improve carer wellbeing, increase their capacity, and support their participation, socially and economically

reinforce carer resilience through effective preventative support services, and

restructure investment in carer support to increase cost effectiveness. [4]

---

[4] See https://www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model (accessed 10 March 2023).

As described by the Australian Government's Carer Gateway website:

> Carer Gateway was first introduced in 2015 as a website and phone line to help carers find and access support to help them in their caring role.
>
> With the Australian Government's commitment to continue improving carer services, an extensive four-year consultation process with carers and the sector was undertaken.
>
> This process found that the best way to support carers is to help them early in their caring role. Through a range of tailored supports and services, carers can be supported to manage their daily challenges, reduce stress, plan for the future, and ultimately improve their wellbeing.
>
> This resulted in an updated Carer Gateway service model, which is what it is today. The full Carer Gateway service was introduced in a two-phased approach from July 2019.[5]

As outlined in the *ICSS Service Blueprint*, (DSS 2018a), the components of Carer Gateway include:

Carer Gateway Website – which 'provides information, advice and resources to help carers in their caring role. Carers can request a call back on the website' (DSS 2018a: 23)

The 1800 Carer Gateway Phoneline – calls are routed to, and triaged by, local service providers (CGSPs)

National communications and social media content

Carer Gateway online services:

- Peer support (online) - an online forum 'to assist carers to connect with people in similar circumstances, engage in peer learning and receive emotional support' (DSS 2018a: 20)
- Coaching (self-guided) - online self-guided coaching courses 'to assist carers to acquire skills and resilience needed in their caring role' (DSS 2018a: 20)
- Online skills courses - 'information and courses to help carers in their caring role' (DSS 2018a: 20)

CGSPs providing the following services:

- Counselling (in-person) - 'a service delivered through a series of counselling sessions in-person with a professional counsellor to support carers experiencing difficulties because of anxiety, stress, depression and low mood as a result of their caring role' (DSS 2018a: 20)
- Counselling (phone/digital) - 'a service that can be delivered online and over the phone with a professional counsellor to support carers experiencing difficulties because of anxiety, stress, depression and low mood as a result of their caring role' (DSS 2018a: 20)

---

[5] See https://www.carergateway.gov.au/about#a1 (accessed 10 March 2023).

- Peer support (in-person) - ‘a facilitated forum intended to connect with people in similar circumstances, engage in peer learning and to receive emotional support’ (DSS 2018a: 20)
- Coaching (in-person) a service to assist carers to acquire skills and resilience needed in their role... facilitated through face-to-face interaction with a coach (arranged by the [CGSP] [formerly known as the Regional Development Partner] (RDP))’ (DSS 2018a: 20)
- Tailored support packages (services and support specific to carer needs, such as education supplies, planned respite, or cooking and cleaning services) (DSS 2018a: 20)
- Emergency respite - ‘a service intended to support carers experiencing an urgent, imminent and unplanned event that restricts their ability to provide care’ (DSS, 2018a:21).

An assessment of carers’ needs is undertaken using the Carers Star^{TM} assessment tool when the client registers and as part of a service review. The Carers Star^{TM} assessment seeks to understand a carer’s aims, responsibilities, care load, living circumstances, support network (including both current paid services and informal support from others), and general relationship with the person they care for. The process identifies the carer’s needs and is important to successfully completing the support planning.

The Carers Star^{TM} assessment tool identifies needs across seven domains (health, the caring role, managing at home, time for yourself, how you feel, finances, work) and is translated into a single mental health, wellbeing, and self-care circumstances SCORE in DEX (Australian Government 2021b).

The five stages related to the level of need in the Carers Star^{TM} are:

Cause for concern (1)
Getting help (2)
Making change (3)
Finding what works (4)
As good as it can be (5).

In each service region there is a lead service provider who works with a consortium of other providers and sub-contractors to supply Carer Gateway services. Service providers also refer to other agencies where this will meet the needs of the carer.

2.3 Objective of the impact evaluation

The objective of this impact evaluation is to assess the appropriateness, effectiveness and efficiency of ICSS. Evaluation findings will inform decisions about the program model and policy development. The overall evaluation includes two other programs covered by ICSS: the Tristate Carer Vocational Outcomes Pilot (TCVO) (known as Your Caring Way), and the Young Carer Bursary Program (YCBP). This report refers only to Carer Gateway.

2.4 Status of the report

This is the final report of the Carer Gateway component of the ICSS evaluation. It updates findings from the Interim Evaluation Report and provides additional analysis of the DEX-DOMINO dataset, DEX-MADIP (Multi-Agency Data Integration Project) dataset, and the Carer Gateway pre-post surveys, as well as additional qualitative interviews with carers. The report triangulates findings from the range of different methods employed for the evaluation and provides conclusions about the Appropriateness (Part A), Effectiveness (Part B) and Efficiency (Part C) of the Carer Gateway component of ICSS for the Australian population, with additional analysis for Aboriginal and Torres Strait Islanders (Part D).

3 Approach

The report is structured around the evaluation questions relating to:

- program appropriateness (Part A)
- program effectiveness (Part B), and
- program efficiency (Part C).

Discussion and implications of the findings are presented in Sections 23 and 23, and the conclusion and implications are presented in Section 24. The evaluation questions are presented in full in Appendix A. This section summarises the key data sources, limitations, and ethical considerations of the evaluation.

3.1 Summary of data sources

The evaluation draws on a range of methodologies and data sources – described in full in Appendices B, C, D and E. Key sources of data informing this evaluation are:

- Data Exchange (DEX) data collected from carers by service providers for the period April 2020 to December 2022
- An integrated DEX-DOMINO data set for the period 2015 to 2022
- The MADIP data (now known as Person Level Integrated Data Asset (PLIDA))
- Financial information provided by DSS
- Surveys of carers conducted by the Social Research Centre (SRC) as part of the evaluation which include:
  - Population surveys:
    - the *Life in Australia*^{TM} survey – a random sample of Australians conducted between January–February 2020 and in November 2022
    - the Carer Payment/Carer Allowance survey (CPA) – a random sample of carers receiving Carer Payment and/or Carer Allowance surveyed in June 2020 and in November–December 2022
    - For some analyses, due to small sample sizes, the data from these two surveys has been combined and is referred to as the ‘combined surveys’
  - the Emergency Respite Care survey (ERC) – a survey of clients using emergency respite from July 2021–September 2022
  - Carer Gateway pre-post surveys – a survey of clients who first registered with CGSPs between October 2022–16 February 2023, who were not receiving emergency respite care (pre-survey). The post-survey was sent to clients from the pre-survey who consented to be recontacted (between March–June 2023).
- Interview data
  - 29 interviews with Aboriginal and Torres Strait Islander carers
  - 40 interviews with non-Indigenous carers

  - 40 interviews with 57 stakeholders (service providers, peak bodies, and policy makers).

- Analysis of Carer Gateway half-yearly performance monitoring reports
- Findings from the Carer Wellbeing Survey (CWS) conducted by the University of Canberra
- Examination of Baseline and Process evaluations of the ICSS
- Analysis of Google website analytics data.

3.2 Limitations

There are several limitations to this evaluation.

- DEX data lacks information about some priority groups of carers, such as carers of older people and mental health carers. Where possible, these carers have been considered in the surveys and interviews.
- There was a low response to the ERC survey (n=79).
- There is limited financial information. This makes it difficult to establish efficiency, and so limits the cost-effectiveness component of the evaluation.
- The population survey data provides information about changes at the population level; however, only a small proportion of carers access Carer Gateway. Any changes (or lack of changes) at the population level cannot be attributed to Carer Gateway.
- Due to the small sample size of carers accessing Carer Gateway in the population surveys, only very limited analysis of demographic groups is possible.
- While the interview sample covered a wide range of perspectives from different groups of carers, there were small numbers of carers from some priority groups, in particular carers in remote areas, and carers with disability.
- Online services, other than Digital Counselling, are not reported in DEX.
- Only 37% of carers have more than one Carers Star^{TM} assessment in DEX. While these are broadly representative of the whole client group, outcomes are only available for a minority of Carer Gateway clients.
- DEX analysis focuses on the first and final DEX score in the dataset. It is possible that for some clients this represents several baseline assessments rather than a pre-post assessment of their engagement with Carer Gateway.
- The CWS samples are recruited through service providers and may not be representative of carers in the general population (see Appendix C for more detail). While the CWS contains information on the demographic priority groups, it does not provide analysis for the category of carers of older people.
- The DEX-DOMINO dataset only contains outcome information about carers who are receiving Carer Payment or Carer Allowance.

- The MADIP dataset linkage rate for the carer support data in DEX is 74% which limits the comprehensiveness of the population analysed.
- None of the integrated datasets have longitudinal information on carer status in the whole population.
- Unit cost data relating to Carer Gateway services was not available.

3.3 Ethics

Ethics approval was obtained from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Human Research Ethics Committee (EO336-20220621). Consistent with the NHMRC's *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders,* and *Keeping Research on Track II*[6], an Aboriginal Advisory Group was established to oversee the evaluation design, conduct and reporting.

---

[6] https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples (10 March 2023).

Part A: Appropriateness

Part A provides findings relating to the appropriateness of the program. This is informed by:

- survey data (the population, Carer Gateway pre-post surveys and emergency respite surveys, and the CWS)
- interview data (carer and stakeholder interviews)
- DEX data, and
- an examination of previous evaluations.

Evaluation questions about program appropriateness focus on the redesign of services to carers; streamlining carer services around preventive services such as counselling, mentoring and peer support; the introduction of routine assessment and review for clients; and the extent to which this redesign meets the needs of different groups of carers.

4 Question 1: Appropriateness of design

Evaluation Question 1: How appropriate is the program design for meeting the needs of Australian carers, including (where applicable):

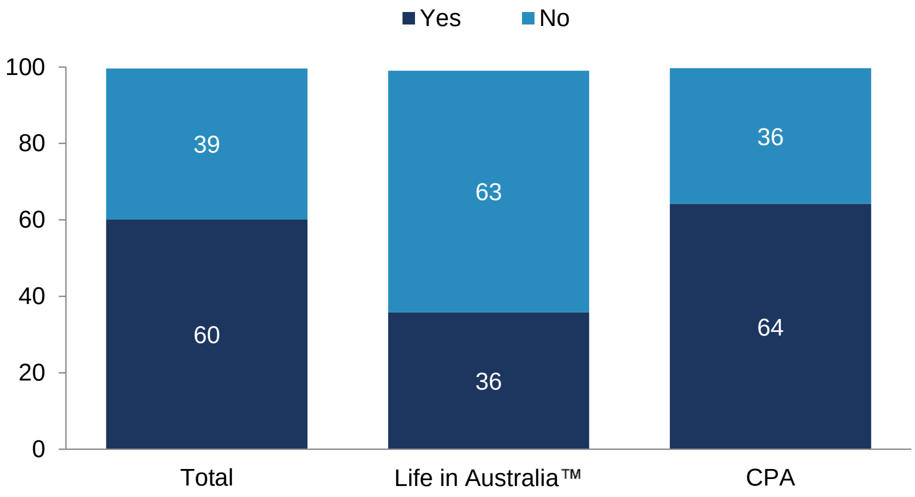
(i) Aboriginal and Torres Strait Islander carers
(ii) female carers
(iii) carers with disability
(iv) regional or remote carers
(v) young carers (aged less than 25 years)
(vi) older carers
(vii) carers of older persons
(viii) culturally and linguistically diverse carers
(ix) mental health carers

4.1 Carers' needs for support

The Baseline Evaluation indicated that in 2020, 35% of the Life in Australia$^{\text{TM}}$ population and 54% of the CPA survey respondents needed more support in their caring role, with the key types of support needed being financial, emotional, physical assistance, and respite care (Edwards et al. 2020:23). The authors note also that there were lower levels of expressed need among carers for courses on how to provide care or training in specific aspects of caring (Edwards et al. 2020:23).

In 2022, 36% of the Life in Australia$^{\text{TM}}$ respondents and 64% of the CPA survey respondents indicated they needed more support (Figure 1). The highest needs identified were for financial assistance, health improvement, emotional support, respite care, and physical assistance (Table 1). As in 2020, a low proportion of carers (4–23%) expressed a need for more courses in how to provide care and training, while 20% of carers sought more aids and equipment to assist in caring (Table 1). Among carers needing more than one support, financial assistance was regarded as the support that would most assist their caring role (42% of these carers in the combined surveys) (Brosnan et al. 2023: 248, Figure 113).

Figure 1 Whether carers need more support or an improvement in situation to aid in role as a carer 2022 (% all)



Base: All respondents. Total n=3868, LinA n=553, CPA n=3315. Question not asked of ERC respondents.
Source: I9. Do you feel you need more support or an improvement in your situation to aid in your role

%

Source: Brosnan et al. 2023, Figure 111

Table 1 Supports which would assist carers in their role 2022 (% those who need more support)

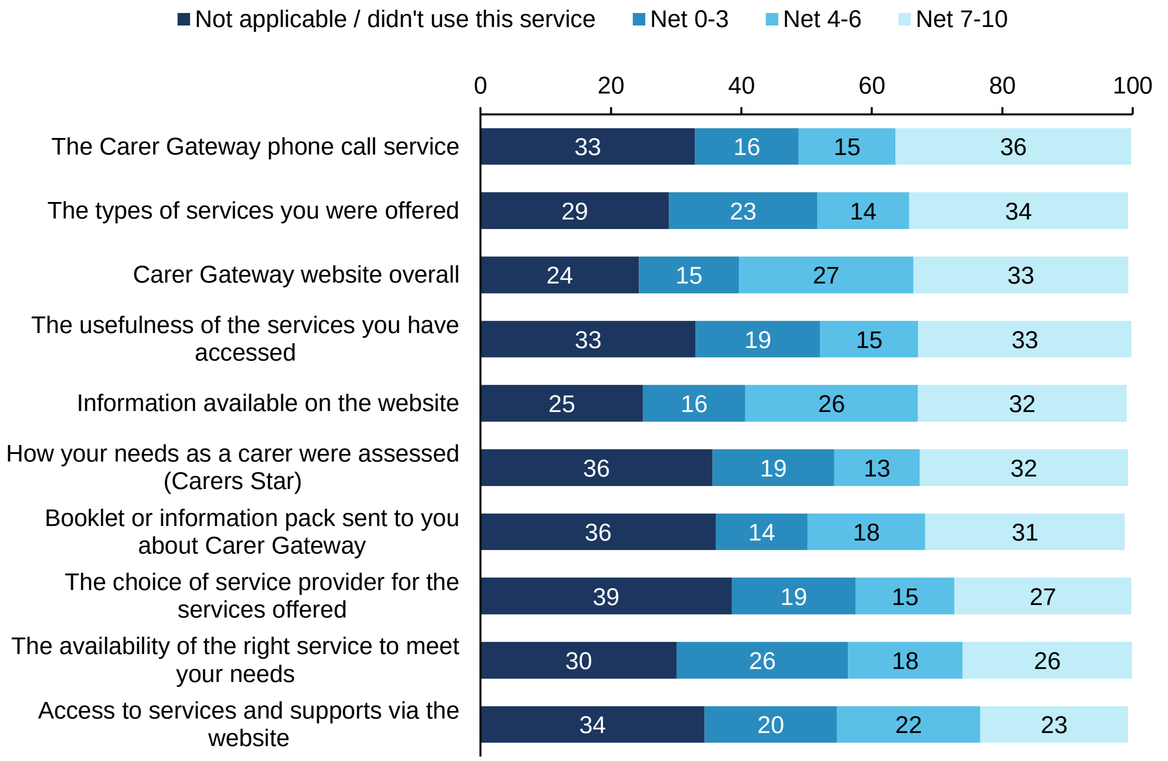
	Total	Life in Australia™	CPA
More financial assistance	67	67	67
An improvement in my own health	56	42	58
More emotional support	51	47	51
More respite care	41	37	42
More physical assistance	37	41	36
More courses available on how to care for persons with particular disabilities (e.g. mental illness)	22	18	23
More aids/equipment to help me assist in my role as a carer	20	23	19
More training in correct methods of lifting to prevent injury to myself	8	10	8
More training on correct use of equipment	4	7	4
None of the above	<10	<10	<10

Source: Brosnan et al. 2023, Data Table 63

4.2 Services to meet carers’ needs

Thirty-seven per cent (26% out of 70% for whom the question was applicable) of carers in the combined population surveys (Life in Australia$^{\mathrm{TM}}$ and CPA surveys) who had used Carer Gateway reported high levels of satisfaction (score of 7–10 out of 10) with the ‘availability of the right services to meet their needs’ (see Figure 2). Among carers who responded to the Carer Gateway post-survey, 54% reported high satisfaction with the ‘availability of the right services to meet their needs’ (Figure 3) (Brosnan et al. 2023: Figure 77). Forty-nine per cent of carers in the combined population surveys (for whom the question was applicable) reported high satisfaction with ‘the types of services you were offered’ (34% out of 71%) and ‘the usefulness of the services’ (33% out of 67%) Figure 2). A slightly higher proportion of respondents in the Carer Gateway post-survey reported high satisfaction in response to these questions: 55% for ‘the types of services you were offered’ and 59% for ‘the usefulness of the services’ Figure 3).

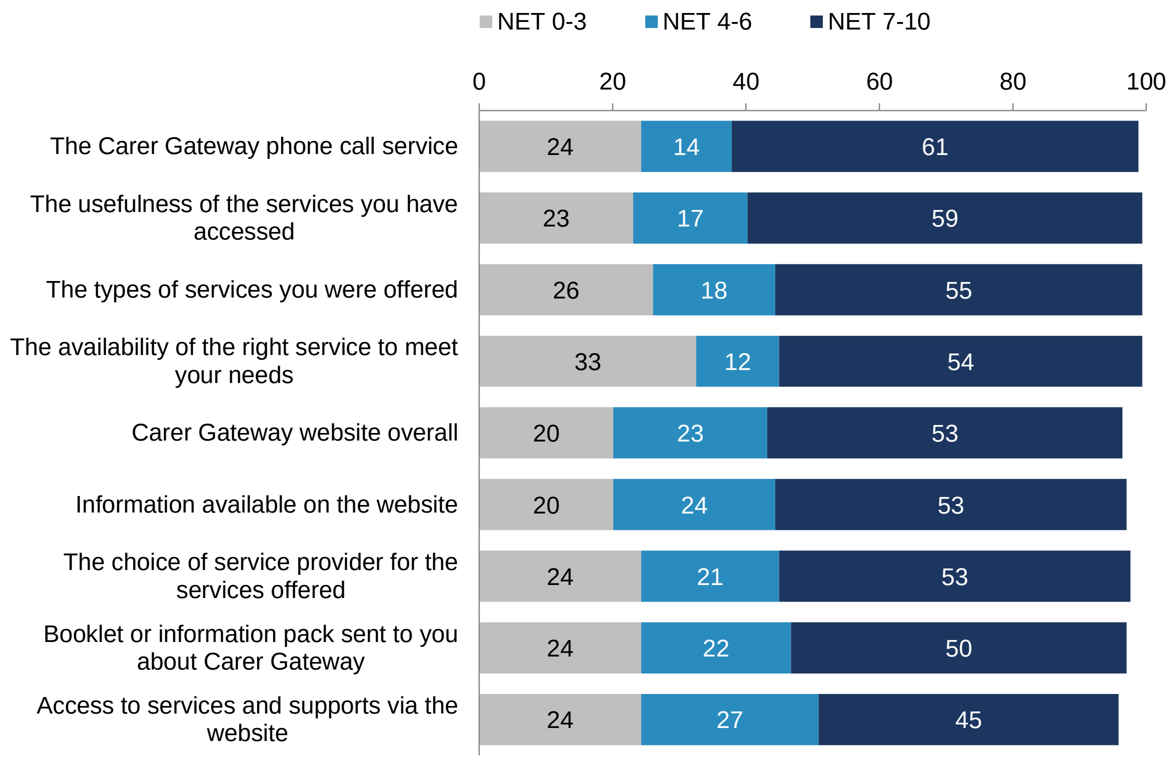
Figure 2 Satisfaction with Carer Gateway (% used Carer Gateway, combined surveys)



Base: Respondents who have used Carer Gateway. Total n=1037. Results for the Young Carers Network not shown on chart due to small base size (n=4).
Source: S17. How satisfied were you with the part of Carer Gateway you have experience with?
Note: Don't know and Refused responses not shown on chart.

Source: Brosnan et al. 2023, Figure 31

Figure 3 Satisfaction with aspects of Carer Gateway (% all, post-survey)



Base: All respondents. Post-survey (Total) n=169. Question not asked in Pre-survey.
Source: S17. How satisfied were you with the part of Carer Gateway you have experience with?
Note: 'Not applicable' and 'Don't know' responses not shown on chart. Results for 'The Young Carers Network' not shown on chart due to small base size (n=2).

%

Source: Brosnan et al. 2023, Figure 77

The CWS also asks respondents how satisfied they are with ‘the types of services available through Carer Gateway’. Overall, the proportion of carers reporting high satisfaction with the ‘types of services available’ decreased from 64.7% to 53.7% between 2021 and 2022 (Schirmer and Mylek 2022: 22), and to 40.4% in 2023 (Mylek and Schirmer 2023a: 31). The majority of carers reported high satisfaction with the ‘usefulness of services’ but this too had changed from 68.0% in 2021 and 71.3% in 2022, declining to 65.2% in 2023 (Mylek and Schirmer 2023a: 31).

Demographic groups

In 2022, the CWS identified groups who were less likely to be satisfied with the types of services available as: female carers, carers aged 25–44 years, carers living in regional and remote areas, carers for people with mental illness or psychosocial disability, those caring for longer periods, or those providing care in situations of high assistance needs (Schirmer and Mylek 2022:24–26). In 2023, low satisfaction with the types of services available was more likely to be reported by carers who were aged 35-44 years, caring for two or more people, or caring for a child or grandchild (Mylek and Schirmer 2023a: 32)

In both 2022 and 2023, carers aged 65 years and over were more likely to be satisfied with the types of services available (Schirmer and Mylek 2022:26; Mylek and Schirmer 2023a:31). In 2022, higher satisfaction was also reported by those caring for shorter periods (Schirmer and Mylek 2022:26); in 2023, carers of people with dementia and those caring for 2–5 years also reported higher satisfaction (Mylek and Schirmer 2023a:31).

4.3 Stakeholder perspectives

There were mixed views about the extent to which the program design was appropriate for meeting the needs of Australian carers. Stakeholders tended to take one of two perspectives: either (1) the program design is good, but it is too early to see the positive outcomes from Carer Gateway; or (2) the program design is not appropriate for some groups of carers, especially in relation to the registration and assessment process, or its capacity to meet immediate needs and provide respite. Some of the findings related to respite are discussed further in relation to the effectiveness of the program (Part B: Effectiveness).

Several stakeholders had different perspectives about the appropriateness of the program design and about whether the new focus on prevention was more appropriate than the former model that was more focused on respite. One explained:

> The old model was a lot more transactional versus this one being a lot more holistic, trying to look at the carer as a whole and their environment as a whole, and trying to look at all the contributing factors. Whereas, like I said, previously it was very transactional, a person just ringing up and saying, I'd like some respite, or I need this, and meeting that individual’s need as opposed to the carer’s more holistic needs. (Service provider 10)

The shift to the new model was identified as a challenge for carers as well as service providers. Both needed to adapt to the new program design, particularly as, through the assessment process, not all carers were provided with respite packages. One stakeholder described this tension between supporting carers through capacity building versus providing financial assistance and respite:

> So I understand the model to be an early intervention, a capacity building approach where we’re building carers’ resilience, their awareness, their tool kit, if you like, their strategies to sustain them in the caring role, and sometimes practical supports are suitable. But I guess the funding doesn’t allow for practical supports for everybody or that financial support for everybody. But the message is quite clear out there that carers come to us with a sense of entitlement that they need to get their financial support because they’re entitled to it. (Service provider 14)

However, several stakeholders believed that providers and staff are adjusting to the new model and that it will take more time to fully realise and see the benefits of this approach (Service provider 6, Service provider 15, Other stakeholder 8). A small number of stakeholders also explained while the old model worked for a limited number of carers, the new Carer Gateway model has the capacity to reach more carers and support them into the future (Service provider 6).

> What the Gateway does is it brings equity. It absolutely allows us to reach more carers and provide more support. (Service provider 6)

While there was consensus among most providers that the shift to the new model was positive, some stakeholders acknowledged that some carers “just want to ring up and get the money” (Service provider 1), making it difficult to support them through other services and supports.

The appropriateness of Carer Gateway was talked about mostly in relation to different cohorts of carers and specifically the cohorts it was not as appropriate for (Aboriginal and Torres Strait Islander carers, young carers, mental health carers).

Some stakeholders considered the design of Carer Gateway was not appropriate for **young carers** because elements (including registration and assessment) were adult focused. In addition to elements of the Carers Star^{TM} assessment (discussed further below), service providers and subcontractors commented that services needed to be ongoing and provide long-term support for young carers. One service provider gave an example of a former peer support program that provided regular, ongoing support for young carers (Service provider 16).

> I do think adults benefit from longstanding programs, but I think specifically for young carers they need that long-term support as they grow up and as they transition through their various stages of life. Also, so that they can build those friendships and social connections. That’s one of the things Carer Gateway is just not offering and it’s not designed to offer at the moment, is those long running programs that are a little bit more open ended so they can be designed specifically for the young people taking into account what they want to learn and what they want access to as well. (Service provider 16)

Others commented on the barriers for young carers in accessing Carer Gateway and its services due to the lack of awareness and poor targeting of the program to young carers. Lack of awareness of Carer Gateway was also reported by young carers in the CWS in 2022. While lack of awareness among young carers was not found in the CWS 2023, the CWS study identified that young carers were more likely to hear about Carer Gateway from family or friends, a medical professional or Facebook, rather than carer organisations (Mylek and Schirmer 2023a: 20). Stakeholders identified barriers for young carers to access Carer Gateway due to difficulty going into schools to talk with potential young carers, as well as the requirements for the young carer to complete the ‘Carers Star^{TM}’, as opposed to a parent or family member of the young carer.

Young carers were identified as a group having a mixed experience with the new service system. Stakeholders explained that some regions have well-defined programs and consortia partners that are delivering programs specifically to young carers, while in other regions providers must refer young carers to other local services, which were not always available. Several stakeholders talked about the need to better engage with schools to reach young carers, which has been more difficult through COVID-19. The quote below provides an example where the provider has established a dedicated young carer program and a network of services.

> They have a really strong young carer program and so they have young carer outreach workers who are actively engaged with schools and so they're going out and they're meeting carers in schools. Nine out of 10 times being able to meet the parent as well and look at what that connection to service is. It's not a simple pathway in. You talk about the pathway but it's not simple. (Service provider 6)

Mental health carers were identified as having difficulty accessing some services because they were either not accessible or not suited to their needs. According to a number of stakeholders, mental health carers tended to contact Carer Gateway when they were at breaking point as they were more likely to be caring for someone with complex and unpredictable health issues and needs (Service provider 6). In some instances, the Carers Star^{TM} created a barrier to accessing respite. Related to this, one stakeholder believed that more if not all staff working for CGSPs should have training in mental health so they can better understand the complexity of circumstances and identify potential supports. One stakeholder identified that advocacy support is ‘a missing piece’ for mental health carers who may be trying to navigate the service systems for their care recipient.

Stakeholders also indicated that some elements of Carer Gateway were not appropriate for **Aboriginal and Torres Strait Islander carers**. Stakeholders identified cultural barriers to accessing Carer Gateway, both in terms of language and geographic remoteness. Service providers explained how program design and service offerings were not appropriate for Aboriginal and Torres Strait Islander carers, including accessing Carer Gateway through a 1800 number rather than through a trusted relationship or connection to a service or individual. One service provider overcame such barriers by connecting with services that were already going to community and connected to potential carers and clients via those services (Service provider 18). Similarly, another service provider indicated that Aboriginal and Torres Strait Islander carers wanted to talk with people that understood the context of their day-to-day living:

> There's a whole lot of things that aren't given when you're dealing with remote Aboriginal communities. Traditional healers are something that people do ask for; they want to talk to a traditional healer. [They want] someone who understands the context that they’re living in and the day-to-day challenges that they’re facing. (Service provider 2)
>
> You can’t just walk into an Aboriginal community or Aboriginal family and go, ‘hi, I’m here to do this. Give me your name and details, and let’s crack on with that’. It’s just not going to happen. That’s even more compounded when you step into the Aboriginal communities, rural and remote. You’ve got to have some credibility in that community first, and if you don’t, then – people just want a handout for money, and we know that that’s not what it’s about, and to have those conversations around the services and appropriateness of services. (Service provider 15)

Other service providers talked about how respite looked different for Aboriginal and Torres Strait Islander carers, who may prefer to stay in community and have access to practical supports (rather than leave community to access respite from caring) (Service provider 2).

Some stakeholders talked positively about how they adapted certain elements to better meet carers’ needs; for example, using some discretion to let tailored support packages be used to purchase tools or appliances where services simply do not exist in communities (i.e. a washing machine or lawn mower when there are no cleaners or gardeners to do the work). They also adapted their approach to implementing the Carers Star^{TM}, which is discussed further in Section 7. One service provider explained how they adapted one of the questions in Carers Star^{TM}:

> So, I do ask about that. I also ask with time for yourself, I will say, ‘do you get time to do some cultural stuff, do you need to get out to the country, do you get enough time to do that, to refill your spirit?’ (Service provider 18)

A couple of service providers had created dedicated positions or teams of Aboriginal and Torres Strait Islander staff members, whose role it was to find and implement effective ways of working with Aboriginal and Torres Strait Islander carers (Service provider 5, Service provider 11, Service provider 15). One service provider explained:

> When I was in that position [Aboriginal Engagement Officer], I did a lot of face-to-face to be able to build up trust to go into their homes and to know that cultural safety as well that they can talk to me and that I can help them and navigate the system for them. (Service provider 11)

Aboriginal engagement teams were talked about positively by the service providers as a way to address some of the program design challenges and to better connect to and attract Aboriginal and Torres Strait Islander carers.

Stakeholders reported that services for Aboriginal and Torres Strait Islander carers were more likely to be effective when providers had the autonomy and resources to adapt and be flexible with the funding packages. For example:

> Carer picnics have been really good. People really, really enjoy that opportunity to leave their community for the day, go out bush. For Aboriginal people, being on country is very healing and [they can] talk to other carers about some of the challenges in the caring role. Having that funding and because we've been able to negotiate peer support to become carer picnics, that's being really, really important. (Service provider 2)

> But respite for Aboriginal and Torres Strait Islander, remote communities and others might be out on country in a way that we would as government go, that's a strange thing to fund. You need what, a troop carrier and a ton of fuel to drive you fishing, doesn't sound like respite to me, you know what I mean? (Other stakeholder 12)

> The other thing too, is about communities and building capacity – is on Aboriginal communities here we can – if we've got the services – offer cleaning, gardening services to go help a carer – out in the community, they've got none of that available. But some of my carers are asking for a whipper snipper or a lawn mower or something to be able to do the garden themselves, and I think that's building capacity, but Carer Gateway don't. They keep coming back at me, well how is this building capacity, they should be able to buy this themselves, we're not just here to buy gardening stuff for the carers, how's this helping them in their caring role, and I can't – it's like, well it's not really helping them in the caring role, but it's not as if they can access that service from the community. They still need to do their yard they just don't have the things to do it. (Service provider 18)

4.4 Non-Indigenous carer perspectives

Due to carers' diverse circumstances and needs it is difficult to assess, from the interviews with non-Indigenous carers, how appropriate the program design is for meeting the needs of Australian carers. However, it was apparent that the program has met the needs of some carers overall and in different cohorts. One carer commented:

> They've definitely provided support. I wouldn't necessarily say we've had a time of crisis where I've had to reach out to them, but I'm sure we have supports in place now that if something happened, I think that I could organise that with them fairly quickly. (Carer 4 regional)

For many carers contacting Carer Gateway helped them to understand the impact of their caring role, the time it takes, and the effort involved. Carers often do not see themselves as carers or downplay their role as a carer. Contacting Carer Gateway and accessing support enabled carers to prioritise their own wellbeing and learn ‘the oxygen mask principle’ – including how to communicate this to the people they cared for.

Carers from a CALD background interviewed were identified by whether they spoke a language other than English at home. Many of these carers were proficient in English and did have difficulties accessing support compared to carers who spoke only English. However, this was not the case for all CALD carers. For example, one carer from a CALD background commented about the registration process:

> There was a form that I filled in and to be honest I was trying to rely on google translation because of my language skills so it was a bit easy sometimes and a bit hard sometimes depending on how it made sense when I used it. (Carer 22 metro)

The carer did not go beyond the registration phase because she felt that she did not have adequate information about the types of support available. The carer added:

> Having the information in more than one language is essential and the information should set out what to do where to go, all the services we can access instead of us being in limbo not knowing what to do or who to talk to. (Carer 22 metro)

Another carer commented that different carers with different needs may struggle to access support:

> If you have someone who struggles with motivation, like someone who’s already depressed and struggles with motivation, to really not have that extra bit of energy, to use the gateway, that is probably the biggest limitation. Also, people who struggle with English as a second language or people who have intellectual limitations, whether they are acquired or whether they are a part of old age, where it just makes it harder to absorb information in written form or over a website. (Carer 2 metro)

Mental health carers had mixed experiences accessing support through Carer Gateway. A carer supporting her husband with a mental health issue and her elderly father was informed that she could not access support for her husband. She commented:

> No, well originally I was told that they don’t deal with people with mental health challenges. So I wasn’t allowed to get anything for [name of husband]…They sent – they gave us some materials like to reset the shower, the bathroom up to help Dad. They organised some coaching for me. They got some sort of initial – I think it was four weeks of nursing care for Dad and setting up those things while we were trying to get the paperwork all done. (Carer 6 metro)

In contrast the experiences of other mental health carers were positive. One carer commented:

> No, I actually think that was a really, really smooth process for me. I think I rang ‘out of hours even’, but I was hooked up straight away with a counsellor and I was actually amazed, because I know – I kind of work in the sector. So trying to get people hooked up effectively with counsellors or psych appointments, it can be really, really difficult. So yeah, I was really grateful to get connected so, so quickly and so effectively. (Carer 8 regional)

A consistent theme to emerge for carers of older people was the difficulty they experienced navigating My Aged Care. Carers experienced barriers especially when the needs of the people or person they cared for changed. For example, one person who provided care for his mother and father needed to get his father’s package of care upgraded when his mother entered residential care. The carer commented:

> At the moment I'm trying to get my father a care package to go up to the next level. Mum was level 4, dad's on level 2, but he hasn't been reassessed again. He needs to get reassessed to get more package, more money. So we're only getting the basic stuff, which is unfortunate. Because mum's disappeared now... So can't even use his – because we don't have enough funds. But we had to pool all these resources because we're going into negative because, as you might know, they lifted all the third-party payments, which they deserve, don't get me wrong, but his package – and I think from what I can understand, the packages don't cover it now, so a lot of people are in the same boat as I'm in where we're waiting for my dad to get reassessed to – it heaps – there's more pressure on me, because we can't use the services, which is unfortunate. (Carer 19 metro)

Although not directly referring to Carer Gateway, this indicates the challenges many carers face negotiating different systems and processes.

Carers of older people also discussed how the people they cared for could be reluctant to accept help, putting additional pressure on them as highlighted by the carer in the quote below:

> Yeah. It’s also the options, like they have respite care but there’s no way I can get him, who sees nothing wrong with himself, to go into a respite cottage… Also, the problem I have, he just refuses to have anybody stay in the house. I was really hoping that I could have someone stay at the house, so I could actually get away, but he absolutely refuses to have someone stay overnight at the house. (Carer 02)

Generally, carers in the sample tended to focus on the difficulties in accessing support for the person they cared for rather than their own needs. Some carers were reassured that support through Carer Gateway would be available if needed. However, when needs are complex carers often experienced difficulties accessing support. For example, one carer who supported her frail aged mother experienced ongoing difficulties organising home modifications and personal care for herself. The carer used a wheelchair but could organise shopping and meal preparation for herself and her mother. However, the bathroom in the house in which she lived with her mother was not designed for wheelchair access. The carer recounted:

> So when the girls come here, we get allocated two hours. The girls would have to wash some of my clothing, and our washing machine doesn’t work, so they have to do it by hand. They had to wash the dishes, they had to vacuum the floor, maybe wipe the floor or mop it. They’d have to check the letter box for our mail. They’d have to take the rubbish bins out, including emptying the rubbish while they’re here. This is the bad part about the situation, is that my wheelchair doesn’t go in the bathroom. I can’t turn around and come out. So I’ve got a toilet commode sitting in the lounge room that those girls empty out every second day. They have to clean me also; they have to wash my hair as well. I can’t get to the shower, turn around and come out because I can’t – there’s no modifications done to the bathroom. There’s no handrails. I can’t even have a shower because there’s a hob and I can’t lift my legs up to go over the hob. There have been times when I’ve been left without having a sponge wash. (Carer 18 metro)

Regional and remote carers noted that it was difficult for them to access support workers at home due to lack of staff and the distance workers had to travel to provide support.

4.5 Aboriginal and Torres Strait Islander carer perspectives

Aboriginal and Torres Strait Islander carers had mixed views about the registration and Carers Star^{TM} assessment process.

> Well' there wasn't anything that felt tailored, Aboriginal cultural-wise, but whether that's just because I was never asked in the beginning, I don't know. Maybe if I was asked early then it would have been offered differently perhaps. I don't know. (Carer 35, metro)

The experiences of Aboriginal and Torres Strait Islander carers appeared to differ across locations/providers. This suggests there may be some inconsistency in how providers are implementing the carer support framework and carer gateway service provider operating manual for working with Aboriginal and Torres Strait Islander carers; specifically, around identifying carers' Indigenous status and offering carers the opportunity to speak with an Aboriginal or Torres Strait Islander staff member.

Importantly, interviews with Aboriginal and Torres Strait Islander carers indicated many were uncertain about what Carer Gateway consisted of. Carers were more likely to refer to an individual or a service provider they were connected to, which, in some instances appeared to be an NDIS or other service provider and not necessarily part of Carer Gateway. This finding points to the potential to improve the awareness of Carer Gateway among Aboriginal and Torres Strait Islander communities, and other social and health services they use.

4.6 Summary

In 2022, 36% of carers indicated they have a need for more support and that financial support, own health improvement, emotional support, and respite would be the most helpful forms of assistance in their role as a carer. Surveys of Carer Gateway users found that 40–55% of carers were highly satisfied with the types of services available to meet their needs and the usefulness of the services provided. Older carers (aged 65 years and over) are more likely to report high satisfaction with the services available. These findings indicate that, overall, Carer Gateway provides appropriate services for some carers. However, there is evidence that some of the priority groups have challenges accessing services that meet their needs. These include young carers who reportedly do not always feel comfortable with the registration and assessment processes. Some CALD carers interviewed faced barriers to accessing Carer Gateway when information was not available in different languages. Mental health carers interviewed had mixed experiences, as did Aboriginal and Torres Strait Islander carers. Their experiences reflect a larger pattern in the data, that experiences of Carer Gateway are variable and are dependent on factors such as the knowledge and understanding of the people they are dealing with, and the availability of services tailored to the specific needs of the carer at that time. Some CGSPs have developed specific services or approaches to engage with some of these groups – in particular, young carers and Aboriginal and Torres Strait Islander carers.

5 Question 1a: Most appropriate supports for carers

Evaluation Question 1a: Which ICSS services are most appropriate for meeting carer needs?

5.1 Overall satisfaction with Carer Gateway

While the majority of carers indicate they are satisfied with Carer Gateway, carer satisfaction (as reported in the CWS and the DEX data) has declined over time.[7]

The CWS (2022) reported that overall, 78.1% of respondents are somewhat or very satisfied with Carer Gateway (score of 5.5 to 10 out of 10) and 13.9% were unsatisfied. In 2023, the overall satisfaction rate reduced to 72.5% and 17.1% were unsatisfied (Mylek and Schirmer 2023a: 28). This 'overall' measure is an average of three other indices as outlined below (Schirmer and Mylek 2022: Figure 8).

The data from DEX indicates that among respondents who provided satisfaction scores:

- Overall, across the program from January 2020–December 2022, 91.2% of carers were satisfied (Accenture 2022b:9).
- The overall satisfaction rate for January 2022–June 2022 was 91.4% (Accenture 2022a:10) and this rate dropped to 85.9% in the July 2022–December 2022 period (Accenture 2022b:9).

Measures are described below.

5.2 Measuring satisfaction in the Carer Wellbeing Survey (CWS)

Satisfaction with services is reported in the CWS in several ways (see Schirmer and Mylek 2022: 25; and Appendix 1).

- Overall satisfaction with communications and interactions with Carer Gateway is measured as the average of responses to three questions: (1) How your needs as a carer were assessed

---

[7] In considering benchmarks for satisfaction measures for carer support services, a baseline could be the findings in national data prior to the introduction of Carer Gateway. The ABS SDAC 2018 found that 50% of primary carers (excluding those who did not know the range of services available or who did not answer) were satisfied with the range of services available to support them in their caring role. (The respective figures for SDAC 2012 and 2015 were 54% and 53%). The SDAC 2018 data also show that 71.5% of primary carers (who had used organised services in the last 6 months) were satisfied with the quality of assistance received (ABS 2019, Table 41.1). The categories in these measures are: satisfied, neither satisfied or dissatisfied, and dissatisfied. These measures differ from the high satisfaction measures (7-10 out of 10) reported here. Sources: AIHW website: National Disability Strategy outcomes reporting: https://www.aihw.gov.au/australias-disability-strategy/outcomes/personal-and-community-support/carer-satisfaction-with-support, details on definitions: https://www.aihw.gov.au/australias-disability-strategy/technical-resources/data-dictionary/personal-and-community-support/carer-satisfaction-with-support; ABS (2019) Catalogue number 44300DO00_2018, Disability, Ageing and Carers, Australia: Summary of Findings, 2018. Carer Tables.

(2); Professionalism of Carer Gateway staff; and (3) Helpfulness of Carer Gateway staff. For current carers in 2022, 76.8% of respondents were satisfied and 15% were dissatisfied using this measure (Schirmer and Mylek 2022: Figure 8). In 2023, 68.7% were satisfied with 21.3% dissatisfied (Mylek and Schirmer 2023a: 28).

- Overall satisfaction with services received is measured as the average of responses to questions about 17 different services, including respite services. In 2022, overall, 84.6% of respondents were satisfied with services and 9.0% were dissatisfied (Schirmer and Mylek 2022: Figure 8). In 2023, the proportion satisfied with services decreased to 78.6% and the proportion dissatisfied was 13.6% (Mylek and Schirmer 2023a: 28).
- Overall satisfaction with the usefulness of services in the last 12 months is measured as the average score across services. In 2022, 75.8 % of respondents were satisfied on this dimension and 14.9% were dissatisfied (Schirmer and Mylek 2022: Figure 8), while the respective figures for 2023 were 69.9% satisfied and 20.3% dissatisfied (Mylek and Schirmer 2023a: 28).
- ‘Overall satisfaction’ with Carer Gateway is the average score from these three indices (Schirmer and Mylek 2022:25).

In 2022, mental health carers were less likely to be satisfied on the ‘overall satisfaction’ measure, while older carers (aged 65 years and over) were more likely to be satisfied (Schirmer and Mylek 2022:27). In 2023, young carers (aged15–24 years) were significantly less likely to be satisfied on all the CWS measures, whereas older carers (aged 65 years and over) were more likely to be satisfied on all the measures (Mylek and Schirmer 2023a: 29, Table 1).

5.3 Measuring satisfaction in DEX for performance monitoring reports

The satisfaction measures available in the DEX data are most often collected at a service review and encompass three domains:

1. The service listened to and understood my issues.
2. I am satisfied with the services I have received.
3. I am now better able to deal with the issues for which I need assistance.

The responses to each question are measured on a scale of 1–5 (1–Disagree, to 5–Agree). Caution must be used in interpreting the satisfaction questions in DEX data, as not all carers who have a service review provided responses to the satisfaction questions. A consistent finding across all periods reported in the half-yearly performance monitoring reports is that the majority of carers for whom data is available in DEX either ‘agree’ or ‘tend to agree’ with the statements, with the first statement receiving a higher satisfaction rating than the second, and the third statement has the lowest satisfaction rating (Accenture, 2020, 2021a, 2021b, 2022 a, 2022b). ‘Overall satisfaction’ reported in Carer Gateway half-yearly performance monitoring reports is an average of these responses (Accenture 2020:9). A second consistent finding in these reports is that there are no significant differences in average overall satisfaction scores across demographic groups including: young carers, female carers, carers with a disability, carers from a CALD background, and Aboriginal and Torres Strait Islander carers (Accenture, 2020, 2021a, 2021b, 2022a, 2022b).

5.4 Satisfaction with aspects of Carer Gateway services

Satisfaction with the Carer Gateway website and phone call service

The CWS, population surveys and Carer Gateway pre-survey report on carer satisfaction with aspects of the Carer Gateway website and phone service. Table 2 reports on the proportion of carers who reported high satisfaction in the CWS and suggests a decline in satisfaction rates on all the aspects of the Carer Gateway website and phone service in 2021, 2022 and 2023. In 2023, 51-56% of the CWS respondents reported high satisfaction with these aspects of Carer Gateway (Table 2).

Table 2 Satisfaction with aspects of Carer Gateway: Carer Wellbeing Survey 2021, 2022, 2023

	2021	2022		2023	
Satisfaction with:	**% High satisfaction Score 7–10**	**% High satisfaction Score 7–10**	**(95% Confidence interval)**	**% High satisfaction Score 7–10**	**(95% Confidence interval)**
Carer Gateway website overall	56.0	56.1	(53.6–58.5)	50.9	(48.6–53.2)
Information available on Carer gateway website	56.8	56.8	(54.3–59.2)	51.2	(48.8–53.5)
Carer Gateway phone service	64.5	63.2	(60.8–65.4)	54.0	(51.7–56.3)
Printed information	60.2	62.9	(60.1–65.7)	56.3	(53.6–59.0)

Source: For 2022 data, Schirmer and Mylek 2022: Appendix 1; For 2023 data, Mylek and Schirmer 2023a:33, Appendix 2).

In the 2022 combined population surveys, among those who had used these aspects of Carer Gateway, between 43% and 55% of carers reported high satisfaction (Figure 2). In the Carer Gateway post-survey (2023), 53% reported high satisfaction with the website and the information available on the website, while 61% reported high satisfaction with the phone service (Brosnan et al. 2023: Figure 77).

The CWS also reports on the satisfaction with these aspects of Carer Gateway for different demographic groups. Groups of carers who were less satisfied with aspects of services in 2022 were:

- female carers who were less satisfied with Carer Gateway information (55.9% vs 71.1% for males)
- Aboriginal and Torres Strait Islander carers who were less satisfied with the phone service (47.1% vs 63.3%) and the friendliness (59.9%) and helpfulness (57.1%) of staff
- carers in regional and remote locations who were less satisfied with the Carer Gateway website (48.0%) and information available on the website (43.6%), and
- carers of people with mental illness/psychosocial disability who were less satisfied with the Carer Gateway website (43.5%) and information (44.6%), phone service (49.2%), printed

information (51.8%), friendliness (66.2%) and helpfulness (62.5%) of staff, and usefulness (61.2%) of services (Schirmer and Mylek 2022:23–5).

In 2023, notable changes to the satisfaction of different groups of carers were:

young carers (aged 15–24 years) who were less satisfied with the phone service, the printed information, and the professionalism of staff

those providing care for more than 40 hours per week who were less satisfied with the website overall and the information on the website, and

older carers (aged 65 years and over) who were more satisfied with all aspects of Carer Gateway (Mylek and Schirmer 2023a:33–5).

5.5 Satisfaction with types of Carer Gateway services

The CWS and population surveys also report satisfaction levels with the different types of Carer Gateway services. The 2023 CWS report notes that the proportion of carers reporting high satisfaction levels for services generally increased between 2021 and 2022 and then declined in 2023; however, in many cases the changes between 2021 and 2023 were not statistically significant (Mylek and Schirmer 2023a:37-40).

Table 3 reports the percentage of high satisfaction scores for different types of services based on CWS data for 2021, 2022 and 2023. In 2022, over 70% of carers reported high levels of satisfaction across all types of services and services, with slightly lower ratings for cleaning services (funded through tailored support packages) and online self-guided coaching (Mylek and Schirmer 2023a:37-39). In 2023, over 60% of carers reported high levels of satisfaction across nearly all service types (Mylek and Schirmer 2023a:37-39).

In 2023, services with the largest proportion of carers reporting high satisfaction were counselling (either in person, phone, or online) (71.2%), in home respite (70.8%), residential respite (70.5%), and in-person peer support (70%). The lowest scores in 2023 were for day care respite (52.9%), cleaning services (62.1%), shopping services (63.1%), and online self-guided coaching (63.9) (Table 3). Satisfaction with some services had significantly declined over time: in-person peer support, cleaning services, day care respite, and support to enrol in education and training (Mylek and Schirmer 2023a:37-39).

Table 3 Carer Wellbeing Survey 2021, 2022 and 2023: Satisfaction with services by service type (% high satisfaction, scoring 7–10 out of 10)

	2021	2022	2023
	% High satisfaction (7-10 out of 10)	**% High satisfaction (7-10 out of 10)**	**% High satisfaction (7-10 out of 10)**
Funding to purchase small assets	72.1	85.2	65.2
Psychological counselling (in person, phone or online)	70.7	75.4	71.2
Carer coaching	64.6	82.8	67.6
Online self-guided coaching	62.2	71.8	63.9
Skills courses	67.1	87.1	67.5
Online forums	55.0	76.9	66.4
In-person peer support		81.2	70.0
Cleaning services	73.6	71.1	62.1
Shopping services	63.6	*	63.1
Transport	70.9	*	69.5
In home respite	71.9	82.0	70.8
Day care respite	70.8	76.9	52.9
Residential respite	75.8	82.9	70.5
Emergency respite	74.5	89.0	67.4

Source: Mylek and Schirmer 2023a:37-40. Note: * not reported due to confidentialising.

Findings from the population surveys and post-survey

Respondents in the combined population surveys were asked to rate their level of satisfaction with Carer Gateway services they had used (Table 4). The service types with the highest level of satisfaction (net 7–10) were counselling in-person (74%), peer support in-person (74%), and emergency respite (69%). Online skills courses on the Carer Gateway website received the lowest satisfaction rating (49%). Carer Gateway post-survey respondents reported high satisfaction with phone counselling (86%) and with the tailored support packages (72%) (Brosnan et al. 2023, Figure 81).

Table 4 High satisfaction with types of services of Carer Gateway (% Used Carer Gateway, combined surveys, 2022)

Service	% High Satisfaction Score of 7–10
Counselling (in-person)	74
Peer support (in-person)	74
Emergency respite	69
Tailored support packages (services and support specific to your needs, such as education supplies, planned respite, or cooking and cleaning services)	64
Counselling (phone)	60
Online skills courses on Carer Gateway website	49

Source: Brosnan et al. (2023) Table 16. Base: Respondents who have used Carer Gateway services. Total n= 12 to 170. Results for Coaching (in-person), Coaching (self-guided on Carer Gateway website), and Peer support (online community forum on Carer Gateway website) not shown due to small base size (n=28, n=12, and n=28, respectively). Question not asked of ERC respondents. Source: S8e. Overall, how satisfied were you with <insert S7 response for loop>' Note: 'Don't know' and 'Refused' responses not shown.

Regression models using the CPA survey data for respondents who had used any Carer Gateway services indicated the following characteristics were significantly associated ($p<0.05$) with higher levels of satisfaction with services: older carers aged 65 years and over, carers being in better health, and carers with lower levels of education (Brosnan et al. 2023: 81, Table 18). At the 10% significance level, caring for older adults was a factor associated with higher satisfaction (Brosnan et al. 2023: 81, Table 18).

Whether carers would use services again

For each of the Carer Gateway services used, respondents from the combined population surveys were asked whether they would use the service again (Brosnan et al. 2023: Figure 34). Across all service types, most respondents said they would use the service again. The largest proportion said they would use tailored support packages again (82%) (Brosnan et al. 2023: Figure 34). Although 49% of carers reported high levels of satisfaction with online skills courses (Table 4), 70% indicated they would use the service again (Brosnan et al. 2023: Figure 34). Among these respondents, 55% indicated they would use the in-person coaching service again, 62% would use the phone counselling service, and 51% would use peer support again (Brosnan et al. 2023: Figure 34).

5.6 Stakeholder perspectives

Emergency respite

Stakeholders had mixed views about the emergency respite provided under the new model. When comparing access to emergency respite under Carer Gateway with the previous model, some stakeholders commented that the previous model was more accessible and more generous (e.g. Other stakeholder 3). However, service providers talked about the effectiveness of providing emergency respite to carers to support them in times of crisis (Service provider 2, Service provider 15). Stakeholders explained, for example:

> With emergency respite, sometimes people don’t quite understand what is in scope for emergency respite. Often it is the carer themselves needing to go to hospital or something along those lines that would fit within our scope. On the whole though, given the challenges we've had, and some of the shortages of staff in terms of support workers and nursing staff amongst others, for the large majority of time we've been able to support carers through what has been a really difficult time. (Service provider 9)

> [The use of] Our emergency respite is actually dropping, which means we've got better planning conversations, we've got more services into place. We're talking about capacity building for carers. They're not coming back for emergency respite. They may be coming back for a planned respite service or some other form or an external referral. […] The less people who are lining up for emergency services or emergency respite, the better we have been at avoiding those crisis management situations. (Service provider 15)

Coaching

Most stakeholders considered coaching unpopular, but potentially effective. Promoting awareness and education about what coaching is, including differentiating between coaching and counselling, was considered necessary (Service provider 12). One stakeholder explained:

> Quite often people don’t know what coaching means – full stop. So sometimes it’s a bit of a harder sell because people don’t know what they’re in for or what to expect. But I think once they are involved in that program or [are] being supported by a carer coach, the benefits have been huge. (Service provider 9)

One stakeholder said coaching could meet the varied needs of carers. Some carers may be trying to sustain employment and a career, some may be trying to manage the stress from their caring role (Service provider 7, Service provider 8), while other carers may require more practical coaching around advocacy and navigating the service system (Service provider 4). Overall, stakeholders indicated coaching needs to be flexible and adapt to carers’ circumstances.

In-person peer support

There were mixed views about the effectiveness of in-person peer support. Some stakeholders believed the model had not been fully realised, partly because of COVID-19 and the restrictions on face-to-face service delivery. Other stakeholders suggested the integrity of the program had been lost. As one stakeholder explained:

> If you want a peer support program that's delivered by peer workers, then you have to actually get on board and understand what it is. Some providers had no experience and they've been fantastic, some have gone leaps and bounds, but the peer piece is big. There's a difference between lived experience and peer [support]. (Service provider 6)

Others thought the program needed more flexibility (Service provider 6, Service provider 7, Service provider 8, Service provider 9). Stakeholders were positive about the willingness of DSS to adjust the in-person peer support model (Service provider 12).

> In-person peer support. So, the intensive workshop that I was just talking about where they get to stay overnight, every single evaluation that we have done on that, everybody has really enjoyed that experience. That definitely gets a lot of good feedback. (Service provider 8)

Some stakeholders felt in-person peer support did not work because it ‘lumps everyone together’ (Other stakeholder 4), rather than supporting specific cohorts and their particular needs.

Counselling

Stakeholders were very positive about counselling, and it was considered the most popular and effective service after tailored support packages. In part, the high demand and need for counselling, including online grief and trauma counselling, was attributed to COVID-19 (increasing domestic violence), natural disasters, and the complex circumstances carers and their recipients have been experiencing since Carer Gateway commenced (Service provider 9, Service provider 14, Service provider 4, Service provider 5, Service provider 17). Some stakeholders talked about the need to extend the number of online counselling sessions (initially set at six), as it was not enough for many carers – especially through the pandemic (Service provider 13, Service provider 17, Other stakeholder 3). Several service providers (n=7) and other stakeholders (n=3) indicated that online and face to face counselling, in addition to respite care, is effective for improving carer wellbeing. For example:

> Again, the counselling and coaching can help really develop their own coping strategies, resilience strategies and identify what works for them to sustain them, which can look different for everybody. But I think that’s a big part of the work that we do, is helping carers to identify what is going to sustain them. (Service provider 14)
>
> [W]e had a course when a carer said okay, I can’t do this anymore. I’m leaving now. You can do whatever you want, I’ll leave my mum or dad or whoever behind… So this is where counsellors come in and play a big role in supporting carers. (Service provider 7)
>
> It's that reduction in isolation because you know, that's the thing that comes up the most, that ‘it was so good to talk to somebody’ and ‘I don't feel so isolated’ and that they feel that they have some skills that they can use that they didn't have before. (Service provider 17).

As noted in other parts of this report, several stakeholders commented on the inappropriateness of some services for Aboriginal and Torres Strait Islander carers, as well as the challenges of providing services in remote communities.

> There’s peer support, there’s counselling, do other things. Are they the right tools for different communities across Australia? I’m not sure at the moment. (Other stakeholder 12)
>
> For [an Aboriginal person] to come and sit and speak to a counsellor, it’s not going to happen. […] . But if it was an Indigenous [counsellor], I think that might change, might look a little different. They might even say oh no, it’s okay. I see my spiritual person here on community or whatever they call that person. They just flat out [say] no, so if you had the appropriate person, I think that might change a little bit for us. (Service provider 4)

Similar to Aboriginal and Torres Strait Islander carers, stakeholders indicated that many culturally and linguistically diverse groups have a different view of what counselling is (Service provider 17). Stakeholders explained services are more effective when there are close connections with the local community (Service provider 3, Other stakeholder 7) and are particularly effective when workers were bilingual (Service provider 6).

Tailored support packages

Stakeholders had much to say about the tailored support packages, particularly when compared to the previous model. They also talked about the adequacy of the packages ($1500 and $3000), and the ability of providers to have discretion over how they are used.

Tailored support packages, particularly when used for planned respite, were identified as one of the most commonly accessed services.

> I think packages are really important, particularly the in-home practical supports for someone who is just finding it really tough. Whether that be for a working carer who just can’t get everything done, or an ageing carer who is just finding it all very difficult, on top of their own health needs, looking after someone else. So, I think yeah, packages are an excellent service offering. (Service provider 12)

Several stakeholders commented that many carers contact Carer Gateway with the understanding they can use their funds as they wish, and do not understand why they need to do an assessment to determine what services and supports would benefit them. The assessment process was sometimes compared with state-funded programs which were perceived to be more flexible:

> I guess it’s quite a rigid model too. So, I guess within that carer directed package there’s quite strict criteria about what that money can be spent on to support a carer, which again, limits the amount of carers we can support who are asking for various things to support them in their carer role. And I’m probably comparing a little bit to state funded programs too that are quite flexible and we’re lucky we’ve got those in conjunction. (Service provider 14)

Related to this, some stakeholders had concerns about the consistency of the tailored support packages across providers (Service provider 15).

Young carers were considered a cohort requiring more tailored supports and services. Some providers talked about effective and popular retreats or camps that have contributed to positive carer outcomes. They also talked about the importance of tailored support packages for young carers and, for example, paying for tutors (Service provider 11, Service provider 12). When asked what services and supports were working well for young carers, one provider responded:

> I would say being able to have brokerage. It's a really big thing for young carers. I think that, especially when you're working with a really financially disadvantaged demographic, even though we don't have a huge pool of funding available for each young carer, it definitely does break down a lot of barriers with things that we can support them with. I'd say also the social aspects of the program, being able to run social groups and actually connect them it – I guess from my perspective – creates a lot more sustainable outcomes in letting them make those natural social connections so they're not so much becoming dependent on the relationship they build with the care planner through that individual support. (Service provider 11)

Overall, there were mixed views about whether the funding was adequate; some stakeholders said they underspent the funds, while others said there needed to be more flexibility to adapt to carers’ circumstances. This was more apparent for providers working in regional and remote communities where the costs of delivering services and transporting items was much higher (Service provider 4). Additionally, some carers in these regions had more complex care needs; for example, they may require longer periods of respite care, away from their community.

Stakeholders overall were positive about DSS' responsiveness to providers' feedback and their willingness to allow for extensions to packages in extraordinary circumstances (Service provider 15). There was consensus that the dollar amount of the packages, how the funds can be used, and how they vary across locations, may benefit from being reviewed.

Online services

Stakeholder feedback about online services was mostly positive as it responded to challenges presented by COVID-19. While there were issues concerning digital access – either due to infrastructure (regional connectivity) or digital literacy – in the context of COVID-19, the online services were overall seen as positive; services were available online or not at all. Due to the pandemic, many carers were now more used to accessing services online and also found them easier to fit into their busy schedules (for example, counselling or coaching sessions). Online forums were also identified as a good way to connect carers with each other and to provide information.

Stakeholders indicated the in-person peer support model is currently not working for young carers; however, several providers were working on ways to adapt and improve it for this cohort (Service provider 4, Service provider 16, Other stakeholder 4). Other stakeholders indicated online forums (and in-person peer support groups) were only beneficial to mental health carers when they were dedicated groups or forums, rather than generic for all carers (Service provider 12, Other stakeholder 10).

5.7 Aboriginal and Torres Strait Islander carer perspectives

This section reports on the few services identified as being accessed by Aboriginal and Torres Strait carers in the interviews.

Emergency respite

The only service that was consistently identified and discussed by Aboriginal and Torres Strait Islander carers interviewed was emergency respite accessed to address immediate needs (Carers 34 and 55 metro and Carer 42 regional). Emergency respite helped these carers avoid a crisis or supported them through an emergency. Several carers also indicated that access to this support prevented further crises from occurring and supported them to continue in their caring role (Carer 39 regional).

A couple of carers did not feel they were able to easily access respite when they needed it (Carer 32 metro), comparing this lack of support with the respite service they accessed prior to the implementation of Carer Gateway (Carers 43 and 47 regional). Many carers indicated during a crisis or emergency, accessing respite, and meeting their immediate needs (for example, food) were the most important services for them (Carer 34 metro).

> Yeah. It's taken – helped with those really peak moments – and taken away a lot of the stress when I just couldn't figure out what to do on my own. I know – I'm on the newsletters, the email newsletter and stuff, and I know that I've still got those counselling sessions there in the background, so I kind of know what I can reach out for if I need it. (Carer 35 metro)

One carer referred to Carer Gateway's intention to support capacity building and prevention, explaining how they thought the Carer Gateway provider could better support carers longer term:

> So, I think Carer Gateway, rather than being a reactive and listening and supporting from reaction point of view, but also have the gear up front to help to navigate, lessen the pain, help people make informed decisions quicker and then still go the journey with them. (Carer 46 regional)

Access to respite

Some Aboriginal and Torres Strait Islander carers talked about regular/scheduled respite (Carer 35 metro), particularly in circumstances where they had children with a disability (Carer 40 regional). However, it was unclear in some circumstances whether this respite was provided through Carer Gateway or the NDIS. In some instances, respite was not accessible or suitable for carers:

> Sometimes – well I booked myself into the [city] Clinic – the private clinic there, for mental health. I went in there for about 5 weeks to give myself a break, because mentally I was just too – I couldn't cope here at home. I would have liked some help through that, and the main help I would have wanted was – and I still do at times when I have a really hard time, if I have a hard week, is sometimes you just might need someone to cook a dinner or something for you – meals. (Carer 47 regional)

One carer talked about wanting respite from caring for her child with a disability but was not satisfied with the options because she was not able to meet the respite worker prior to using the service. She did not feel comfortable with this approach and consequently did not use the service (Carer 37 metro).

> Yeah, the respite person wasn't replying and, quite honestly, it all became too hard for my head when I'm already stressed enough with what I deal with. So, I just dropped it, put it in the too hard basket. (Carer 37 metro)

Respite care, housework, gardening, and rubbish removal were the most common services that carers wanted better or more access to (Carers 31, 33, 34 metro, Carer 42 regional). Another example of tailored support that one carer wanted was access to transport to get to medical appointments. One carer indicated they were referred to services but were unable to afford them, which may point to a lack of flexibility by the provider, or a lack of understanding by the carer about how the tailored support packages can be used. One carer expressed their frustration at not being able to access supports they felt they were entitled to:

> They're not giving the services I really need and there's money sitting there […]. All I ask for is to have some time for myself. They won't even do that. (Carer 33 metro)

Other carers indicated they did not access any supports or services, but they found it helpful to know who to ring if they needed it (Carer 32 metro).

Counselling

A couple of Aboriginal and Torres Strait Islander carers talked about counselling. One said she was offered counselling but felt there was too much going on in her life to fit it in (Carer 33 metro).

> I still stress. I still stress something chronically. They did offer me, because my dad died, as I told you Friday – got me services – I have got counsellors and that, but I don’t want to use them sort of thing. I don’t want to go down to the office [down at location] and sit there in the office and do it and come all the way back. (Carer 33 metro)

Another carer indicated their preference for telephone counselling because she could fit it around her work and care responsibilities (Carer 43 regional).

> The telephone counselling, just because it was hard to start off with. Yeah. I don’t work fulltime. So, I am at home all the time. I’m pretty much on-call for [care recipient] when he’s at school. He’s not at school fulltime either. (Carer 43 regional)

Summary

Overall, interviews with Aboriginal and Torres Strait Islander carers demonstrated the complexity of their lives, often caring for multiple family members across generations. Immediate respite can offer support, but other services do not appear to be culturally appropriate or accessible to many carers. This is consistent with findings from the stakeholder interviews.

5.8 Non-Indigenous carer perspectives

Based on interviews with non-Indigenous carers, different Carer Gateway services have met carer needs including those living in diverse circumstances and caring situations. Some carers were helped by receiving cleaning services or appliances. These types of support lessened the load of caring and allowed them to continue to provide care. One carer commented on how receiving support helped them to consider their own wellbeing:

> I'm thinking, but how's that helping my mum? It took me a little while to get my head around the fact that it was about my mental health wellbeing and my physical wellbeing and those sorts of things. I suppose struggling for years and years and years with no help for me, it took me a little while to get my head around it. (Carer 7 metro)

Counselling

Counselling services both online and in-person were consistently identified as meeting the needs of carers. Carers also found that counselling provided them with someone to talk to about what they were going through. Counselling services also provided carers with advice and helped them to develop skills to ‘put things into perspective’. (Carer 25 metro) One carer commented:

> So I got quite a few really good, structured I guess frameworks of how to think about what I was going through as a carer and trying to understand what my partner was going through. (Carer 8 Regional)

Other carers commented:

> What I needed was counselling…I needed someone I could just dump it all on who wasn't connected and having, you know, just understanding the value of that. (Carer 13 metro)

> So I didn't know that I needed counselling, it's just that's what sort of was offered and I fell in with this amazing counsellor who I think I've now seen six times in the two years, and she is remarkable. (Carer 03 metro)

Coaching

Other carers found the coaching sessions provided them with useful skills to help them prioritise their needs, particularly during a time of crisis. One carer said:

> They were asking me about, you know, how am I feeling now? What was I doing and stuff like that? And so through that they. They put me in contact with a coach because I was having a lot of troubles with Services Australia. At that point I was also having a little bit of trouble with the nursing home as well in terms of just the financials and things like that. So they were just kind of helping me kind of prioritize and plan things and stuff like that. (Carer 25 metro)

The coaching sessions helped other carers focus on their own wellbeing. As one carer reflected:

> I had never really done anything like that before, so I was a bit unsure as to what it was going to entail. They rang to book me in and they kind of explained what it was about… But then when it actually got to the day and I spoke with the lady who was doing it, it was really good. She helped me set some goals around trying to have half an hour a day just for myself, just to go for a walk and just have that time just for me, which is something that I have been wanting to focus on, but just find it difficult to actually find the time for yourself, because you're just, you know – just with life just gets in the way. (Carer 4 regional)

For a number of carers it was access to a combination of supports that helped them to continue to care, increase their knowledge and skills, and improve their wellbeing. As one carer highlighted:

> By just access to the coaching and the counselling and the groups and leading off to [find] what's available through the Department of Health. I guess some of the group sessions we had, which informed us what was available online for us to improve our health and what we could get access to and where we could get answers. I found those things helpful in just increasing my general knowledge of what was out there to help me as a carer. (Carer 2 metro)

Respite

Access to respite was also viewed by carers as helping them to continue to provide care.

> I think the respite and the fact that Carer Gateway are so accessible. I have no support for myself. I mean I'm getting older too. I have no support for me. Familywise or anything. My family are on the mainland. Sometimes, I'll feel a little bit frightened, I suppose, especially when he gets sick or things like that. I get a bit - sort of, what am I going to do, who can I talk to. Just knowing they're there is a really great comfort. They've been so very reassuring in – I just know if I walked in today and said, I'm a mess, somebody would sit me down and give me a cup of coffee (Carer 6 regional)

Other carers had access to respite services in the form of a retreat. As one carer explained:

> Well the other thing that I've found really useful is getting together with other carers…like a carers getaway for a weekend. I thought that was really nice because it gave me a total break. It was so good, with a group of people. When phone rings and you go, what's wrong,

> you answer the phone, and you don’t say, hello or whatever, you say, what’s wrong? Nobody at the table around you think there’s anything strange about that response because they’re all sitting in the same situation. (Carer 2 metro)

Peer support

Online or in-person peer support provided carers with access to information, skills to help them manage caring, and reassurance that a support network was available if they needed additional assistance.

> There were a couple of online things I registered for, just because it made me feel really good - that they were people of both support and knowledge that was there, a network should I choose to tap into. (Carer 13 metro)

The online forums provided carers with advice and support from people who understood their circumstances.

> I just think at the time my wife was in hospital and I was isolated and felt alone– I just needed to speak to someone about it, that was basically it. I was just like go to the hospital because of my wife, come back depressed…I think it was just initially, it was just go on the forums and post when I feel a bit stressed and just wanted to vent or just say something. That was basically it, I didn’t use any of the other resources. I was going in every day, that was draining. They [forum participants] said ‘just think about yourself, think about yourself more, not just [your] wife and… oh look don’t go in every day, have a break from visiting’. (Carer 01 regional)

Access to in-person peer support was difficult to organise for carers. One carer recounted how she was given a list of contacts for different carer groups and found that the numbers were either disconnected or the details for the contact person had changed. She said, ‘Like it was just - I made 10 phone calls and eight of them that answered was all inaccurate’. (Carer 06 Metro). The carer also noted that COVID-19 made it difficult to meet up with other carers for coffee groups.

5.9 Summary

Although the CWS and population surveys reported a declining level of satisfaction of carers with Carer Gateway services, the overall level of satisfaction for all services remains relatively high, with 72.5% of carers in the CWS 2023 being highly satisfied on the overall measure and over 60% reporting high satisfaction for most types of services. Respite, in-person counselling, and in-person peer support had relatively high satisfaction ratings across the surveys. Respite, counselling, and in particular tailored support packages were also considered by stakeholders and carers to be the most appropriate services to meet carers’ needs; however, other services were also valued when they met the needs of particular carers. Some services were considered by stakeholders to be less appropriate for particular groups of carers; for example, counselling and some other Carer Gateway services were considered less appropriate for Aboriginal and Torres Strait Islander carers. Some services were also not accessible for carers living in regional and remote areas.

6 Question 1b: Use of Carers StarTM assessment

Evaluation Question 1b: How appropriate is the service provider use of Carers Star^{TM} assessment for assessing and meeting carer needs?

Carers Star^{TM} is a validated assessment tool which is a key component of Carer Gateway service provision. The Carers Star^{TM} assessment covers seven key outcome areas (domains), each of which is scored separately:

1. Health
2. The caring role
3. Managing at home
4. Time for yourself
5. How you feel
6. Finances
7. Work

The assessment takes about an hour to complete and is conducted at intake and at service reviews. The scores from the different sections of the Carers Star^{TM} are combined and are entered by the service provider into DEX, giving an overall wellbeing score which is graded between 1–5, with 1 being very low wellbeing ('Cause for concern') and 5 being good wellbeing ('As good as it can be').

6.1 Surveys: Satisfaction with assessment and planning

Data on how satisfied carers were with how their needs were assessed were collected in the CWS, in the population surveys, and the Carer Gateway pre-survey. Across these data sources, 48.4-69.9% of carers who had their needs assessed were highly satisfied:

In the CWS, 69.6% of respondents in 2021, 66% in 2022, and 60.2% in 2023, reported high satisfaction (score of 7–10 out of 10) with this process (Schirmer and Mylek 2022: Figure 9; Mylek and Schirmer 2023a: 33). Groups of carers who were identified as less satisfied with the needs assessment were Aboriginal and Torres Strait Islander carers and carers of people with mental illness/psychosocial disability (in 2022), and carers who were caring for 2 or more people (in 2023).

In the combined population surveys in 2022, 63% of carers who had used Carer Gateway had a needs assessment; of this group, 48.4% reported high levels of satisfaction with this process (Figure 2).

In the Carer Gateway pre-survey in 2022/23, 60% of respondents had completed a needs assessment and, of this group, 65% reported high satisfaction with how their needs were assessed (Brosnan et al. 2023: Figures 75, 76).

6.2 Stakeholder perspectives

There were mixed views about Carers Star^{TM,} with most stakeholders recognising both positive and negative aspects of the tool. As one service provider summarised:

> I think there's positives and negatives about it. I think in some ways, the conversation is good, but I think, as a measurement for outcomes and other things, which I think the department is trying to use it for, it's not the tool for that. (Service provider 5)

Overall, many stakeholders believed the Carers Star^{TM} tool is not meeting the assessment needs of all carers. Several stakeholders indicated the Carers Star^{TM} assessment was sufficient for some carer cohorts, but that it was not appropriate for Aboriginal and Torres Strait Islander carers, young carers, and some CALD carers. The reasons the Carers Star^{TM} was considered inappropriate differed for each of the cohorts. Some stakeholders were critical about the ability of the Carers Star^{TM} assessment to capture the needs of carers. The amount of time assessment takes was a barrier to assessing and providing the support carers need (Service provider 12). Other service providers believed that the tool could not be adapted, and, because of this, it restricted their practices and ability to adequately assess the needs of different groups of carers.

> I think reinstating some of the governance aspects would be good, as well, and potentially looking at the tool around intake and assessment, and whether Carers Star^{TM} is really the right tool, because it's also not young carer friendly, it's not Aboriginal friendly, or relevant. It's not CALD friendly or relevant. It is owned and operated by one company that is so specific about what they do. You're locked into their training and their things, and it's not great. (Service provider 5)

Other providers expressed neutral or positive views, indicating that with skilled staff the Carers Star^{TM} assessment tool could be adapted to the needs of different groups. They recognised that some carers (notably those caring for older people) ‘quite enjoy it’ (Service provider 1) and indicated they adapt the tool to meet their needs. For example:

> I've got a one pager that I'm just capturing notes and I might be talking to them. I'll say we're having a conversation about the different aspects of your life but as I'm asking them about health, they might say to me I feel really overwhelmed and stressed. Then I'll just go yeah, okay, how that's the how you feel part. So, it's rather than let's have their seven answers to seven questions kind of thing, let's have a conversation and I'll see where I can piece it together. I don't with Indigenous people use the numbering system for rating. I make that assessment myself. (Service provider 4)

One service provider also commented on how they adapted the Carers Star^{TM} for young carers to allow them to lead the conversation:

> So, we take the initiative to make it more digestible to young carers as well by changing the language and make it more – speaking to them in sort of like plain English or jargon that the young person can relate [to] and don't feel formal when they do the Carers Star^{TM}. We don't follow the structure of from health to work, so we let them decide which area they want to start. Also, the time is much easier for young carers to relate when we start with the questions like ‘what do you do during your free time’ and ‘when was the last time you did it’. (Service provider 4)

While some saw its adaptability as a strength, others saw the way Carers Star^{TM} was being implemented differently by different providers contributing to inconsistency in how supports and services for carers were being delivered. This inconsistency was evident in the way providers explained their process for undertaking the Carers Star^{TM}; yet the inconsistencies appeared to reflect providers' willingness to adapt the registration and assessment process to better meet carer needs. For example, some providers indicated that if a carer called up in crisis, they would triage them to ensure they received emergency respite and would follow up to conduct the assessment (usually within two weeks) when the carer was out of the crisis. As outlined in the *Carer Support Framework*, the Carers Star^{TM} assessment is not required prior to accessing emergency respite and review, and a 'Worker only' assessment option can be used. The 'Worker Only' assessment is a snapshot recorded by the Carer Support worker where it is not possible/appropriate to conduct a full Carers Star^{TM} assessment (see Carer Support Framework, 2019). One stakeholder explained this occurred when:

> It's quite an immediate crisis, the carer is not in a place where they can actually sit down and have a reasonable conversation, there might be too much going on, there could be cognitive impairment in the carer themselves, those sorts of situations I suppose. Often at closure, when we're trying to do a final Star, we may only do a ['worker only' assessment] if the carer doesn't want to engage because we're closing, we're finishing, and they don't see the need to have that detailed discussion again. (Service provider 14)

Only two providers explicitly talked about the 'Worker only' assessment as an option for when carers call in a time of crisis, or when Carers Star^{TM} was not an option at the time they called.

Other stakeholders indicated that having to do the Carers Star^{TM} was a barrier to receiving emergency respite, explaining that 'according to the Guidelines', a Carers Star^{TM} needed to be completed before providing any services or supports and, as a result, created a barrier for some carers in accessing any respite or support (Other stakeholder 3). However, as noted above, the Carers Star^{TM} is not a requirement to access emergency respite. The nuances, and potential inconsistencies (compared with the quote above) of the model across different providers, are identified by the following service provider:

> In an ideal world we would have exactly what [name] is saying, like the emergency respite component within the system within the service model, is that you would be able to get people into a service quickly and then have the flexibility to come back and then work, as [name] is saying, to get a better detail because what that does is create trust already. It's different than other government services. At the moment, the view of carers [is] 'I've got to go through a whole process before I can get to something'. (Service provider 17)

Relevance of Carers Star^{TM}

In addition to being seen as time consuming to administer, some stakeholders also considered the Carers Star^{TM} to be inappropriate for Aboriginal and Torres Strait Islander carers, given the need to build trusting relationships before expecting carers to share information about themselves and their families. As one provider explained:

> It might be five or six hours of conversation or yarning time that would take place before we can even get to a Carers Star^{TM} assessment. Not only allowing the carers to understand that their caring role is quite significant, and it does need to be – and that we can provide some guidance and support there. So, it's gathering that understanding as well. So, the staff do have to be quite persistent. Then also not too pushy because we're trying to build trust and rapport as well. (Service provider 15)

Several providers talked about adapting the Carers Star^{TM} when working with Aboriginal and Torres Strait Islander carers or finding alternative approaches to identify their needs and services. Some examples included having Aboriginal engagement workers or teams that went out to communities and were available to have in-person meetings with carers – this often required multiple visits. One service provider explained:

> When we put in our Aboriginal team, we said, it might take 60 or 90 minutes to do a Carers Star^{TM} planning session, whereas now it could be 8 or 9 hours for an Aboriginal and Torres Strait Islander family. (Service provider 15)

Others worked closely with local clinics and mobile services where workers already had established trusting relationships with carers and could help to identify them and refer to them to appropriate services and supports.

Many of the questions in the Carers Star^{TM} were also identified as culturally inappropriate for Aboriginal and Torres Strait Islander carers. For example, one of the questions asks about having time to themselves; however, as one provider described, Aboriginal and Torres Strait Islander carers were considered to be culturally 'very communal and collective, and people actually don't want to be by themselves' (Service provider 2). Thus, respite for Aboriginal and Torres Strait Islander carers might look very different to respite for non-Indigenous carers. One stakeholder commented that respite sometimes required taking them away from their care recipient and community, which was often not what they wanted. The quote below demonstrates that while providers adapted the Carers Star^{TM} to engage more effectively and appropriately with Aboriginal and Torres Strait Islander carers, it meant they sometimes completed fewer assessments:

> Well, I only did 25 Carers Star^{TM} sessions this week when I should have done 50, but I've had 18 conversations with Aboriginal families? So it's that KPI level[8], and it doesn't work for CALD and Aboriginal and Torres Strait Islander families. (Service provider 15)

Stakeholders also identified reasons why the Carers Star^{TM} did not work for young carers. First, because questions were mostly adult-centric (e.g. finance); and second, because of a lack of flexibility over the mode of delivery (i.e. phone, website, in-person), venue (i.e. school or not), and having other family members involved in the Carers Star^{TM} process. One stakeholder indicated there needed to be an intake and assessment process designed specifically for carers under 25 years old (Service provider 16). Another explained how they adapted the Carers Star^{TM} for young carers:

> So, we developed interpretation cards, which have just been accepted and distributed nationally now because young carers don't have the vocabulary to be able to interpret what they're doing, and coming in with a tick sheet doesn't work, neither does that planning session over the phone. (Service provider 15)

Mode of delivery

The mode of delivery of the Carers Star^{TM} assessment is at the discretion of the service provider. The mode of delivery was raised by many stakeholders; most stakeholders completed the Carers Star^{TM} assessment by phone but said this was not the most appropriate or desirable way to

---

[8] Note that Carer Gateway does not impose KPIs on providers. The KPIs referred to here are set by the service provider.

complete the assessment for some groups of carers. The mode of delivery is at the discretion of the service provider. There should therefore be a distinction between the appropriateness of the Carers Star^{TM} instrument itself and the appropriateness of how service providers deliver Carers Star^{TM} assessments.

The *Carer Support Framework* (2019) notes that while the Carers Star^{TM} can be conducted over the phone:

> Face-to-face is appropriate or preferred when:
>
> - The person is Aboriginal or Torres Strait islander, and it isn't culturally appropriate to engage over the phone.
> - The person requires an interpreter to communicate, and the Translating and Interpreting Service (TIS) isn't available or appropriate.
> - The person is a young carer under 18. (Carer Support Framework, 2019: 10-11)

Again, young carers and Aboriginal and Torres Strait Islander carers were the two groups stakeholders most commonly identified for which Carers Star^{TM} was perceived to be not working. For Aboriginal and Torres Strait Islander carers, many stakeholders identified other ways to do the Carers Star^{TM} assessment, either by having outreach and engagement teams go out to communities or by working closely with other services (i.e. community clinics) to help identify and undertake the assessment on their behalf. Others had specific days where carers were encouraged to come into the service to do the Carers Star^{TM} assessment face-to-face. It was suggested that a phone call was also not the most appropriate approach for doing the Carers Star^{TM} assessment for many young carers. Instead, it was suggested that there should be more outreach and engagement with schools to identify and engage young carers in the assessment process. It was also suggested there should be options for young carers to do some or part of the Carers Star^{TM} assessment online; while it was acknowledged there were some limitations to online assessments, it could be one way to initiate engagement with young carers. In addition, a couple of stakeholders felt strongly that family members should be able to do a Carers Star^{TM} assessment on behalf of or together with a young carer.

Carers Star^{TM} review

6.2.1.1 Carers Star^{TM} Assessments

A review (currently in draft form) of the Carers Star^{TM} (Carers NSW, 2022) undertaken by Carers NSW and service providers suggests the assessment process may not be appropriate for some carers or carers may decline an assessment for several reasons. For example, carers may be time poor, prioritise obtaining supports for the person they provide care for, perceive the process as a duplication of other services, or have a change in their caring role (Carers NSW, 2022: 15-16). The review also noted inconsistency in service providers' recordings of incomplete or refused assessments or not applicable domains in the Carers Star^{TM} and suggested that clearer options for recording such responses would be useful (Carers NSW, 2022: 15-16). Further, the review found some carers did not wish to discuss specific domains, particularly work or finances; carers may be of school age, retired, or not in the labour force, and not perceive these topics relevant to discussion with Carer Gateway staff – or they may feel stigmatised for receiving income support (Carers NSW, 2022: 13-15).

6.2.1.2 Recording Carers Star^{TM} data

The review of Carers Star^{TM} also highlighted concerns about how the domain scores are translated into a single score and recorded in DEX. Based on analysis of the seven domain scores for a subsample of clients in 2021, the review noted the averaging of the Carers Star^{TM} score recorded in DEX would not provide an understanding of carers needs or provide information on which to understand changes to their needs over time. For example:

- Without an analysis of the scores for different domains, it is not possible to identify the variation in domain scores for carers (Carers NSW 2022: 8-10) and therefore which are carers' most pressing needs.
- Average change in mean domain scores between assessments obscures changes in specific domains between assessments. Their analysis notes some carers report positive changes in most or all domains, some all negative changes, and some a combination of positive and negative changes for different domains (Carers NSW 2022: 16).
- Having only an average score across all domains for the analysis of changes in scores also means that it is not possible to identify the impact of services on the different aspects of carers lives (Carers NSW 2022: 17-18).

The review recommends 'accounting for individual domain scores and changes in individual domains over time' to better 'understand carer outcomes and service effectiveness' (Carers NSW 2022: 26), noting that changes may be attributable to services or the carers' contexts (Carers NSW 2022: 16).

The review also suggests the current use of average scores recorded in DEX does not accurately represent the extent of carer distress and that analysing Carers Star^{TM} domains would provide the opportunity to examin[e]: 'the lowest scoring individual domain(s); …. the individual domains with the highest prevalence of scores indicating "Cause for concern" (1); and … the average scores for domains that approximate distress and crisis, e.g. "How you feel" and "Managing at home"' (Carers NSW 2022: 23).

These findings should be borne in mind when interpreting DEX analyses that use the mean scores for Carers Star^{TM} in this impact evaluation.

Summary

Many felt Carers Star^{TM} was a necessary process to identify carer needs but saw it more as a case management tool rather than an assessment tool. There was a consistent view that it was not suitable for some carers; in particular, young carers, CALD carers, and Aboriginal and Torres Strait Islander carers. Stakeholders also recognised that while it could be administered by telephone for some carers, it was best administered face-to-face for others. There were mixed views about whether the tool could be adapted to meet the needs of these cohorts. Service providers also raised several issues about the use of the Carers Star^{TM} average score in DEX to assess carers' outcomes and argued that analysis of individual domain scores would be more meaningful.

6.3 Aboriginal and Torres Strait Islander carer perspectives

Most Aboriginal and Torres Strait Islander carers interviewed were happy with the registration and Carers Star^{TM} assessment process, indicating they felt comfortable with the person they spoke with, and felt they provided the information and referrals they needed at the time. However, many Aboriginal and Torres Strait Islander carers said that they were unclear about what the Carers Star^{TM} assessment was, as they tended to view any contact and communication with the service provider as part of the process of identifying needs and services. A couple of carers commented on the complexity and confusion of the process, also indicating they would prefer more cultural support during the process (Carer 51, 52, regional).

> I think face-to-face. I think telephone or Skype and Zoom, or Teams and all of that is very daunting. I think face-to-face makes it a lot better. Giving the option to have a support person with them, or if that's not available, maybe like a local liaison officer or someone, or an Aboriginal Liaison Officer, to be that person's support. (Carer 51, regional)

> I think I had to ring and then they ended up making an appointment with me to discuss things further. So I guess what could have made it easier is if we could have just got straight into what I needed sorted and not have to wait a few days. (Carer 37, metro)

The Carers Star^{TM} itself did not appear to be either meaningful or very valuable for carers themselves to identify their needs.

As with the initial registration/intake phone call, there were differences across the locations/providers in terms of whether staff members asked carers if they identified as Aboriginal or Torres Strait Islander and whether they would prefer to talk to an Aboriginal or Torres Strait Islander staff member. There were mixed experiences about the length of time the Carers Star^{TM} assessment took, which is likely an indication of providers adapting the Carers Star^{TM} to improve the cultural appropriateness for the carer and their needs. When asked, one carer responded that the support worker communicated well, and that they would not expect a support worker to understand the complexities of different local cultures and family structures that came into play while navigating care for a family member (Carer 46, regional). This overall positive experience with the registration and assessment process contrasts with the stakeholders' views that the Carers Star^{TM} is not appropriate for Aboriginal and Torres Strait Islander carers. A couple of carers noted their fluency in English as a reason why they were not asked, or chose not to request, an Aboriginal and Torres Strait Islander staff member (Carer 44, regional).

There were a couple of carers who were not satisfied with the process of the Carers Star^{TM} assessment. One carer would have preferred to do the Carers Star^{TM} assessment at the same time they called the 1800 number, while another carer said they kept calling the 1800 number, but no one called them back to do the Carers Star^{TM} assessment (Carer 31 metro). This carer required immediate respite following a child leaving hospital and was unable to access the supports needed because they were not called back to undertake the assessment[9]

Overall, the Carers Star^{TM} assessment did not resonate with many Aboriginal and Torres Strait Islander carers. Most talked about the process in a neutral way, indicating the conversation took anywhere from 5 minutes to 60 minutes. Carers did not appear to make a clear distinction between the initial phone call and the Carers Star^{TM} assessment. A couple of carers viewed the Carers Star^{TM} as a barrier to receiving respite and supports they were entitled to as part of the tailored support packages (Carer 33, metro). These different experiences may also reflect providers' discretion to do a Worker Star^{TM} assessment to provide the immediate respite to support the carer's immediate needs (Carer 36, metro).

A couple of carers talked about Carers Star^{TM} negatively, noting:

> The conversation was on the phone, and it was emotionally draining because you've got to go through everything that you do for your person you're caring for. I felt a bit emotionally drained, but you've got to do what you've got to do when you're registering for something new. (Carer 37, metro)

Another carer explained that they were very confused and would have liked more information about the process and pathways after the assessment:

> I do remember feeling like – and I think in that moment when you don't know what's going to happen, you don't know what's happening, you're just … upside down. I think some sort of like a timeline would be – even if it's just an estimate or like a stage … going to do this now, going to do this now. They might have even sent that to me but not explained it in the way that made me feel like – not that everything was going to be okay but just like what I knew was ahead. What was going to come next. Because I had no idea, I was new and I guess [if the service provider] treated me like somebody that this was all new to it would have – that would have been more helpful, I do remember that. (Carer 48, regional)

6.4 Non-Indigenous carer perspectives

Carers who could recall their Carers Star^{TM} assessment described varied experiences of interacting with staff members. One carer commented:

> I remember I spoke to someone initially, and they were really helpful and really good. Then I called back about a year later, and the person I spoke to was, I don't know, borderline – well unhelpful, and borderline rude. (Carer 2 regional)

For some carers the assessment process was a positive experience and helped them to reflect on their caring role.

> Yeah, that was good. When you actually get to talk to the person who is meant to be doing – whether it's the coaching, or the Carers Star^{TM} – they're really good. They're really good at their job, they're really friendly, understand a lot about what a caring role is. There's no

---

[9] Note that the Carers Star^{TM} is not required to be conducted for emergency respite services and that this may reflect lack of contact rather than lack of assessment.

> fault with them in terms of that, I found that process actually was really good and really beneficial. (Carer 4 regional)

However, for other carers their experience of the assessment process was impacted by the complexity of their needs and their caring situation. Among carers who contacted Carer Gateway during a crisis, the time between the assessment and provision of support was too long, although staff were considered helpful.

> So, and if I had have called when I wasn't in crisis, [laughs] that would've been a different thing. But I guess, yeah, that – but I think in a lot of those situations if you've not used a service before, and you're not sure if you're eligible for it or not, then you don't reach out for those things unless you feel like you absolutely have to. (Carer 10 metro)

A few carers commented on the need to repeatedly answer the same questions from different service providers and questioned whether services and the service system had mechanisms in place to reduce duplication in assessment processes.

6.5 Summary

Overall, there were mixed views about the appropriateness and utility of the Carers Star^{TM}. The assessment process is generally viewed by both stakeholders and carers as a useful way for carers to discuss their situation in detail with services, and to provide a consistent way to assess progress and outcomes. However, Carers Star^{TM} was reportedly not appropriate for some Aboriginal and Torres Strait Islander carers or young carers and was not suitable to conduct over the phone for either group. Some service providers have adapted the assessment process to meet the needs of these carers or developed tools to support the assessment which have been shared nationally. Consideration should be given to develop a more consistent approach to using the Carers Star^{TM} with these groups of carers, recognising the diversity within each group. There appears to be inconsistency across providers in how the Carers Star^{TM} is used in crisis situations, and more clarity around good practice in this area would be helpful for service providers. The DEX entry for the Carers Star^{TM} is a summary of the seven domains of the assessment, and a report by Carers NSW and service providers indicated that more granularity in DEX would reveal important differences in carers' trajectories in different aspects of their caring role.

7 Question 1c: Early intervention and high levels of need

Evaluation Question 1c: How appropriate is the program for carers as an early intervention service, and for carers who are in high levels of need?

7.1 Emergency respite use

The shift to focus on preventative services aims to encourage carers to access support before reaching crisis or emergency situations. Emergency respite sessions, as a proportion of all reported sessions, reduced from 22% in the 6-months from July–December 2020, to 18.5% from January–June 2022 (Accenture 2022a:20), and to 9.4 % from July–December 2022 (Accenture 2022b:19).

7.2 Carers of people with high needs for assistance

Based on an analysis of the Carers Star^{TM} data in the DEX, relatively few carers who engage with Carer Gateway are assessed as having high needs. Overall, less than 10% of carers are assessed as having higher needs (score 1 or 2) on initial assessment (0.9% of carers received a score of 1, with 7.2% receiving a score of 2), with an additional 42.1% of carers assessed at level 3 (DSS supplied analysis of DEX data).

Data on service use, satisfaction and outcomes for carers who reported that they support people with high needs for assistance (and therefore may have high needs themselves) is collected in the CWS surveys (2022 and 2023). The CWS 2022 data indicate carers of people with high needs for assistance were: more likely to use Carer Gateway services (Schirmer and Mylek 2022:23) and less likely to be satisfied with the types of services available (Schirmer and Mylek 2022:26). Further, carers of three or more people were less likely to be satisfied with Carer Gateway overall (Schirmer and Mylek 2022:21), and with the website and information, the phone service, needs assessment, types of services, friendliness and helpfulness of Carer Gateway staff, and the usefulness of services (Schirmer and Mylek 2022:24–5). In 2023, CWS data indicate carers with high assistance needs were less satisfied with the usefulness of services, while carers caring for two or more people were less satisfied with the needs assessment process, as well as the usefulness of services (Mylek and Shirmer 2023a:32). Carers who provided care for more than 40 hours a week also reported being less satisfied with the website overall and the information available on the website (Mylek and Shirmer 2023a:32).

7.3 Stakeholder perspectives

Most stakeholders talked about the ability of emergency respite providers to support carers to avoid a crisis. Several examples were provided, including people who cared for family or friends with mental health issues, as well as carers of children with disability, or those experiencing domestic violence or housing issues. Many stakeholders also talked about carers being impacted by recent floods and bushfires, and the extraordinary ways that providers supported carers during these crises. In these circumstances, service providers talked about needing to find flexible ways to use Carer Gateway to organise immediate support by providing respite for the carer or referring them to local services (Service provider 1).

> We call them out of scope requests. I drive DSS to distraction. I do them constantly because that's where the Gateway in a short-term capacity can actually be really, really helpful in our emergency respite program […] After two weeks that carer actually got to a point where she said I don't need another couple of weeks. I'm well enough now. My daughter can come home. I've connected with the planning team. I've had a really good Carers Star^{TM} conversation. I now have support who is going to help me advocate on behalf of my daughter. That is when your systems work together and fill a gap and it's beautiful, but too much of that is happening where that carer will come back to us because we know that that [the NDIS] review will not happen in time. The piece I guess I want to draw out of that is how do we work together a little bit more to push [NDIS] reviews through or to be involved in what we're seeing from a carer perspective, or the NDIS think about their funding a little bit differently. (Service provider 6)

> And that’s when we get most of our calls. I would love to see us get better at preventing crises but unfortunately, carers don’t necessarily reach out to us until they’re in that crisis mode. (Service provider 4)

Overall, Carer Gateway was considered appropriate for carers with high needs who were requesting emergency respite. However, as noted elsewhere, there were gaps in service provision – particularly in regional and remote areas where there are sometimes long waiting times to access support, even when carers were experiencing a crisis. The interaction with the NDIS – discussed in Section 8 – is another challenge for some carers with high needs.

7.4 Summary

The program data (DEX) indicate that less than 10% of carers accessing Carer Gateway are assessed as having higher needs (score of 1 or 2) on the Carers Star^{TM}. The CWS data indicated that carers who report that they are providing support for people with high needs were less satisfied than other carers with a number of aspects of Carer Gateway. With regards to high needs carers, stakeholders were concerned that Carer Gateway packages were less flexible than previous offerings and that interventions are intended as short-term, disadvantaging high needs carers and those who would benefit from ongoing support. Emergency respite sessions as a proportion of all Carer Gateway sessions has declined between 2020 and 2022. This outcome may be a combination of carers accessing preventive services, and the lack of respite services available, especially in rural and remote areas. Among stakeholders, there was consensus that the shift to early intervention is a positive development, but also that this shift is a longer-term process; many carers still focus on respite and other emergency services during times of crisis. Increasing awareness of Carer Gateway and the relatively good outcomes for counselling suggest there may be a shift towards more uptake of early intervention services. Access to Respite and Emergency Respite is limited in some areas due to workforce shortages and thin markets.

8 Question 2: Interaction with the NDIS and other policies

Evaluation Question 2: How has the program interacted with the NDIS and other policies supporting carers and those being cared for?

8.1 Eligibility, referrals and access

Data on the interaction of Carer Gateway and the NDIS and other programs is reported in the CWS reports. Key findings from the available CWS reports are:

- A small proportion of carers, among those who have not accessed Carer Gateway, think they are not eligible for Carer Gateway, with one of the reasons being that the person they care for receives services through either the NDIS or other sources (Centre for Change Governance and NATSEM 2021:5; Schirmer and Mylek 2022:12)
- In the 2021 CWS, 30.9% of carers heard about Carer Gateway from other carer organisations or service providers. In 2022, 25.9% of carers heard about Carer Gateway through carer organisations and 11.2% heard about Carer Gateway from service providers, such as organisations providing respite services or other support services (Schirmer and Mylek 2022: Figure 4), while in 2023 the respective figures were 16.5% for carer organisations and 10% for service providers (Mylek and Schirmer 2023a:17, Figure 4).
- In the 2022 CWS, 57.7% of carers reported a decline ‘in ability to navigate systems such as the NDIS’ over the last 12 months, while 29% reported an improvement (Schirmer et al. 2022: Figure E4). The CWS also find that carers report poor access to services for the person being cared for; over half of carers completing the CWS in 2022 and 2023 had difficulties in accessing respite, mental health support services, and transport services (Schirmer et al. 2022: Table 3; Mylek and Schirmer 2023b: 49, Table 6).

The challenges and issues in accessing services for the person being cared for may impact on carers’ needs for support from Carer Gateway. This may affect some groups of carers more than others.

8.2 Stakeholder perspectives

Interaction with the NDIS

Stakeholders discussed the complexity of the service system for carers, including its relation to the NDIS, My Aged Care, and other state funded services. Overwhelmingly, stakeholders described poor interactions between Carer Gateway and the NDIS and in some areas there was a lack of clarity relating to how the different policies interacted.

> I think the key one that stands out to me initially is the broader ecosystem of supports, the interaction of Carer Gateway with the NDIS, with My Aged Care, with those services systems. I think there’s still a lot of misunderstanding about the responsibilities of each,

> what each can provide, the role of Carer Gateway within that context. We’re seeing Carer Gateway becoming a sort of stop gap for a lack of services or delays in NDIS and My Aged Care services. I think that’s definitely a challenge to implementation of the program for its intended purpose because there are contributing factors that are outside of the control of our area that are putting pressures on the delivery where a lot of it, again, is going towards that crisis service and COVID-19. (Other stakeholder 8)

Providers described carers contacting Carer Gateway in a crisis because they had been waiting for or had been denied NDIS plans for the person they provided care for, or those plans had changed.

> What I do see is the contact from the NDIS is sending them through their families that are obviously at screaming point and in crisis. Carer Gateway was never set up to be a crisis intervention service. So by the time families are reaching those, they're at real breaking point. (Service provider 15)

> I think there's only a few cases where we've actually put in the respite with an NDIS participant and that's due to risk and harm. Other than that, we try and work alongside them and work out a long-term goal with them. (Service provider 11)

A reduction in NDIS packages was identified as a particular challenge for carers where the care recipient is under 18 years old (Service provider 9). Reductions in other services placed more stress on the carer and potentially increased their need for services from Carer Gateway. Other examples included implications for resources and reporting for CGSPs:

> There’s been so many gaps with people in [the] NDIS that we’ve had so many calls from really desperate people in really desperate situations that aren’t quite eligible for Carer Gateway. But how do you – you have to at least point them into the right direction or link them up with someone else if we can’t help them. That takes a lot of time. We’ve got targets[10] for our intake workers or assessment and planning officers, and they might spend two or three hours dealing with someone and trying to put them in touch with the right support. But that doesn’t actually translate into any outputs because you can’t report on it. They don’t get registered as a Carer Gateway client. (Service provider 10)

One stakeholder explained that the tailored support packages, in relation to support for carers, are inequitable when care recipients have an NDIS package, compared with an Aged Care package:

> I also think that people who are caring for someone who is supported in the NDIS are sort of disadvantaged in the gateway in a way, particularly if the NDIS hasn’t planned well for respite within the NDIS service system. So obviously it's not called respite in NDIS, it's short-term accommodation. But if the planner believes that the carer can access respite through Carer Gateway, they can absolutely. But what can be funded [as respite support for a carer] in that $3,000 through the NDIS service system is very limited. It would last about four days of respite a year. Whereas somebody who is caring for someone in the aged care system where respite is subsidised, that same amount of funding would equate to about six weeks of respite a year. So, there's an inequitable amount of access to respite for those different carer cohorts. (Service provider 8)

---

[10] Note these targets are set by the service provider and not by Carer Gateway.

Interaction with My Aged Care

Views on the interaction between Carer Gateway and My Aged Care were more mixed. Several stakeholders identified effective referral pathways between local My Aged Care planners and CGSPs. However, some stakeholders indicated that delays with carers' My Aged Care assessment with the Aged Care Assessment Team led to carers approaching Carer Gateway when in crisis. However, overall, more stakeholders indicated that the interaction and communication between Carer Gateway and My Aged Care was improving, and, in some regions, there were well-established local referral pathways and processes from My Aged Care to Carer Gateway. Some solutions to improving the interaction included more awareness and education among staff at both My Aged Care and Carer Gateway about the scope of each scheme.

> So, I think the boundaries around what is accessible between services is actually very hard to navigate and so what we tend to do is recommend it might be really good to reach out and link in with them and see what they can provide. (Service provider 13)

Additionally, there were challenges with the interaction between Carer Gateway, the NDIS, and My Aged Care due to workforce shortages.

Interaction with other policy areas for different groups

As with other parts of Carer Gateway, the service system is working better for cohorts in some policy areas than others. Mental health carers were one cohort identified as having insufficient services available, while also often having difficulty accessing NDIS packages.

> The Gateway can only do so much, if there are no services there as well. So, it's great that the government is funding this Gateway, but where are the actual on the ground services for mental health carers? (Other stakeholder 3).

8.3 Aboriginal and Torres Strait Islander carer perspectives

Some Aboriginal and Torres Strait Islander carers were uncertain about which services were provided by the NDIS and which were provided by Carer Gateway (Carer 42 regional, Carer 43 regional, Carer 48 regional). This makes it difficult to determine whether Carer Gateway services are accessible or effective. This confusion suggests a lack of awareness about Carer Gateway which may prevent it reaching more carers and achieving the intended outcomes of the program. One carer understood the difference and explained that during their initial assessment phone call with Carer Gateway they were requesting more information about the NDIS – questions which the staff member could not fully answer (Carer 45 regional).

8.4 Non-Indigenous carer perspectives

Non-Indigenous carers provided limited information about the interaction between Carer Gateway and the NDIS. Their responses suggest the interaction between programs does not often operate smoothly. There appears to be some conflicting information about carers who are caring for someone receiving support through the NDIS. One carer said:

> So when I rang back and she said, ‘oh, who told you that we wouldn’t do that?’ [provide support] I said, ‘oh I don’t recall’. Then she sort of went on to ask me more questions. She said, ‘oh, well he’s on an NDIS [plan] now’, which we got through – help through other people, ‘so I can’t help you anymore’. [Laughs] I’m like, ‘I’m a bit confused. I’m not getting help for him, I’m getting help for me’. (Carer 06 metro)

Another example of the problematic interactions between Carer Gateway and other policies and programs is provided in the quote below. The carer had to push to get support though Carer Gateway because her parent received an Aged Care package. She explained:

> So as a carer, well someone gets an Aged Care package that alleviates your responsibilities as a carer. [However] I spend 40% of my time advocating with the provider to try and get my mother services. How is that improved? So, and in the end with the commode, the only reason I got it through is because I said to them, here's the thing, at night, when my mother has to go to the toilet, she has to walk from [one] end of her house to the other. She has to walk down two bluestone steps and across a floor that's sunken into the ground, which is a greater risk to her. So you really have to push that safety aspect to get anything through, but it's exhausting. (Carer 04 metro)

In another example, a wife caring for her husband commented on the interactions with Veterans supports:

> I was given the person’s name and the address, which I sent it all off to. Months went by, never heard a thing. So, on the phone again trying to follow it up. ‘Oh no, we don’t know where it is’. ‘Oh yes, we’ve found it’. ‘Oh no, it’s going to take a while. It’s got to go to Centrelink’. In the course of all this – following that up – was when I got this woman – or several women in different places. One in Coffs Harbour. I told her the story. I said, ‘I keep coming up against brick walls’, and she said, ‘I promise I will follow this up and I will call you back’. Well, I never heard from her. This went on and on until, finally, I got that woman from DVA to say, he didn’t have qualifying service. (Carer 09 regional)

8.5 Summary

The carer support service system is complex and difficult to negotiate, with varying eligibility criteria for different schemes (including disability, aged-care, veterans supports and carers). Some CGSPs have addressed this issue through co-location with NDIS and/or My Aged Care services, or by providing services for multiple programs. However, it appears the coordination between Carer Gateway and the NDIS is not working well for carers overall. Some carers were reportedly accessing Carer Gateway because of delays or problems accessing the NDIS; there appear to be gaps and overlaps between these programs, and different funding rules, which carers find challenging to navigate. This is also reflected by stakeholders at the policy level, where there was reportedly limited engagement with the NDIA. The interaction with My Aged Care at both a service and policy level was reported to be much better; this could provide a template for the interface with other schemes affecting carers. However, it should be noted that workforce issues are challenging for the whole social care sector, and a whole of government approach is required to address this challenge especially in regional and remote areas (National Skills Commission, 2021).

9 Question 3: Governance and funding processes

Evaluation Question 3: How effectively have governance and funding processes contributed to the achievement of program aims?

9.1 Stakeholder perspectives

Most stakeholders, both internal and external to DSS, spoke positively of the Carer Gateway governance structure and funding processes. Providers had very positive and constructive relationships with DSS. They found DSS were approachable and responsive to feedback, and willing to be flexible and adapt to providers' and carers' needs. Providers spoke highly of the governance meetings and Communities of Practice initiated by DSS.

Stakeholders attributed these strong relationships with DSS – including good communication, regular meetings, and responsiveness to feedback – as key reasons the implementation of Carer Gateway had been effective. Providers all talked about the benefits of the Communities of Practice at different levels of DSS and organisations, from operational levels to management.

However, while recognising staff turnover is to be expected, some stakeholders commented that communications and meetings had become less regular following staff changes within the DSS Carer Gateway team. There was also some critique of high-level governance arrangements, particularly the lack of integration between Carer Gateway and the NDIS, which impacted on the effectiveness of service delivery. Additionally, some stakeholders who were not CGSPs indicated they would value more opportunities to engage and communicate with the Carer Gateway team within the Department (Other stakeholder 4).

Most consortia members and providers talked positively about their own relationships, and explained how they managed the allocation of carers and service delivery across partners. Most lead providers and consortia partners indicated the model worked well, each having different approaches and processes to service delivery and interaction with carers. Lead providers and consortia members experienced a couple of initial glitches in referral systems and processes; however, these were technical issues that were managed internally. Some stakeholders felt the high number of providers in NSW created confusion in this and other service systems, and among carers seeking support (Service provider 3).

Some consortia members would like opportunities for direct communication with DSS, but recognised this was not always possible. One consortium partner found the bureaucracy involved with receiving funds from the lead partner somewhat cumbersome and impeded achieving outcomes for carers (Service provider 16).

Overall, providers felt the funding amounts and processes worked well. A few providers had concerns about funding flexibility, indicating that some of the discretions allowed during the COVID-19 pandemic to providers to meet carers' needs (such as increasing package size, or being flexible with how the package is used) should remain in place, rather than return to the pre-pandemic guidelines.

Several stakeholders commented on the benefits of the Carers Star^{TM} for program governance, and the use of Carers Star^{TM} and other data for providing accurate and timely information about implementation and carer outcomes. However, they also identified a need for more thorough and consistent data reporting and evaluation (of which it is expected this evaluation goes some way to address). Some stakeholders identified a lack of resources for data collection and monitoring (i.e. limited administrative overheads) as a possible barrier to more effective governance and improvement of the program. For example, one stakeholder explained:

> So, I think internal resourcing has been challenging over the last couple of years and remains challenging. If you had greater internal resourcing, I think we could be doing more – a lot better use of data, more rapid adjustments to meet the needs to respond to the early feed program design. Which I'm not saying that's an extreme risk or an extreme barrier but one that I think where we would if – it would be an opportunity if – relative to the size of the program, it's quite a large investment, I think we could have more substantial resourcing into it. (Other stakeholder 12)

An issue raised by several stakeholders was the program underspend, which was attributed to COVID-19 and that the National Communications campaign for Carer Gateway had been delayed. Most providers were frustrated that it took so long for DSS to launch the campaign and that, when they did, providers were given very little notice. Most providers indicated they found out about the launch only a few days prior to the campaign starting.

9.2 Summary

Governance arrangements were considered to be effective by most stakeholders. Carer Gateway is in some ways a pioneering Commonwealth program because of its routine focus on outcomes, assessments, and the use of data dashboards to develop and manage the program. In addition, stakeholders valued the close relationships and generally good communication between DSS and service providers, and this has supported program development and implementation. Nevertheless, there were some suggestions for how to improve governance including better resourcing to collect, use and report data, and more flexibility in the use of resources.

10 Question 4: Implementation of prior recommendations

Evaluation Question 4: How effectively have the recommendations from previous evaluations been implemented?

The *Process Evaluation of Integrated Carer Support Service (Carer Gateway): Final Report (Urbis 2021b)* made several recommendations. This section considers each recommendation in turn and whether it has been addressed.

10.1 Raise awareness of the model

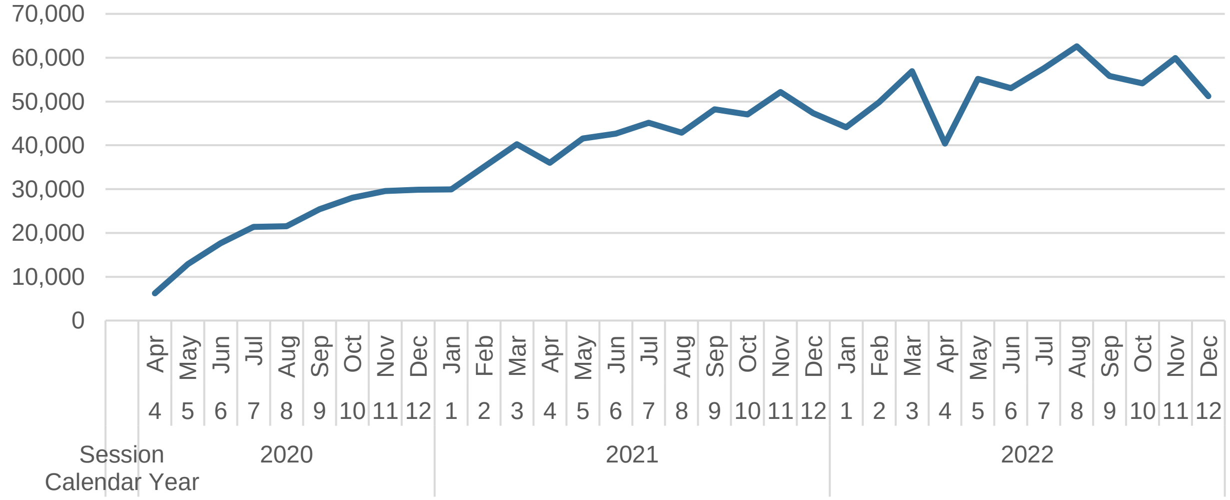
One recommendation was to increase awareness and understand about the model across the sector, service providers, and carers. Enacting this recommendation, the Carer Gateway communications campaign was launched in October 2022 and stakeholders indicated this raised awareness of Carer Gateway. One stakeholder noted that:

> [We] look at the reach, response and impact, have we reached the people that we think we need to reach and our recent tracking shows that that yes we are reaching those people, they're responding well to the campaign, they're recalling the key messages in the campaign. (Other stakeholder 14)

Feedback showed the communications campaign was informative, engaging, easy to understand, and helped carers to find out more about Carers Gateway. This was reflected in increased visits to the website since the launch of the campaign (Other stakeholder 14).

Indeed, the use of Carer Gateway has increased continuously since its launch in April 2020. As shown in Figure 4, the number of sessions increased from 12,867 in May 2020, to a peak of 62,596 in August 2022, and was over 50,000 per month for the second half of 2022.

Figure 4 Session numbers by year



Source: Authors analysis of DEX data April 2020-December 2022. Note: Count of sessions. Excluding group and support clients and clients with 100+ sessions

10.2 Improve capability to collect and use Carers Star^{TM} data

To improve the capability of frontline staff to collect and use Carers Star^{TM} data, DSS commissioned *Unique Outcomes* to provide additional in-person training to CGSPs from September 2021, and develop a Better Practice Guide in conjunction with CGSPs. As indicated below, this has resulted in improvements in data collection. Stakeholders also indicated that that the 6-monthly reports based on DEX data had also been helpful in improving program implementation.

10.3 Increase monitoring Carers Star^{TM} completion rates

In terms of monitoring completion of Carers Star^{TM}, the *Process Evaluation* (Urbis 2021b) reported a third of carers accessing Carer Gateway completed at least 2 rounds of Carers Star^{TM}. In 2021, DSS started to benchmark providers initial and full assessment rates. As of December 2022, the proportion of carers completing Carers Star^{TM} before receiving a preventative service reached 93%. Rates of fully assessed carers is yet to reach the target of 50%. As indicated in Section 6 (Evaluation Question 1b), some service providers are hesitant about the appropriateness of Carers Star^{TM} for some groups of carers, and different practices have evolved to adapt it to different contexts. This may be a factor limiting the increasing use of the assessment tool.

10.4 Continue COVID-19 ‘fast-track’ intake for carers with extreme need

Carers in emergency situations are not required to complete the Carers Star^{TM}; although, as discussed above, practice is not consistent in this area. Findings indicate some but not all carers are able to access respite care and other high-cost services quickly, and many carers continue to face delays and service gaps.

10.5 Integrate online, telephone, and face-to-face components

DSS commissioned and finalised user research and website development, along with content updates to the Carer Gateway website over 2021 and 2022. The Carer Gateway website update is scheduled to be delivered in 2024 and it is expected that this will integrated the online component with the telephone and face to face components of Carer Gateway.

10.6 Review respite processes in greater detail

Respite care continues to be outsourced and there continue to be significant challenges in the carer workforce. Services for carers, including respite, are not uniformly available – especially in regional and remote areas. DSS has been reviewing the situation and should continue to monitor this and take action where necessary; however, it appears this is a bigger issue than outsourcing of respite care and is a factor of the broader challenges faced by the care workforce and the carer services markets. As indicated by analysis of DEX data and the CWS, the number of carers accessing respite has declined in recent months (between July and December 2022); however, it is not clear to what extent this is related to the availability of respite care or whether, as proposed by the Carer Gateway program logic, this is due to counselling and other preventive services reducing the need for respite.

10.7 Re-incorporate social connection for carers

DSS commissioned and finalised a review of the in-person peer support operating model in 2021 to 2022 and have adjusted the operating model according to the recommendations of the review.

Summary

DSS has responded to, or is in the process of responding to, all the recommendations of the previous evaluations. The effectiveness of some of these responses – for example, the integration of online, telephone and face-to-face components – will need to be assessed in the future. This evaluation has shown that awareness of Carer Gateway has improved, and that completion of the Carers Star^{TM} has also risen and continues to rise. The communications campaign which was launched in October 2022 has successfully increased awareness of Carer Gateway. Some recommendations, such as those relating to respite care, can only partly be addressed by Carer Gateway and progress has also been made in that respite is becoming a smaller proportion of all services. However, there continue to be broader systemic challenges for some carers to access respite.

10.8 Summary – Appropriateness

Findings indicate that the Carer Gateway model has been successfully implemented. The design, governance and range of services are considered appropriate, and governance was perceived to be particularly effective.

Carer Gateway was designed to streamline services to carers and provide greater access to preventive services, such as counselling and peer support, so that carers could avoid having to access crisis services. Overall, the findings show the range of services provided by Carer Gateway is appropriate for carers. Evidence from surveys, interviews with carers, and interviews with stakeholders all indicate carers value the focus on prevention and the range of services provided by Carer Gateway and the majority are satisfied with their engagement with Carer Gateway and the services they receive. Awareness of Carer Gateway is also increasing, while use of emergency respite is falling as a proportion of services offered by Carer Gateway.

However, satisfaction with services does not appear to be increasing over time, and there are some indications that it is in fact decreasing. Further, there is strong evidence service quality and availability is not consistent; some carers report lack of access to desired services, and some were dissatisfied with their interaction with Carer Gateway. In terms of the priority groups, young carers, Aboriginal and Torres Strait Islander carers, CALD carers (particularly those with low proficiency in English), and mental health carers were identified as the groups for whom Carer Gateway was least appropriate, both in terms of service provision and in relation to their engagement and assessment using the Carers Star^{TM}. Young carers reportedly find the telephone interface with Carer Gateway challenging, and some of the Carers Star^{TM} domains are not relevant to their circumstances. Some Aboriginal and Torres Strait Islander carers reported that Carer Gateway services were not culturally appropriate for them, and stakeholders confirmed that some services such as respite and peer support need to be specifically tailored to meet the needs of Aboriginal and Torres Strait Islander carers, particularly those in regional and remote areas. With regards to CALD carers, Carer Gateway was reported to be appropriate for those who had good proficiency in English. CALD carers who were not proficient in English struggled with the engagement and assessment processes. Carer Gateway services were also considered less appropriate for mental health carers, who require intermittent but long-term support due to the episodic nature of many mental illnesses.

Overall carers were satisfied with the services they received, and Carer Gateway was successful in providing services that met the particular needs of each participant. Tailored support packages, respite and counselling appeared to be the most valued services. There were some concerns expressed by stakeholders and carers about the flexibility of some services and that some carers required ongoing support rather than time-limited interventions. As indicated above, there was a strong finding that service availability and quality is not consistent across the country.

A consistent finding across different data sources related to the interface between Carer Gateway and the NDIS. Carers, in particular Aboriginal and Torres Strait Islander carers, found the task of negotiating these different schemes very challenging. Stakeholders also reported challenges for service providers and carers in negotiating this interface, given the different policy and funding settings of the two schemes. On the other hand, Carer Gateway was reported to work well with My Aged Care.

Overall, the two challenges which were identified across the different data sources were the inconsistent quality of services, mainly due to workforce issues and the difficult interface with the NDIS. However, the strongest finding was that, overall, the design of Carer Gateway is appropriate, and the shift to preventive services is welcomed by carers using them.

Part B: Effectiveness

Part B provides findings relating to the effectiveness of the program – specifically, program reach and the outcomes for carers who access Carer Gateway. This is informed by:

Survey data (SRC population and emergency respite surveys, and the CWS)

Interview data (carer and stakeholder interviews), and

DEX data from 6-monthly reports.

The effectiveness questions report on access to services, which services are most effective and for which groups of carers and whether Carer Gateway has achieved its intended outcomes; to ‘improve carer wellbeing, increase their capacity, and support their participation, socially and economically, reinforce carer resilience and restructure investment in carer support to increase cost effectiveness. Only a small minority of carers access Carer Gateway, so any population-level changes in wellbeing, participation and resilience in the carer population cannot be attributed to Carer Gateway.

11 Question 5: Program reach

Evaluation Question 5: To what extent has the program successfully reached Australian carers, including carers from the following demographic groups (where applicable):

(i) Aboriginal and Torres Strait Islander carers
(ii) female carers
(iii) carers with disability
(iv) regional or remote carers
(v) young carers (aged less than 25 years)
(vi) older carers
(vii) carers of older persons
(viii) culturally and linguistically diverse carers
(ix) mental health carers.

11.1 Program reach

Program reach is assessed using DEX Carer Gateway client data, the linked DEX-DOMINO dataset, and ABS national surveys. The data sources have different definitions of carers and different methods of data collection which have implications for the analysis and findings. Carer Gateway supports all carers who meet the definition of a carer under the *Carer Recognition Act 2010 (Cth).* In the DEX client data, carer characteristics, such as disability status, are disclosed by carers (or not) to service providers who then record this information in DEX. SDAC identifies carers and primary carers and their characteristics through household and personal interviews which are then recorded in the dataset. Finally, the *Census* data is directly self-reported data and requires individuals to self-identify as a carer (and any other demographic characteristics).

The estimate of total number of carers in Australia varies in the different data sources. The 2018 SDAC estimated the carer population in Australia to be around 2.65 million (all ages), while the 2021 Census estimated the carer population to be 2.47 million (carers over the age of 15). DEX data indicates 140,172[11] carers accessed Carer Gateway local service providers and digital counselling between April 2020 and December 2022. Based on the above SDAC 2018 estimate, this is approximately 5.3% of Australia's carers (by June 2023, 6% of Australia's carers had accessed Carer Gateway (DSS supplied information)).

Table 5 compares the profile of carers who access Carer Gateway (as recorded in DEX) with the broader Australian population of carers. The table shows the proportion of carers in different categories in the general population as indicated by SDAC for carers and primary carers, and as indicated in the Census 2021 for Aboriginal and Torres Strait Islander carers and CALD carers.

---

[11] This total includes digital counselling and CGSP clients, and some known and possible double counting of clients. To December 2022, 2,113 clients had used both digital counselling and Carer Gateway services. Other clients may be counted twice if they change service providers; for example, when moving between states.

Table 5 Carer Gateway clients compared to potential carer population

	Population estimates			Number of Carer Gateway clients	% of Carer Gateway clients	% of carers in population	
	SDAC 2018 Primary carers	SDAC 2018 All carers	Census 2021 All carers	DEX 2020–2022	DEX	SDAC/ CENSUS All carers	SDAC Primary carers
All carers	861,600	2,645,600	2,476,681	140,172			
Aboriginal and Torres Strait Islander carers			76,568	5,576	4.0	3.1	
Female carers	618,800	1,513,000		104,812	74.8	57.2	71.8
Male carers	241,900	1,128,600		31,354	22.4	42.7	28.1
Carers with a disability	322,600	849,800		21,748	15.5	32.1	37.4
Location							
Major Cities	590,900	1,821,800		87,945	62.7	68.9	68.6
Inner regional	192,200	578,400		35,497	25.3	21.9	22.3
Outer regional & remote	80,500	243,500		16,730	11.9	9.2	9.3
Age							
Young carers (aged 15–24 years)	18,600	187,800		7783	5.6	7.1	2.2
Older carers (aged 65 years and over)	22,800	647,200		48,971	34.9	24.5	26.6
CALD carers*			*	7,901	5.6	15.0*	

Source: SDAC 2018: ABS (2019) 44300DO030_2018 Disability, Ageing and Carers, Australia: Summary of Findings, 2018; ABS 2022: Census 2021: https://www.abs.gov.au/census/find-census-data/quickstats/2021/AUS; https://www.abs.gov.au/census/find-census-data/quickstats/2021/IQSAUS. *CALD carers defined as speaking a language other than English at home and being born overseas in a non-English speaking country as proportion of the 2021 Census data noted in Accenture (2022a) Carer Gateway Half Yearly Performance Monitoring Report Jan 2022 – June 2022:27. Carer Gateway DEX: SPRC analysis: Individual clients, characteristics recorded at first session.

The demographic composition of Carer Gateway clients (DEX data) was compared with data on primary carers and all carers. SDAC defines ‘primary carers’ as those who provide the ‘most informal assistance to a person with disability for the core activities of mobility, self-care and communication’, while ‘carers’ include primary carers and other carers and are defined as those who provide ‘any informal assistance’.[12]

The data indicate carers accessing Carer Gateway are broadly representative of the overall population of carers and have a similar demographic composition to primary carers. However, there are some differences. Compared with the overall population of carers, some carers are under/overrepresented in the group accessing Carer Gateway:

---

[12] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers

- Carers with disability are ***under***represented (15.5% vs 37.4% of primary carers and 32.1% of all carers). Some of this difference may be due to differences in data collection between SDAC and DEX.
- Carers from a culturally and linguistically diverse (CALD) background also appear to be underrepresented (5.6% are recorded in DEX compared with 15% of all carers identified as CALD in the Census 2021). The DEX and Census 21 definition is based on the carer speaking a language other than English at home and being born in a non-English speaking country (Accenture 2022a:27). The DEX CALD definition may differ from the Census as it identifies the main language spoken at home rather than the main non-English language spoken at home. Eleven per cent of carers connected with Carer Gateway identify as speaking a language other than English at home as their main language; in the 2021 Census, 21.4% of carers reported speaking a language other than English at home (Accenture 2022a: 27).[13]
- Male carers are slightly ***under***represented compared to the primary carer population (22.4% vs 28.1% primary carers) and more so if compared to all carers (22.4% vs 42.7%).
- Young carers are slightly ***under***represented when considering all carers (5.6% vs 7.1% in SDAC).
- Older carers are ***over***represented (34.9% vs 26.6% primary carers).

Overall, Table 5 indicates Carer Gateway has been successful in reaching carers from most demographic cohorts. However, more resources could focus on engaging with carers from culturally and linguistically diverse communities.

11.2 Program reach: Carer Allowance recipients

Using DEX-DOMINO data, Table 6 shows the percentage of Carer Allowance recipients who accessed DSS carer support services and the number of Carer Allowance recipients in different demographic groups of carers from 2015–2022. The data show:

- The percentage of Carer Allowance recipients receiving support services increased from 3.0% in 2015 to 4.9% in 2016 and has remained relatively stable since then and dropped in 2020 potentially due to the COVID-19 pandemic.
- In 2022, in terms of priority groups, there were higher rates of service receipt among Carer Allowance recipients who were: women (5.4% compared to 3.4% for men), older carers (5.9% for carer aged 65 years and over), non-Indigenous carers (4.9% compared with 4.4% of Aboriginal and Torres Strait Islander carers), and people born in English-speaking countries (6.4% compared with 5.3% for Australian born carers and 3.4% for carers born in non-English speaking countries).
- Regionally, there were higher rates of service use in the NT, Tas, SA; in more socio-economically advantaged regions (as measured by the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)), and in remote or very remote locations (analysis not shown below).

---

[13] SDAC does not report % for CALD or Aboriginal and Torres Strait Islander primary carers due to low numbers.

Table 6 Carer allowance recipients receiving client DSS carer support services, by year and characteristics (% receiving services and number of Carer Allowance recipients)

Period	Pre-Carer Gateway*						Carer Gateway	
	2015	2016	2017	2018	2019	2020	2021	2022
	% Receiving services							
Gender								
Female	3.3	5.6	5.5	4.9	4.1	3.2	4.1	5.4
Male	2.2	3.7	3.7	3.4	2.9	2.2	2.6	3.4
Age group								
Under 26 years	1.3	2.1	2.2	2.2	1.4	1.4	2.0	2.8
26-49 years	2.3	3.8	3.7	3.2	2.5	2.1	3.0	4.3
50-64 years	3.3	5.5	5.4	4.8	4.0	3.1	3.8	4.9
65 years and over	4.0	7.1	7.0	6.4	5.6	4.2	4.6	5.9
Indigenous status								
Non-Indigenous	3.0	5.1	5.0	4.5	3.8	3.0	3.7	4.9
Aboriginal and Torres Strait Islander	3.1	5.1	4.6	4.2	3.6	2.6	3.1	4.4
Country of Birth								
Australia	3.3	5.7	5.6	5.0	4.2	3.2	4.0	5.3
Main English speaking countries	3.7	6.2	6.3	5.6	4.9	3.8	4.7	6.4
Other Countries	1.8	3.0	2.9	2.7	2.3	1.9	2.5	3.4
All	**3.0**	**5.1**	**5.0**	**4.5**	**3.7**	**2.9**	**3.7**	**4.9**
	All Carer Allowance recipients ('000s)							
Gender								
Female	531.7	530.8	531.2	532.2	530.2	522.0	527.7	531.5
Male	190.9	192.1	191.5	190.8	189.5	185.6	185.8	185.6
Age								
Under 26 years	24.7	23.4	22.0	20.8	19.4	17.8	16.7	15.6
26-49 years	299.4	296.6	296.4	295.0	291.3	282.7	283.5	282.1
50-64 years	213.2	213.7	213.2	213.0	211.9	209.7	212.5	214.7
65 years and over	185.4	189.1	191.0	194.2	197.0	197.5	200.9	204.7
Indigenous status								
Non-Indigenous	691.1	691.1	690.6	690.5	686.5	674.8	680.2	682.9
Aboriginal and Torres Strait Islander	31.5	31.8	32.1	32.6	33.1	32.8	33.4	34.2
Country of Birth								
Australia	493.3	492.8	493.0	492.9	490.2	481.0	484.9	487.3
Main English speaking countries	57.2	56.8	56.1	55.5	54.1	52.4	52.4	52.0
Other Countries	172.1	173.3	173.6	174.7	175.4	174.1	176.3	177.8
All	**722.6**	**722.9**	**722.7**	**723.0**	**719.6**	**707.6**	**713.6**	**717.1**

Source: Authors' analysis of DEX-DOMINO integrated data set 2015–2022. *Pre-Carer Gateway DSS carer support services include 2015–2020: Commonwealth Respite and Carelink Centres, Consumer Directed Respite Care, Dementia Education and Training for Carers, and Mental Health Respite, National Carer Counselling program, Carer Information and Support Services, Counselling, Support, Information and Advocacy.

The groups with the biggest **increases** in service use between 2016 and 2022 were:

- young carers (0.7% increase), although this group of Carer Allowance recipients had the lowest rate of access in all years, and
- carers aged 26-49 (0.5% increase).

The groups that **decreased** their rates of service use most between 2016 and 2022 were:

- Aboriginal and Torres Strait Islander carers (0.7% decrease), and
- carers aged 50–64 (0.6% decrease).

The total number of Carer Allowance recipients has declined over this period, from 722,600 in 2015 to 717,100 in 2022. Part of this decrease may be due to the introduction of the $250,000 family income threshold eligibility criteria for Carer Allowance in September 2018. The number of carers who received Carer Allowance decreased for most demographic groups, except for older carers (aged 65 years and over), Aboriginal and Torres Strait Islander carers, and carers born in non-English speaking countries, which had small increases in numbers.

Overall, the proportion of carers in this cohort receiving support from DSS carer support services did not change substantially between 2016 and 2022, although it has grown each year since Carer Gateway was implemented in 2020.

11.3 Awareness and access of Carer Gateway

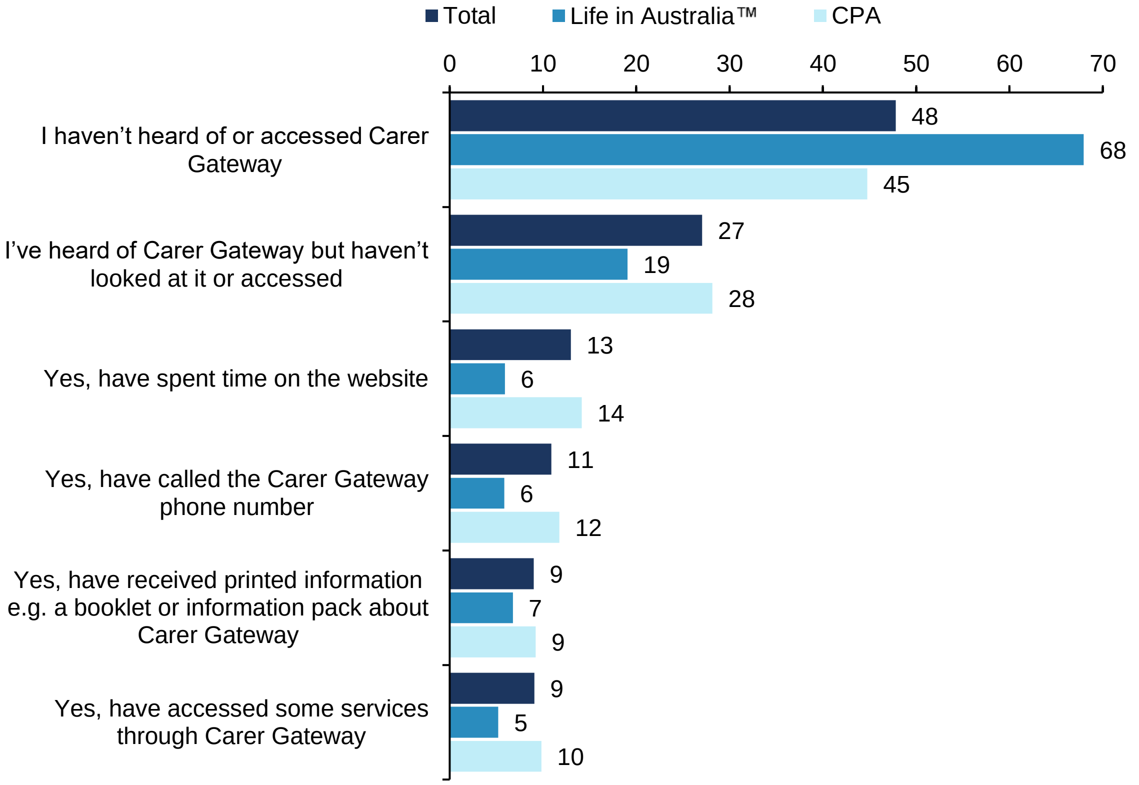
Data on awareness of carer services and Carer Gateway was analysed in the Life in Australia^{TM} Survey, the CPA Survey (2020 and 2022), and the CWS (2021–2023).

As outlined below, the majority of carers who completed the Life in Australia^{TM} and the CPA surveys in 2022 had either not heard of the Carer Gateway or had not accessed services. The questions asked in these surveys differ between 2020 and 2022; the responses at different time periods are therefore not comparable. In contrast, the majority of respondents to the CWS (2021–2023), some of whom were recruited through carer organisations and services, were aware of Carer Gateway.

General population

In 2022, among the Life in Australia^{TM} survey carer respondents, 68% indicated they had not heard of or accessed Carer Gateway while a further 27% had heard of it but not looked at the website or accessed services (Figure 5). Only 5% of carers had accessed services through Carer Gateway in 2022 (Figure 5).

Figure 5 Awareness and access of Carer Gateway 2022 (% all respondents)



Base: All respondents. Total n=3868, LinA n=553, CPA n=3315. Question not asked of ERC respondents.
Source: S14. Have you heard of or accessed Carer Gateway? Source: Brosnan et al. 2023 (Figure: 28).
Note: Don't know and Refused responses not shown on chart.

%

In 2020, Life in Australia^{TM} respondents were asked a different question about access to carer services, therefore the responses are not comparable with 2022 data. In 2020, 32% of Life in Australia^{TM} respondents reported they were not aware of the services including: Carer Gateway, Commonwealth Respite and Carelink Centres, Emergency Respite Support (after hours service), or My Aged Care services (Table 7). A further 41% had heard of the services but had not used them (Table 7). In 2020, carers were most likely to have accessed services through My Aged Care (21%) and Commonwealth Respite and Carelink Centres (7%) (Table 7).

Table 7 Awareness and access of Carer Services in 2020

Carer support service	Life in Australia^{TM} 2020	CPA 2020
Carer Gateway - carergateway.gov.au or 1800 422 737	<10	4%
Commonwealth Respite & Carelink Centres	7%	5%
Emergency Respite Support (after hours service)	<10	1%
Through My Aged Care	21%	13%
I am not aware of any of these services	32%	41%
Have heard of but haven't used any of the above	41%	39%
Prefer not to say	<10	<10
Not sure	<10	n.p.

Source: Brosnan et al. 2023: Table 11. Notes: n.p. indicates not published for confidentiality

Population of Carer Payment and/or Carer Allowance recipients

In the 2022 CPA survey, 45% of respondents were not aware of Carer Gateway, while 28% were aware of Carer Gateway but had not interacted with it (Figure 5). One in ten (10%) had accessed services through Carer Gateway (Figure 5).

In 2020, 41% of CPA respondents were not aware of any of the carer support services (Carer Gateway, Commonwealth Respite and Carelink Centres, Emergency Respite Support (after hours service), or My Aged Care services), while a further 39% were aware of but had not accessed any of those services (Table 7). Further, 13% of CPA respondents had accessed services through My Aged Care and 5% had accessed services through Commonwealth Respite and Carelink Centres (Table 7). In 2020, 4% of this group had accessed services through Carer Gateway (Table 7).

Carer Wellbeing Survey

As outlined in Appendix C, the CWS recruits some survey respondents through carer organisations and carer service providers; therefore, findings from these data are likely to overestimate awareness of Carer Gateway among the general population of carers in Australia. The analysis of the CWS reports on responses from new participants to the survey in each year. Key findings from CWS respondents are:

Awareness of Carer Gateway has increased since 2021; only 14.7% of respondents in 2023 and 16.3% in 2022 indicated they had not heard of or accessed Carer Gateway compared with 23.1% in 2021 (Schirmer and Mylek 2022:10; Mylek and Schirmer 2023a: 13-14).

Only 16.8% of respondents indicated they had heard of Carer Gateway, but had not looked at it or accessed services, similar to 2021 (15.7%) and 2022 (12.1%) (Mylek and Schirmer 2023a:15, Figure 2).

In 2023, 32.2% of respondents had accessed services through Carer Gateway, a slight increase since 2022 (27.1%) (Mylek and Schirmer 2023a:15, Figure 2).

Awareness of Carer Gateway has also increased for ‘early-stage carers’ (respondents who had become carers in the last 12 months); the proportion who had not heard of or accessed the carer gateway decreased from 28% in 2021, to 13.6% in 2022, and to 7.8% in 2023 (Mylek and Schirmer 2023a: 15).

Some groups of carers reported lower levels of awareness of Carer Gateway in some years. The 2022 CWS reported that 25.2% of young carers (aged 15–24 years) had not heard of or accessed Carer Gateway compared with 16.3% of carers overall (Schirmer and Mylek 2022: Appendix 2). However, in the 2023 CWS, young carer respondents had the highest level of awareness of the Carer Gateway (Mylek and Schirmer 2023a:14).

Demographic groups

Table 8 shows that among the combined population survey respondents (Life in Australia™ and CPA surveys) in 2022, carers who received Carer Payment or Carer Allowance were more likely to be aware of Carer Gateway than those who did not (55% compared to 25%). In 2022, 47% the combined population survey respondents who had not used services previously reported they were aware of Carer Gateway. There were some differences in awareness among subgroups. Of note:

Respondents from the combined surveys who spoke a language other than English at home (44%) reported a lower awareness of Carer Gateway than respondents whose main language was English (53%).

Male carers (41%) were less likely to be aware of Carer Gateway than female carers (56%).

Table 8 Awareness and access of Carer Gateway 2022 (% combined survey respondents by subgroups)

Awareness by subgroup	Total (%)
Carers who receive Carer Payment and/or Carer Allowance or not	
Receive Carer Payment and/or Carer Allowance	55
Do not receive Carer Payment and/or Carer Allowance	25
Carers who that have used Carer Gateway services	
Used services	100
Not used services	47
Gender	
Female	56
Male	41
Disability status	
Person with a disability	58
Person without a disability	46
Aboriginal and Torres Strait Islander status	
Aboriginal and Torres Strait Islander	47
Not Indigenous	52
Language other than English spoken at home	
English main language	53
Speaks language other than English	44

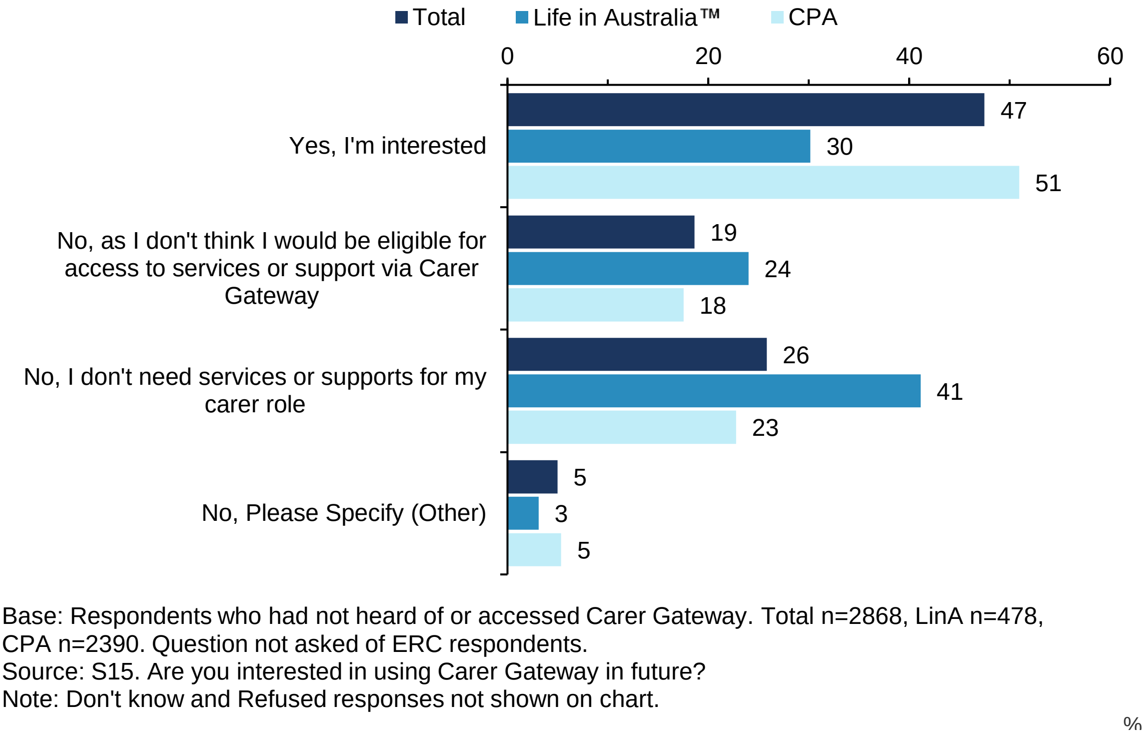
Source: Brosnan et al. 2023: Table 12

Base: All respondents. Total n=3868, Life in Australia™ n=553, CPA n=3315. Question not asked of ERC respondents. Source: S14. Have you heard of or accessed Carer Gateway? Note: Don't know and Refused responses not shown in table. Life in Australia™ and CPA not reported separately because of low numbers in each survey

Interest in using Carer Gateway

Across the combined population surveys in 2022, 47% of respondents who had not heard of or accessed Carer Gateway said they would be interested in using it in the future (Figure 6). Of these combined survey respondents, 26% said they did not need services or supports for their carer role, and 18% said they did not think they would be eligible to access services through Carer Gateway. CPA survey respondents more commonly reported they would be interested in services or supports (51%), while Life in Australia^{TM} survey respondents more commonly said they did not need services or supports (44%) (Figure 6).

Figure 6 Interest in Carer Gateway in future 2022 (% not heard of Carer Gateway)



Base: Respondents who had not heard of or accessed Carer Gateway. Total n=2868, LinA n=478, CPA n=2390. Question not asked of ERC respondents.
Source: S15. Are you interested in using Carer Gateway in future?
Note: Don't know and Refused responses not shown on chart.

Source Brosnan et al. 2023: Figure 29.

Base: Respondents who had not heard of or accessed Carer Gateway. Total n=2868, Life in Australia^{TM} =478, CPA n=2390. Question not asked of ERC respondents. Source: S15. Are you interested in using Carer Gateway in future? Note: Don't know and Refused responses not shown on chart.

Finding out about Carer Gateway

In 2022, the most common ways respondents from all the population and carer surveys (including the ERC survey) had heard of Carer Gateway were via a carer organisation or service provider (18%), an advertisement (14%), or a My Aged Care service provider (12%) (Brosnan et al. 2023, Figure 30). Respondents who had used a Carer Gateway service most commonly said they found out about the service via Carer Gateway itself. One-quarter (25%) of respondents who had used emergency respite services through Carer Gateway found out about the service from a My Aged Care service provider. Carer organisations or service providers were another common source of awareness about Carer Gateway services (Brosnan et al. 2023, Figure 30).

11.4 Accessing Carer Gateway website and online services

Website visits and phone calls

The program data shows that visits to Carer Gateway website pages have increased from around 850,000 views over the 6-month period July–December 2020 to over 3.1 million in the 6-month period July–December 2022 (Table 9). Between the same two periods, phone calls to Carer Gateway have also increased (Table 9).

Table 9 Carer Gateway: Website views and phone contacts

	July–December 2020	January–June 2021	July–December 2021	January–June 2022	July–December 2022
Carer Gateway website page views	853,195	972,977	1,208,499	2,025,456	3,166,648
Phone calls to Carer Gateway	85,624	112,427	112,783	123,892	119,788

Sources: Accenture 2020: 29; Accenture 2021a: 27; Accenture 2021b:31; Accenture 2022a: 24; Accenture 2022b: 25

The Process Evaluation Interim and Final reports (Urbis 2021a, 2021b) identified “low levels of engagement with the website”, noting there were relatively few returning users, few pages being visited each time, and short durations of visits to the website in the period July 2019 to June 2021 (Table 10). Subsequent periods have shown significant increases in the number of new users of the website (from an average of 41,463 per month in July 2019–June 2021 to 138,100 per month in the period July 2022–December 2022); further, 21% of users are returning users in that period. There has been a very small increase in the average number of pages visited per session (from 2 to 3 pages) over the same period. However, the average duration of each session has also decreased from between 1 to 1.5 minutes to less than one minute. As reported in the Process Evaluation (Urbis 2021a: 19), the short average time viewing the website may suggest carers do not find what they are looking for or that they find information quickly, such as contact details, and then exit. The Process Evaluation (Urbis 2021a, b) also found that carers with high needs reported the website did not meet their needs as they were looking for “immediate assistance” with regard to respite services or financial support (2021a:21).

A key indicator for Carer Gateway is the percentage of the carer population visiting the website. It is not possible to determine that every unique user who visits the website is a carer; however, the number of unique and new users who visit the website has increased over time (Table 10).

Table 10 Website analytics

	July 2019–June 2021[1]	July 2021–June 2022[2]	July 2022–December 2022 (6 months)[2]
Number of unique users		855,765	830,745
Number of new users		842,015	828,600
Average number of new users per month	41,463	70,168	138,100
% of returning website users	7.5 % (3093 per month)*	24.3 % (17,050 per month)	21% (29,001 per month)
Number of pages visited	2*	2.81	3.02
Average session time (minutes)	1.14	1.16	0.47

Sources: 1. Urbis 2021 b:16; 2. Google analytics data supplied by DSS

Use of online services

Data on the use of online services is available in the program data, the population surveys, Carer Gateway client surveys, and the CWS surveys.

The program data indicate the use of Carer Gateway online services – such as phone counselling, new registrations for online coaching, completion of online coaching modules, and the number of community forum posts accessed – has been fairly consistent across the program to date (Table 11). The number of visitors to the websites for coaching and online skills, and the number of new Community Forum members in each 6-month period, has generally increased over time.

Table 11 Use of Carer Gateway Online services 2020–2022

	July–December 2020	January–June 2021	July–December 2021	January–June 2022	July – December 2022
Phone counselling – number of carers	1,137	1,335	1,326	1,399	1503
Phone counselling – number of sessions[1]	3,595	4,244	4,167	4,346	4712
Online coaching – visitors	5,133	6,337	5,402	8,484	9101
Online coaching – new registrations	664[2]	664[2]	714	598	675
Online coaching – modules completed	598	715	795	598	654
Online skills – visitors	8,176	26,416	11,609	16,284	21,287
Community Forum – new members	492	679	927	1,772	4080
Community forum posts	4,376	4,612	5,143	4,277	4170

Sources: Accenture 2020: 29; Accenture 2021a: 27; Accenture 2021b:31; Accenture 2022: 24. Note from Accenture reports:1. Phone counselling sessions include sessions cancelled within 24 hours of start time or no show for a booked session. 2. Annual figure divided over two six-month periods.

Another key indicator for access to Carer Gateway is the percentage of carers visiting Carer Gateway who go on to register or access online services or educational resources. As noted above, it is not possible to determine that each unique or new user to the website is a carer. However, based on the number of new users to the website for July 2021 to June 2022 (842,015) (Table 10) and the number of carers using online services (Table 11):

- 2,725 (0.3%) participated in phone counselling
- 1,312 (0.16%) registered for online coaching
- 2,699 (0.3%) joined the community forum
- 27,893 (3.3%) visited the skills website.

Data from the population and client surveys is limited due to small sample sizes. Among respondents to the Life in Australia™ and CPA 2022 surveys who had used or contacted Carer Gateway, 7% had used online services, 36% had used non-online services, and 61% had not used either type of service (see Figure 33, Brosnan et al. 2023).

The CWS survey reports on the number of carers who used services and whether these were sourced through the Carer Gateway. While there has been no significant increase in the overall proportion of carers accessing self-guided coaching, skills, and online forums between 2022 and 2023, carers were more likely to access these services through the Carer Gateway in 2023 than in 2022 (Table 12).

Table 12 Use of online services 2022–2023 (% of carers in Carer Wellbeing Survey)

	2022 % using this service	2022 % using this service through Carer Gateway	2023 % using this service	2023 % using this service through Carer Gateway
Self-guided coaching	13.7	6.3	15.1	9.7
Carers skills courses	6.7	4.5	7.8	7.1
Online forum for carers to support each other	6.8	4.4	7.4	6.7

Source: Mylek and Schirmer 2023a: 23, Figure 6

Types of Carer Gateway services used

11.4.1.1 Whether used any services

Data on types of non-online Carer Gateway services used by carers is available from the program data (DEX), from population surveys, and from Carer Gateway client surveys.

DEX data indicate, oveer the life of the program (2020–2022), that 55% of registered carers received only ‘intake and assessment’ or information sessions (33% intake and assessment only, 7% information only, 15% both). This group did not go on to receive a preventative service (counselling, education and skills, peer support, coaching, respite, material goods or a carer package) or emergency respite at the time of reporting (Accenture 2022b:18).

Most respondents to the population surveys – 53% of Life in Australia^{TM} survey respondents and 63% of CPA survey respondents – who had contacted the Carer Gateway also indicated they had not received any of the listed services (Brosnan et al. 2023, Figure 32). At the time of the Emergency Respite Survey, 54% of respondents had not received any services (Brosnan et al. 2023, Figure 32). In the Carer Gateway pre-survey, 60% of respondents reported they had completed a needs assessment and 49% had not received any services; in the Carer Gateway post-survey, 33% of respondents reported they had not received any services (Brosnan et al. 2023, Figure 75).

11.4.1.2 Types of services used

DEX data (Table 13) shows the number of different types of sessions provided, and the proportion of all sessions they represented (both overall and excluding intake). It also shows the number of carers attending different services at least once, and the proportion who did so (excluding intake). Other than Information/advice/referral, intake/assessment, and service review, the most common services were counselling (in-person and digital) (8.12%, second column), respite (13.1%), and specialist support (7.2%).

Across the program (2020–2022) 31.5% of carers who were recorded in DEX had received an information, referral and advice session, 23.7% had received a service review, 11.1% counselling, 9.4% respite, 8.5% specialist support (funded through tailored support packages), and 5.1% emergency respite. A smaller proportion of carers received material goods (funded through tailored support packages), (2%), carer support (2.1%) and education (2.7%).

Table 13 Carer use of Carer Gateway services – DEX data 2020–2022

Service Type	Sessions (n)	Sessions (%)	% excluding Intake/Assess	Carers attending at least 1 session (n)	% excl. Intake/Assess
Carer support	13,366	0.92	1.29	4,462	2.1
Counselling (including Digital services)	118,121	8.12	11.36	23,314	11.1
Education and Skills training	23,336	1.60	2.24	5,598	2.7
Emergency Respite	103,552	7.11	9.96	10,690	5.1
Information/advice/referral	313,129	21.51	30.12	66,020	31.5
Material Goods	5,640	0.39	0.54	4,271	2.0
Mentoring/Peer Support	73,270	5.03	7.05	8,021	3.8
Respite	191,068	13.13	18.38	19,806	9.4
Service review	93,151	6.40	8.96	49,709	23.7
Specialist support	104,846	7.20	10.09	17,750	8.5
Intake/assessment	416,027	28.58	–	127,079	–
Total	1,455,506	100.00	100.00 (N=1,039,479)	140,181	100.0

Source: Authors analysis of DEX data Note: The data refer to Individual Clients only (N=140,181) and include services provided online. The number of sessions usually related to a service vary. For example, material goods would typically only represent 1 session max per client per year, counselling would typically represent 6 sessions per client. Also, the total number of carers in Table 10 is not equal to the total number of unique carers who have accessed Carer Gateway because some Carers have accessed multiple services.

In the combined population surveys, respondents who used or contacted Carer Gateway had most commonly accessed phone counselling services (16%) or tailored support packages (18%). The use of counselling services was more common among Emergency Respite Care survey (ERC) respondents –27% accessed phone counselling services, while 29% accessed tailored support packages (Brosnan et al. 2023: Figure 32). Cooking or cleaning services were the most common types of services respondents said were included in their tailored support package (57%), followed by planned respite (28%). Twenty-eight per cent of respondents said they received ‘other’ services (Brosnan et al. 2023: Figure 35).

The frequency of using Carer Gateway services in the last 12 months varied by the type of service accessed. The majority of those who accessed tailored support packages (61%), or emergency respite services (64%), only accessed the service on one occasion; those who accessed online skills courses on the Carer Gateway website most commonly accessed this service two to three times (52%) (Brosnan et al. 2023: Table 15).

In 2022 and 2023, the main types of Carer Gateway services accessed by carers reported in the CWS were psychological counselling (in-person, online or phone), assessment and planning, and cleaning services (funded through tailored support packages), and in 2023 only, in-person peer support (Table 14). Carers were more likely to access cleaning, transport, and shopping services from sources other than Carer Gateway (Mylek and Schirmer, 2023a: 23). Use of respite services is discussed in detail in Section 13.

Table 14 Types of Carer Gateway services accessed by carers (CWS 2022 and 2023)

Service type / % carers accessing service type	CWS 2022 % of carers	CWS 2023 % of carers
Assessment and planning	17.9	14.4
Funding to purchase small assets	7.2	7.3
Psychological counselling (in-person, online, phone)	19.5	22.4
Carer coaching with coach	8.1	12.1
Support to enrol in education and training	2.0	4.9
In-person peer support	8.5	13.1
Cleaning services	13.0	13.0
Shopping services	1.7	3.3
Transport	2.4	4.6

Source: (Schirmer and Mylek 2022, Appendix 1; Mylek and Schirmer 2023a: 21–24).

11.5 Summary

A small proportion (6% at June 2023) of Australia's carers have ever accessed Carer Gateway services. Carers with disability, young carers, and CALD carers are underrepresented in the cohort using Carer Gateway. There are also indications that regional and remote carers lack access to a range of services, in particular respite care; however, there are relatively small numbers of carers in these areas. This calculation is based on broader population surveys that use different definitions of carers and different data collection methods – this may affect these findings.

The proportion of Carer Allowance recipients who have accessed DSS carer support services between 2016 and 2022 has remained relatively stable – 4.8% in 2022. Groups of Carer Allowance recipients who have had relatively lower rates of access are male carers, young carers, Aboriginal and Torres Strait Islander carers, and carers born in non-English speaking countries. Carer Allowance recipients who have had the largest *increase* in rates of service use are those aged under 49 years, while Aboriginal and Torres Strait Islander carers and carers aged 50–64 years have had the largest *decrease* in rates of service use.

The majority of carers in the population surveys in 2022 were either not aware of the Carer Gateway, had not looked at the website, or had not accessed services. Only a minority of these survey respondents had accessed services through Carer Gateway. Among those who had not accessed services, around half would be interested in doing so in the future, a quarter thought they did not need services, and a fifth thought they would not be eligible for services. Carers had most commonly heard about Carer Gateway through a carer organisation or service provider.

The number of users accessing Carer Gateway via the website and phone service has increased over time; however, engagement with the website and online services offered remains relatively low. A significant proportion of carers who access the Carer Gateway do not go on to use other services beyond the 'intake and assessment' process and information and referral. The most common non-online services (not including respite services which are discussed below) accessed are counselling and cleaning services (funded through tailored support packages).

12 Question 6: Impact on the services system

Evaluation Question 6: What has been the impact of the program on the service system for carers?

12.1 Stakeholder perspectives

Stakeholders provided mixed views about the impact of the program on the service system for carers. Most believed Carer Gateway is an improvement on the previous model, which was fragmented with little consistency across and within states. Having a single ‘gateway’ was, in principle, considered to be an effective approach. The positive and negative perceptions of Carer Gateway are summarised as follows:

- **Positive perceptions**: provides a ‘one-stop-shop’, is preventative, provides social connection, increases awareness, increases the volume of carers accessing support, aims to provide consistency (although this may not occur in practice), and gives providers a good sense of the local service system.

- **Negative perceptions**: reduces access to respite / retreats, provides less support for some carers, is inconsistent, and has a poor interaction with the NDIS, My Aged Care, and state-funded services creating some inequity for both services and carers.

Some providers talked about developing their connections with local services so they could make and receive referrals (Service provider 1). Compared with those in large service regions, providers in small service regions tended to talk more about their service networks and referral partners.

> I think one of the other things that's also worth mentioning is as well as we actually do have contracts across the board for a variety of different other services that we offer as well. So, while we sit in a unique position where we actually are both broker and a provider, I do think that actually gives us flexibility because there's a lot of carers that we're able to support through other contracts that are not necessarily aligned to the Carer Gateway. That actually is really, really advantageous to us because we can get that deep understanding of what they need and then we're able to actually influence how quickly and how easily we're able to get them into those services. (Service provider 11)
>
> We also, with our brokered providers, so in that engagement space, we use it as an opportunity around the education of them, identifying carers, of the person that they’re actually supporting through their other means, whether it’s Aged Care or NDIS. We do have some really good referral pathways that are working but it’s always a work in progress too. There’s always new providers that are emerging. There’s always more to reach. There’s different regions ...it’s our engagement team and our ability to put resources into that, that has enabled that to actually work quite well. (Service provider 17)

Providers in large service regions identified the complexity of the service system and the challenges of connecting with all services.

As noted in relation to program design, some stakeholders felt Carer Gateway had impacted carers’ access to some types of services and supports, such as the ability to purchase household items or access immediate respite. However, as discussed elsewhere in this report, there was no consensus among providers about whether or not Carers Star^{TM} was a barrier to accessing immediate support (and if so how), and the actual services or supports that could be delivered as part of the tailored support packages. The overall findings indicate that access to and engagement with Carer Gateway and Carer Gateway services varies considerably – some carers were able to access services quickly and efficiently, while others were unable to access services to meet their needs which included being culturally safe and appropriate.

Some stakeholders also identified a lack of awareness and transparency about what services carers could access through Carer Gateway as a limitation of the program design and service system.

> People need to know what's within their rights to access and for it to not be kept private or secret and held under the guard of a certain particular individual who's running the assessment. That transparency will help people trust in the system better, but also help people to then ask for what they truly need and are rightfully entitled to. I think also really clear communication lines with partnerships and other organisations (Service provider 16).

Some stakeholders identified challenges due to the interaction between Carer Gateway and the NDIS, and between Carer Gateway and My Aged Care (discussed in Section 8, Evaluation Question 2, above). A common issue identified was workforce shortages, particularly in regional and remote areas, as well as some urban locations. Providers explained that the lack of workers, for example to provide respite care, in many locations led NDIS, Carer Gateway, and other services, to compete for a limited number of staff.

A couple of stakeholders believed that a more integrated approach to service delivery was desirable, noting the benefits of having a single service provider delivering NDIS and Carer Gateway services to avoid competition among workers and services in some locations.

> I think one thing that works well for a lot of the Carer Gateway providers is they're not only Carer Gateway providers, they might also be NDIS providers or Aged Care providers, so they have that level of expertise where they can support the carers to navigate those services and understand how they work which is – from my experience across different policy areas – something that people struggle with, that navigating services and systems. (Other stakeholder 8)

As with other parts of Carer Gateway, the service system is working better for some cohorts of carers than others. Mental health carers were one cohort identified as not having sufficient services available. This group also reported difficulties accessing NDIS packages.

> The Gateway can only do so much, if there are no services there as well, so it's great that the government is funding this Gateway, but where are the actual on the ground services for mental health carers? (Other stakeholder 3)

As indicated above, there was consensus the interaction of Carer Gateway with the NDIS was not going well, and this affected the engagement and outcomes of carers with disability and carers of people with disability.[14]

---

[14] Note that NDIA was invited to participate in the interviews, but no interviews were conducted with NDIA stakeholders.

12.2 Carer perspectives

Several Aboriginal and Torres Strait Islander carers talked about the transition from the previous funding programs for carers to Carer Gateway. In most instances this transition was talked about negatively, referring to the difficulty in accessing respite (Carer 31, 35, metro), and the difficulty in being able to contact the Carer Gateway provider when they needed support (Carer 36, metro).

Interviews with non-Indigenous carers indicated that Carer Gateway has provided access to a variety of supports and services that help them to manage their caring role, reduce stress, and continue to provide care. Carers also had increased knowledge about available services and self-care strategies. However, carers’ experience of access to Carer Gateway ranged from a streamlined process through to one of frustration and disappointment. This variation in experiences is related to factors that contribute to and distract from achieving the program’s intended outcomes (see Section 16, Evaluation Question 7b).

12.3 Summary

Overall, the interview findings indicate Carer Gateway had a positive impact on the service system. Carer Gateway provides a more streamlined and accessible entry point for carers into the service system and provides carers access to a range of services based on a comprehensive assessment of their needs. Challenges related to the broader service system for carers and their recipients. Carers found the complex range of services difficult to navigate and negotiate, particularly when they also accessed the NDIS. Carers had a range of different experiences of Carer Gateway, and some services appeared difficult to access – particularly in regional and remote areas. This was due mainly to workforce shortages, multiple requirements of this workforce (Carer Gateway, disability, and aged care), and challenges in recruiting and retaining workers, rather than the nature of Carer Gateway itself.

13 Question 6a: Impact on respite services

Evaluation Question 6a: What has been the impact of the ICSS on access to, use of, and satisfaction with respite services for carers?

13.1 Need for more access to respite

Data on self-reported need for access to more respite was collected in the surveys and the CWS. The population surveys found an increase in the need for access to more respite between 2020 and 2022:

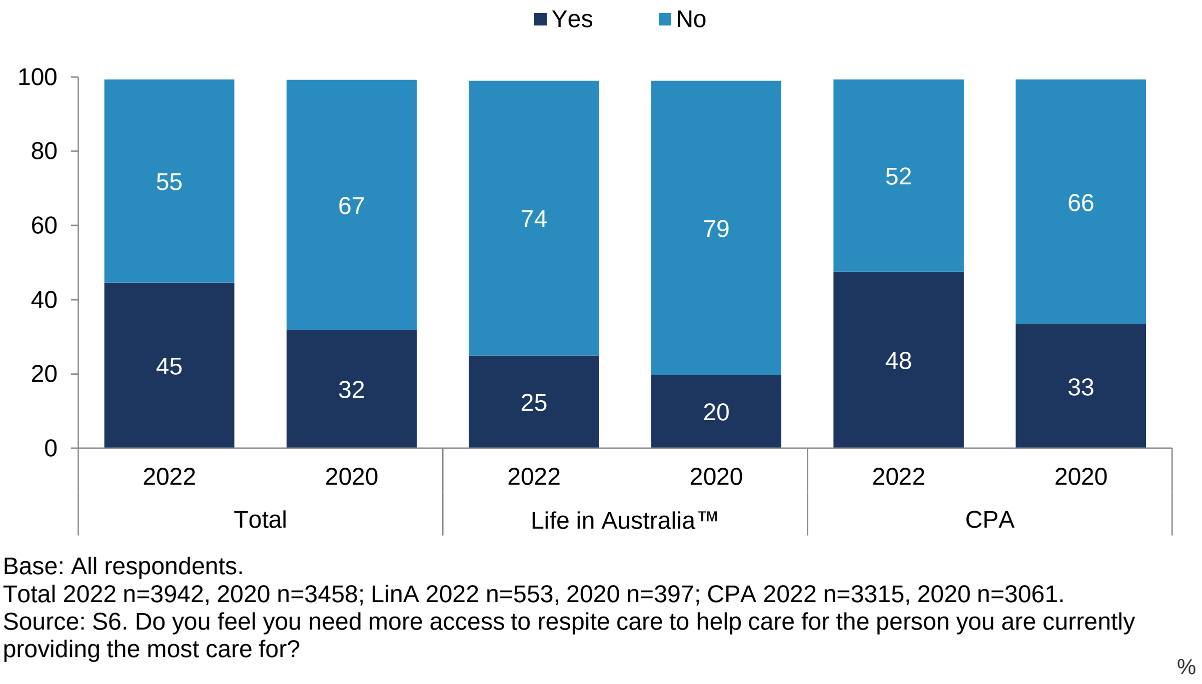
In the general population of carers survey (Life in Australia™), 20% of carers in 2020 and 25% of carers in 2022 indicated that they needed more access to respite care (Figure 7).

In the CPA survey 2022, 48% of respondents said they needed more access to respite compared with 33% of respondents in the CPA survey 2020 (Figure 7).

Carer Gateway clients reported a greater need for more access to respite; 61% of the 2022 ERC and the Carer Gateway pre-survey respondents indicated more respite was needed (Brosnan et al. 2023, Figures 26 and 72).

Fifty-one per cent of mental health carers across the combined 2022 surveys said they needed more access to respite services to help care for the person they provide the most care for (Brosnan et al. 2023).

Figure 7 Whether need more access to respite care to help care for the person currently providing the most care for (% Carers, time series)



Base: All respondents.
Total 2022 n=3942, 2020 n=3458; LinA 2022 n=553, 2020 n=397; CPA 2022 n=3315, 2020 n=3061.
Source: S6. Do you feel you need more access to respite care to help care for the person you are currently providing the most care for?

Source: Brosnan et al. 2023, Figure 27.

13.2 Use of respite

Use of respite care is documented in the program data (DEX data) for the period 2015–2022, which encompasses the pre-Carer Gateway and Carer Gateway periods. Data on the use of respite care was also collected in population surveys for 2020 and 2022 and in the CWS for 2021–2023.

Respite use 2015–2022

Prior to Carer Gateway, respite services were provided through several DSS carer support programs which were recorded in DEX. This includes Commonwealth Respite and Carelink Centres, Consumer Directed Respite Care, Dementia Education and Training for Carers, and Mental Health Respite.

Table 15 shows the number of attendances for individual clients in these pre-Carer Gateway programs and in the Carer Gateway program between 2015 and 2022 as recorded in DEX. The total number of attendances have decreased from 410,600 in 2016, to 124,900 in 2022 (comprising 85,600 respite and 39,300 emergency respite attendances in 2022).

Table 15 Number of individual client attendances for respite for DSS carer support services 2015–2022

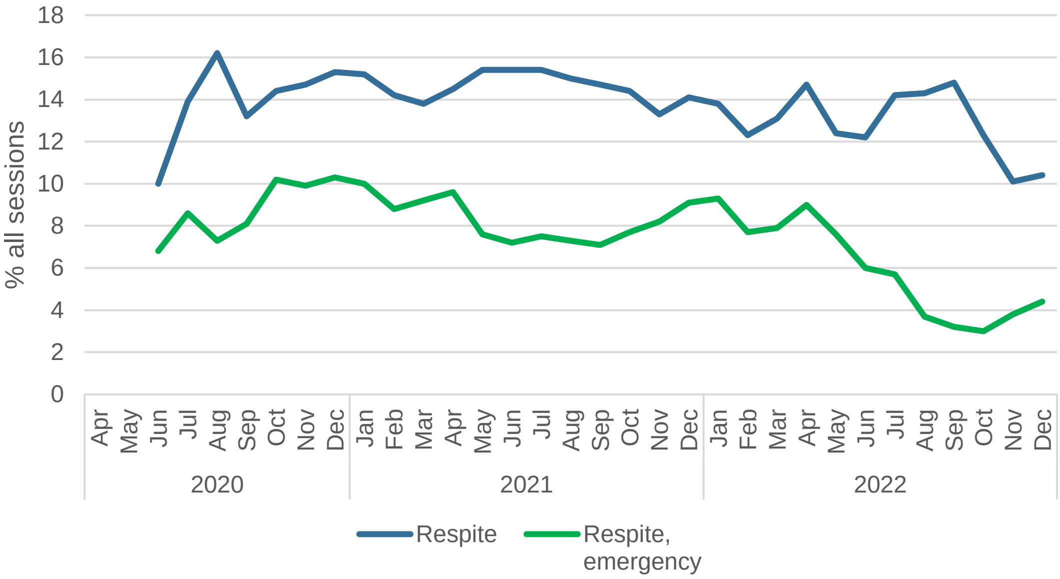
Service Type	2015	2016	2017	2018	2019	2020	2021	2022
Respite	34.2	76.6	37.8	28.5	13.5	29.9	78.4	85.6
Brokered respite	151.8	334.0	307.1	271.3	212.5	54.9	.	.
Emergency Respite	.	.	.	.	.	18.2	46.0	39.3
Total respite attendances	186.0	410.6	344.9	299.8	226.0	103.0	124.4	124.9
All individual attendances (all services)	453.1	998.2	970.3	873.0	687.9	405.3	570.1	693.7

Source: Author's analysis of DEX data. All services includes Digital services, YCBP and TCVO program services.

Respite sessions in Carer Gateway 2020–2022

Figure 8 shows that, after the initial roll out of the program, the proportion of respite and emergency respite sessions has remained relatively constant up until 2022. During 2022 there was a fall in the proportion of reported services which were for respite and, later in the year, for emergency respite. This is consistent with the program logic, which predicts a fall in the need for respite and emergency respite services over time due to the increased resilience of carers. However, there may also be other causes for this pattern – specifically, a lack of respite services or the ability to access respite services via pathways other than Carer Gateway, as is reported above in relation to Evaluation Question 6 (see Section 12).

Figure 8 Proportion of respite and emergency respite sessions 2020–2022



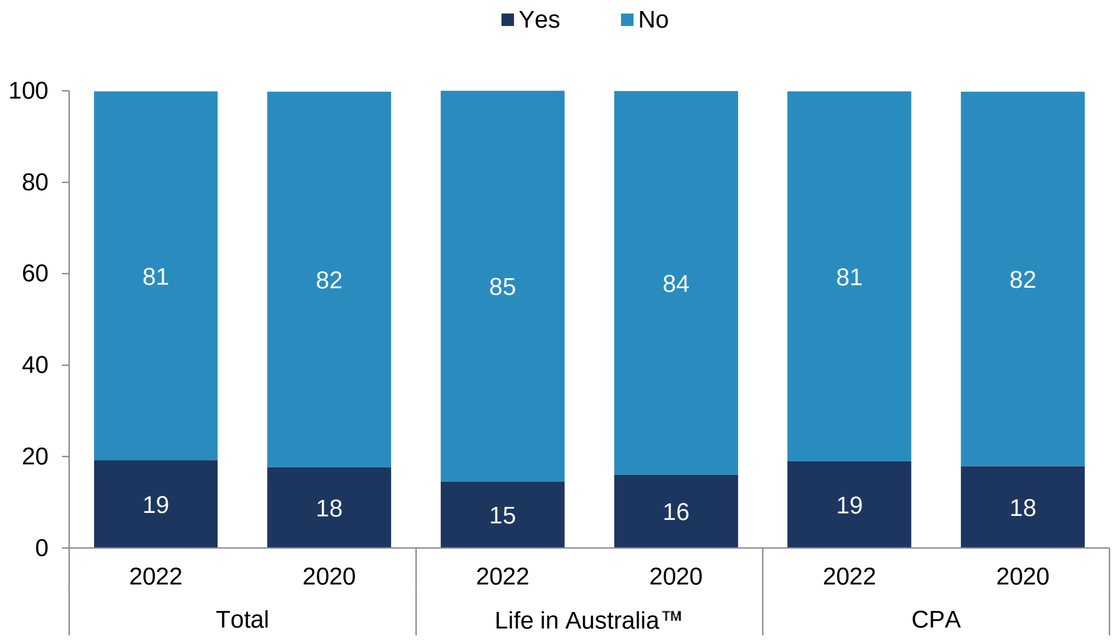
Note: The figure shows the proportion of service sessions that were respite or emergency respite sessions in each month June 2020–December 2022. The denominator is the total number of client sessions in each month (i.e. excluding group and support person sessions). Also excluded are the sessions of clients who have 100 or more recorded sessions (about 0.3% of clients). Source: Author’s analysis of DEX data

Respite use in 2020 and 2022

13.2.1.1 Proportion of carers who have ever used respite care

In the combined population surveys in 2022, the proportion of carers who had ever used respite care (19%) remained consistent with 2020 data (18%). In 2022, 15% of carers in the Life in Australia^{TM} survey and 19% of carers in the CPA survey had used respite (Figure 9). Note that these carers may not have used Carer Gateway services and could have accessed respite from other providers.

Figure 9 Whether ever used respite care to help care for the person currently providing the most care for (% Carers, time series)



Base: Respondents who provide care to another member of their household an / or someone outside their household. Total 2022 n=3942, 2020 n=3458; LinA 2022 n=553, 2020 n=397; CPA 2022 n=3315, 2020 n=3061.
Source: S1. Have you ever used any of these services to help care for the person you are currently providing the most care for?

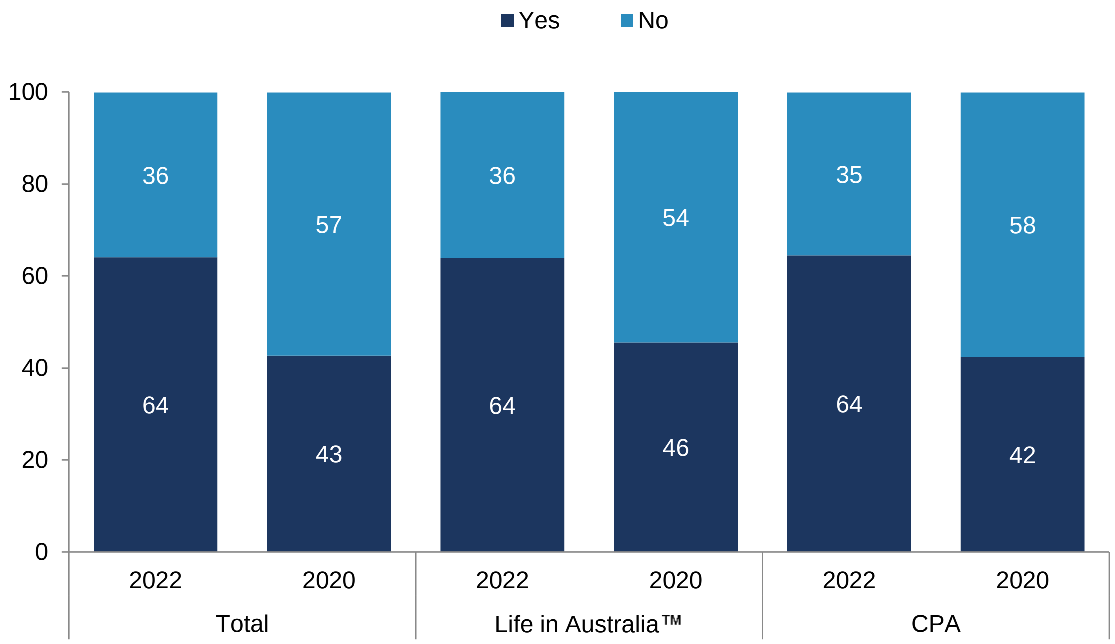
%

Source Brosnan et al. 2023: Figure 20

13.2.1.2 **Use of respite care in the last 3 months**

Of all survey respondents who had ever used respite services, 64% had used them in the 3 months prior to completing the survey (Brosnan et al. 2023: Figure 22). A similar proportion was found among mental health carers (62%) (Brosnan et al. 2023: 55). Among the Life in Australia^{TM} survey respondents who had ever used respite, use of respite care in the past 3 months has increased from 46% in 2020 to 64% in 2022 (Figure 10). Similarly, for CPA survey respondents, respite care was higher in 2022 (64%) compared to 2020 (42%) (Figure 10).

Figure 10 Whether used respite care past 3 months to help care for the person currently providing the most care for (% Respite care ever used, time series)



Base: Respondents who have used respite services. Total 2022 n=765, 2020 n=655; LinA 2022 n=76, 2020 n=596; CPA 2022 n=643, 2020 n=655.
Source: S3. Have you used these services in the last 3 months to help care for the person you are currently providing the most care for?
Note: ERC, Don't know and Refused responses not shown on chart.

Source: Brosnan et al. 2023, Figure 23.

The increase in respite care use since 2020 in the CPA may be because the CPA was administered during the 2020 COVID-19 lockdown period (June 2020). Stakeholders indicated that respite care (and other service) use declined considerably during lockdown periods. Thus, this may indicate a temporary dip in respite care use in 2020, rather than an increasing trend over time. Overall, these surveys indicate respite care use remains consistent or may be increasing slightly over time in the population. Given there is a decrease in Carer Gateway use of respite over this period, these findings indicate that carers may be accessing respite from sources other than Carer Gateway.

Respite use 2021–2023

The 2021 CWS Carer Gateway report noted that some carers may not be aware of the source of respite service funding and so may not identify their respite services as a Carer Gateway service. Of the 30.6% of carers who had used respite in 2021, at least 3.7% had accessed this via Carer Gateway (Centre for Change Governance and NATSEM 2021:24). Table 16 outlines the sources of respite services used in 2022 and 2023. In 2023, Carer Gateway respite services comprised 46% of all in-home respite services, 52% of residential respite, and 46% of day care services used by carers and 93% of the emergency respite services used.

Table 16 Carer Wellbeing Survey 2022 and 2023: Use of respite services in the last 12 months by source (% of carers who had used services)

	2022		2023		
	Used any source of respite service % of carers who had used services	Used Carer Gateway respite service % of carers who had accessed CG services	Used any source of respite service %	Used Carer Gateway respite service % of carers who had accessed CG services	% of all respite services used that were carer Gateway services*
In home respite	13.4	6.1	13.3	6.1	46
Residential respite	9.6	3.9	9.3	4.8	52
Emergency respite	4.2	2.6	4.5	4.2	93
Day Care	6.9	1.8	7.2	3.3	46
Other	5.7	1.5	5.4	1.6	30

Source: Schirmer and Mylek 2022: Figure 6: 17; Mylek and Schirmer 2023a: 24, Figure 7. *Author's calculations.

13.3 Barriers to respite use

Reasons that carers have never used respite care

Table 17 shows that, among Life in Australia™ survey respondents who have *never* used respite services, the main reasons were that they did not need the service (44% in 2020 and 2022), the care recipient did not want the service (17% in 2020 and 18 % in 2022), and they were unaware of their entitlement (which had increased from 9% in 2020 to 13% in 2022). Life in Australia™ survey respondents were more likely than CPA survey respondents to indicate they did not need respite services (44% vs for CPA 19% in 2022 and 28% in 2020). For 2022 CPA survey respondents, the main reasons respite was not used were that the care recipient did not want the service (20% in 2020 and 23% in 2022) and that they were unaware of their entitlement (which had also increased between 2020 and 2023 (from 18% to 23%). Less than 10% of carers reported availability and affordability issues, or the COVID-19 pandemic, as the main reason for not accessing respite services.

Among mental health carers in the combined surveys, the main reason for never using respite care was that the care recipient did not want the service (31%).

Table 17 Main reason never used respite care (% Carers never used respite care, time series)

	Total 2022	Total 2020	Life in Australia™ 2022	Life in Australia™ 2020	CPA 2022	CPA 2020
Don’t need service	23	30	44	44	19	28
Care recipient doesn’t want service	23	20	18	17	23	20
Unaware of entitlement / services	22	17	13	9	23	18
I don’t want the service	7	9	9	7	7	9
Available services not suited to needs	6	6	4	6	7	6
No affordable services available	4	4	n≤10	n≤10	4	4
Respite care services not available in area	3	2	n≤10	n≤10	3	2
COVID-19 pandemic	2	n≤10	n≤10	n≤10	2	n≤10
Other	10	n.p	98	13	11	n.p.

Source: Brosnan et al. 2023, Table 8. Base: Respondents who have not used respite services. Total 2022 n=3170, 2020 n=2799; Life in Australia™ 2022 n=477, 2020 n=337; CPA 2022 n=2666, 2020 n=2462. Source: S2. What is the main reason you have not used these services? Note: ERC, Don't know and Refused responses not shown; n.p. indicates not published for confidentiality.

Reasons for not using respite care in the last 3 months

Population surveys also indicate barriers to using respite care in the last 3 months. Due to sample sizes, robust data was available for the CPA survey only. In the 2022 CPA survey, the main reasons respondents gave for not using respite care were that the care recipient did not want the service (21%), ‘other’ reasons (20%), and that they did not need the service (13%) (Brosnan et al. 2023, Table 10). Changes in reasons from 2020 to 2022 included a drop in the proportion of respondents indicating that the COVID-19 pandemic was a reason (38% in 2020 to 7% in 2022) and slight increases in the suitability (9% in 2020 to 12% in 2022), availability (3% in 2020 to 7% in 2022) and affordability (8% in 2020 to 10% in 2022) of services being the main reason (Brosnan et al. 2023, Table 10). The CPA 2020 survey was conducted in June 2020, and it is expected that the pandemic associated lockdowns would have affected these responses. The main reason for both the 2020 and 2022 Life in Australia^{TM} respondents was that they did not need the service (Brosnan et al. 2023, Table 10).

CWS respondents reported a decline in the use of respite services over time. In 2021, 30.6% of carers had accessed respite services (from any source, not just Carer Gateway) in the last 12 months; in 2022, 27.7% had accessed respite services, and in 2023 this figure reduced to 26.8% (Mylek and Schirmer 2023b:44). In 2022 and 2023 CWS, the majority of carers reported poor access to different types of respite care during the last 12 months for the person they were caring for, although fewer carers reported poor access in 2023 compared with 2022. Specifically, they reported poor access to:

- In-home overnight respite care (80.6%in 2022 and 71.0% in 2023)
- Out-of-home overnight respite care (73.9% in 2022 and 66.3 in 2023)
- Out-of-home day respite care (65.7% in 2022 and 60.7% in 2023)

- In-home day respite care (61.8% in 2022 and 58.2% in 2023) (Schirmer et al. 2022; ix, Figure E5; Mylek and Schirmer 2023b: 49).

13.4 Satisfaction with respite

Data on satisfaction with services is collected during service reviews and recorded in DEX and is also collected in population surveys and the CWS. All of these data sources relate to the post-Carer Gateway period (2020 onwards), therefore satisfaction with respite cannot be compared before and after this program was introduced.

The satisfaction data in DEX is also limited as the responses can only be attributed to a single type of service if that is the only service the carer used. The performance monitoring reports provide average satisfaction measures for types of service which indicate the majority of Carer Gateway clients who provide satisfaction responses are satisfied with respite services (e.g. Accenture 2022b:11). The number of respondents in the combined population surveys (Life in Australia^{TM} and CPA) who had use respite services was also small. Overall, as noted above, 69% reported high satisfaction with emergency respite and 68% would use the service again (Table 18).

Satisfaction data is collected in the CWS for specific types of respite services and the relatively small sample sizes mean that findings are not disaggregated by demographic groups. Table 18 reports the mean satisfaction scores for respite services in 2021, 2022 and 2023. Between 2021 and 2022, findings from the CWS suggest there was an increase in average satisfaction scores with emergency respite and in-home respite, but no change in reported satisfaction with other forms of respite (Schirmer and Mylek 2022: Figure 10). While mean satisfaction scores were generally lower in 2023, few changes were significantly different from 2021. Satisfaction with respite decreased significantly for day care and ‘other’ types of respite between 2021 and 2023; however, the authors caution that these findings may be influenced by small numbers of carers in the CWS survey using these services (Mylek and Schirmer 2023a:39).

Table 18 Carer Wellbeing Survey: Mean satisfaction score for respite services

Respite type	2021	2022	2023
In-home respite	7.3	8.4	7.2
Residential respite	7.7	8.3	7.3
Emergency respite	7.4	8.4	7.2
Day Care	6.8	7.7	6.2
Other	6.7	7.9	5.9

Source: Schirmer and Mylek 2022: Figure 10; Mylek and Schirmer 2023a, Appendix 2)

13.5 Summary

Access to respite services may be more limited in the post-Carer Gateway period (April 2020 onwards). In 2022, a higher proportion of carers reported a need for more access to respite compared with 2020. The number of respite attendances for DSS carer support programs between 2015 and 2022 (as recorded in DEX) has decreased. The number of respite and emergency respite service sessions has decreased between 2020 and 2022 and reduced as a proportion of all Carer Gateway services.

Use of respite and reasons for not using respite have remained the same between 2020 and 2022. Similar proportions of carers report using respite between 2020 and 2022, with most using respite in the last 3 months. The data in the CWS 2023 survey suggests that 46% of in-home respite, 52% of residential respite, 46% of day care respite, and 93% of emergency respite services used by carers are accessed through Carer Gateway. The main reasons for not using respite reported by carers were that it was not needed, that the care recipient did not want it, and not being aware of entitlements.

Satisfaction data for respite services in the surveys is only available for the Carer Gateway period. The majority of carers who have accessed Carer Gateway respite services are satisfied with the services they have received, and satisfaction ratings have remained fairly stable.

There are some indications that access to respite, and particularly emergency respite, has been restricted for some carers due to the lack of services (Section 5.6.1) and that there is inconsistency across providers in their perceptions of whether it is necessary to conduct a Carers Star™ assessment for carers seeking emergency respite. However, when the surveys and other datasets are considered, overall, there is a high satisfaction rate for these services. There is also some evidence that carers are accessing respite from sources other than Carer Gateway.

The interviews with stakeholders (Section 5.6.1) carers (Sections 5.7.1 and 5.8.3) demonstrate that respite and emergency respite continue to be extremely important services for carers with high needs and at a time of crisis – access to respite services helped carers to continue to provide support. However, some carers were concerned about the consistency and quality of staff providing respite, particularly for those with complex needs (Section 5.7.1).

14 Question 7: Were intended outcomes achieved?

Evaluation Question 7: To what extent has the program achieved the intended outcomes in its program logic?

The intended outcomes of Carer Gateway services for carers, as outlined in the ICSS Outcomes Framework (see Appendix B), are to ‘improve carer wellbeing, increase their capacity, and support their participation, socially and economically and reinforce carer resilience’. Findings related to these outcomes are discussed below.

14.1 Wellbeing

Data sources and measures

Data on wellbeing outcomes for carers in the population generally, and carers accessing Carer Gateway, is collected in the program data (DEX- Carers Star^{TM}), in the population surveys and surveys of Carer Gateway clients, and in the CWS (General Health Question, Personal Wellbeing Index (PWI) and Kessler Psychological Distress Scale (K10)).

Given the small number of carers who had accessed services in the Life in Australia^{TM} and CPA surveys, data from the population surveys provide contextual insights into how carers in the population are tracking overall between 2020 and 2022, but any changes over time cannot be attributed to Carer Gateway services.

The Carer Gateway pre-post surveys provide insights about the circumstances of carers at their initial point of accessing the Carer Gateway, as well as some longitudinal data about changes in wellbeing, capacity and participation outcomes over a 6-month period for carers who have interacted with Carer Gateway or accessed Carer Gateway services.

The CWS reports (Schirmer and Mylek 2022; Mylek and Schirmer 2023a) note that not all Carer Gateway services would be expected to affect each outcome, and that some changes in outcomes – including wellbeing, stress, social participation (loneliness), and economic participation (employment and study) – would only be expected to be evident over the longer term (see discussion in Schirmer and Mylek 2022: Table 1).

The CWS analysis compared self-reported outcomes for carers who have accessed Carer Gateway in the last 12-months compared with carers who did not. The authors compared groups distinguished by the level of assistance needed (low, medium, and high) in their analysis and it should be noted that small sample sizes may affect the findings. The more robust differences identified are discussed in this section (see Schirmer and Mylek 2022:39–52; Mylek and Schirmer 2023a, Section 6).

Carers Star^{TM}

Wellbeing in the performance monitoring reports is analysed using DEX data. In DEX, a single score labelled as “mental health, wellbeing and self-care" is derived as an average from the seven dimensions of the Carers Star^{TM} assessment (health, the caring role, managing at home, time for yourself, how you feel, finances, and work). Across the program from April 2020 to December 2022, 34.6% of clients recorded a second Carers Star^{TM} assessment (Accenture 2022b:8).

The half yearly performance monitoring reports indicate that, overall, 34.9% of carers who have two or more Carers Star^{TM} scores report a positive change, while the majority report no change across the program from April 2020 to December 2022 (Accenture 2022b:12–13). This analysis of changes in Carers Star^{TM} outcomes across the program from April 2020 to December 2022 finds no significant difference across the five demographic groups considered, the service types, or by remoteness (Accenture 2022b:12–13).

Analysis of the DEX data on wellbeing outcomes for demographic groups is presented in Section 17.1 and for service types in Section 18. Section 17.1 finds that, overall, 33.6% of carers with more than one Carers Star^{TM} assessment improved their score, 10.7% deteriorated, and for 55.7% there was no change.

General health

General health was measured in the population surveys and Carer Gateway pre-post surveys by the question: “In general, would you say your health is excellent, very good, good, fair or poor?”. In the Life in Australia^{TM} survey, 24% of respondents reported ‘fair or poor’ health, which was slightly lower than 2020 (29%). Among CPA respondents, 44% reported their health was fair or poor compared to 35% in 2020 (Brosnan et al. 2023, Figure 38). These estimates for carers are higher than the Australian general population estimate of 15.2% reported in the National Health Survey 2017/18. The Life in Australia^{TM} survey estimate is comparable to the estimate for primary carers in the 2018 SDAC where 24% respondents reported they were in fair and poor health.

Across the combined population surveys in 2022, 42% of all respondents reported fair or poor health. Demographic groups that reported worse health included mental health carers (56%) and carers with a disability (70%) (Brosnan et al. 2023, Figure 38).

Carer Gateway clients in the Carer Gateway pre and post surveys also reported relatively worse health at 47% and 45% respectively having fair or poor health (Brosnan et al. 2023, Figure 88).

Personal Wellbeing Index (PWI)

The PWI collects satisfaction ratings on seven aspects of life: standard of living, personal health, achieving in life, personal relationships, personal safety, community connectedness, and future security. PWI data was collected in the ERC and pre-post surveys and the CWS.

In the client surveys, 46% of ERC respondents reported low wellbeing (a score of 59 and under on the PWI scale) (Brosnan et al. 2023, Figure 39), while 48% had low wellbeing in the pre-survey and 43% in the post-survey (Brosnan et al. 2023, Figure 89). While changes in wellbeing outcomes cannot be attributed to Carer Gateway services without controlling for other factors, the analysis of the pre-post survey data showed that among respondents for both the pre-post surveys, for 64% their PWI score remained same at both times points, for 23% their score improved, and for 13% the score declined (Brosnan et al. 2023, Figure 103).

The CWS analysis in 2022 identified that participation in the assessment and planning process or skills building and coaching was associated with increased wellbeing (as measured by the PWI) for carers caring for a person with higher needs for assistance (Schirmer and Mylek 2022:39–52).

Psychological distress (K10)

As shown in Table 19**,** Carers have much higher levels of psychological distress than the general population. The Life in Australia™ survey, the CPA survey, and SDAC 2018 showed that carers report 2 to 3.5 times the rates of high or very high levels of psychological distress compared to the general population (as measured in the 2018 National Health Survey). The levels of psychological distress for carers with a disability status is higher than those without. In the combined surveys, 62% of carers who reported having a disability, health condition, or injury that has lasted 6 months or more (67% in the 2020 CPA survey) had high or very high psychological distress; however, 45% who reported no disability also had high or very high levels of psychological distress.

Table 19 Carer psychological distress compared to general population (% all)

Level of psychological distress	Life in Australia™ 2022 (%)	Life in Australia™ 2020 (%)	CPA 2022 (%)	CPA 2020 (%)	ERC 2022 (%)	Carers with a disability 2022 (%)	Primary Carers SDAC 2018 (%)	General Population National Health Survey 2018 (%)
Low	50	34	22	22	28	16	47	61
Moderate	25	31	23	25	25	22	26	22
High	14	21	27	28	22	27	17	9
Very High	10	13	28	25	25	35	10	4
Net High / Very High	24	35	55	54	47	62	27	13

Base: All respondents. 2022 Life in Australia™ n=553, 2020 Life in Australia™ n=397, 2022 CPA n=3315, 2020 CPA n=3061, 2022 ERC n=79. Source: KSCORE Constructed Variable: H2. In the past 4 weeks, about how often did you feel...?

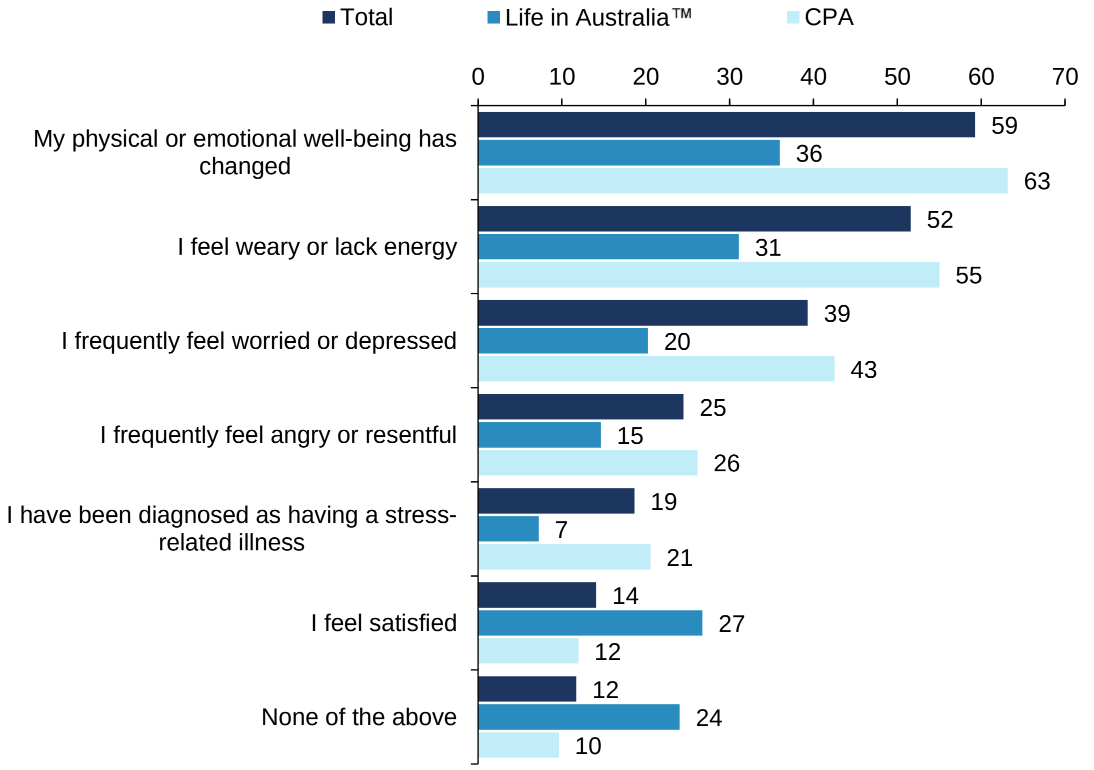
Among carers in the Carer Gateway pre-survey, 63% reported high or very high levels of distress as measured by the (K10), with a slightly lower proportion (59%) of carers in the post-survey (Brosnan et al. 2023, Table 42). Among pre-post survey respondents, 57% had the same stress scores at both time points, 19% had lower stress levels, and 24% had higher stress levels (Brosnan et al. 2023, Figure 104).

Similar to the improvement with the PWI, the CWS analysis identified that participation in the assessment and planning process, or skills building and coaching, was associated with lower psychological distress (K10) for carers caring for a person with higher support needs. Schirmer and Mylek 2022:39–52).

Impact of caring on wellbeing

In 2022, the physical and emotional effects of caring have resulted in changes to wellbeing for 59% of carers (see Figure 11). Among carers who had used Carer Gateway services, 60% reported that their physical and emotional wellbeing had changed compared to 35% of those who had not used the services. A higher proportion, 69% of carers in the pre-survey and 71% of carers in the post-survey, reported their physical and emotional wellbeing had changed (Brosnan et al. 2023, Figure 91).

Figure 11 Physical and emotional distress 2022 (% All)



Base: All respondents. Total n=3868, Life in Australia™ n=553, CPA n=3315. Question not asked of ERC respondents.
Source: I8. What physical or emotional effects have you experienced as a result of your caring role?
Note: Refused responses not shown on chart.

Source: Brosnan et al. 2023, Figure 41

As shown in above, among carers the Life in Australia^{TM} and CPA surveys in 2022, many felt weary or lacked energy (52%), were worried or depressed (39%), were angry or resentful (25%), or had been diagnosed with a stress related illness (19%). Carers in the CPA survey were more likely to feel this way. Carers in the pre-survey and the post-survey also commonly reported feeling weary or lacked energy (64% pre-survey, 62% post-survey) or were worried or depressed (53% pre-survey, and 45% post-survey) (Brosnan et al. 2023, Figure 91).

Carer distress as proxied by use of prescriptions

MADIP data were used to examine the association between being prescribed selected drugs indicating psychological distress and engagement with Carer Gateway.

MADIP links data from several government programs and data collections. For this analysis, we used data from the DEX data collection, the 2021 Census, and the Pharmaceutical Benefits Scheme (PBS). More details of the data definitions, analysis methods, and results are shown in Appendix F.1

Following Mikkola et al. (2021, 2022), we look at the use of three classes of prescription drugs among carers: antidepressants, anxiolytic benzodiazepines and related drugs (BZDRD), and hypnotic benzodiazepines and related drugs. Mikkola et al. argue that demanding care responsibilities can lead to chronic stress and social isolation, increasing the risk of depression, insomnia and anxiety and, in turn increasing the likelihood of being prescribed these three classes of drugs. In a study comparing family caregivers in Finland with comparable non-caregivers, they find that carers were more likely to be receiving both antidepressants and BZDRD drugs (mainly hypnotic BZDRDs). We identify people who received any of these drugs via the PBS in 2020 and 2022.

In this analysis, we identify caregivers using the 2021 Census, where people aged 15 years and above were asked if “In the last two weeks, did the person spend time providing unpaid care, help or assistance to family members or others because of a disability, a long-term health condition or problems related to old age”. Some 2,406,809 people indicated yes to this question. In 2020, of these carers, 19.3% were prescribed antidepressants, 5.2% anxiolytic benzodiazepines, and 3.5% hypnotic benzodiazepines. The corresponding percentages for medication use in 2022 were similar (20.9%, 5.3% and 3.4% respectively).

Participation in any of the ICSS carer support programs between 2020 and mid-2022 was extracted from linked DEX administrative data. ICSS participants who could not be linked (about one-quarter) were assumed not to have received any ICSS services.

Using this data, we estimated several logistic regressions for the population of 2021 Census carers. The dependent variables were whether people were prescribed any of the three groups of drugs in 2022 and sub-populations were defined based on whether they were prescribed the drug in 2020. The analysis explored whether later use of the drugs was associated with participation in the ICSS program (disaggregated by service type).

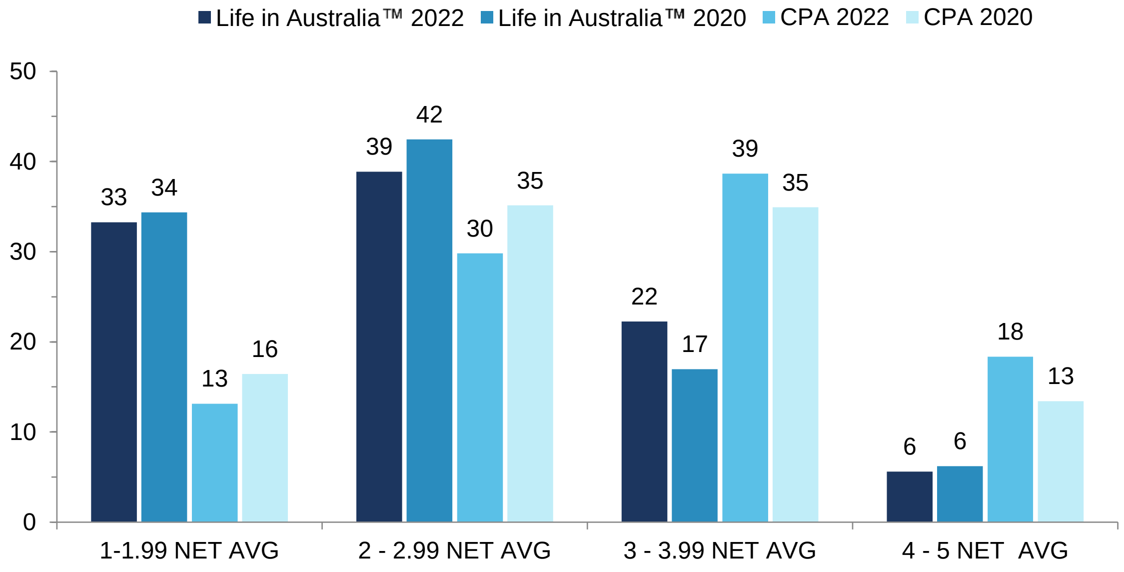
Overall, we found that participation in the ICSS program was associated with an *increase* in the likelihood of being prescribed one of the prescription drugs in 2022. This effect is relatively small for those who were already using the same drug in 2020, but larger for those who were not using the drug in 2020 (odds-ratio of approximately 1.5 for each of the three drugs). We interpret this result as reflecting selection effects, with those carers who are most vulnerable most likely to be referred to ICSS services and also most likely to continue or commence receiving antidepressants and benzodiazepines. While we control for several demographic characteristics associated with prescription drug use, the available data is insufficient to generate a comparison group which is likely to have the same vulnerability characteristics as the ICSS participant population. We are therefore unable to draw a conclusion as to whether participation in the program has or has not reduced use of these prescription drugs.

Carer sentiment

Respondents to the Life in Australia™ survey tended to report less burden in caring for the person they provided the most care to than respondents in the CPA survey. As shown in Figure 12:

- One-third (33%) of carers in Life in Australia™ survey 2022 scored an average of 1–1.99 on the Zarit Burden Inventory (ZBI) scale, similar to the 2020 results (34% scored an average of 1–1.99).
- Conversely, 39% of those in the CPA survey scored an average of 3–3.99 in 2022, indicating a higher level of burden. This has increased from 35% since 2020. In addition, 18% of CPA respondents reported the highest level of burden (4–5) in 2022 compared to 13% in 2020.
- The analysis of the Carer Gateway pre-post survey showed a significant change in the proportion of carers reporting that they felt extremely burdened reducing from 14% of carers in the pre-survey to 7% of carers in the post-survey (Brosnan et al. 2023., Figure 96).

Figure 12 Impact on Carer Sentiment 2020 and 2022 (ZBI – BURDEN, % All)



Base: All respondents. 2022 Life in Australia™ n=553, 2020 Life in Australia™ n=397, 2022 CPA n=3315, 2020 CPA n=3061. Question not asked of ERC in 2022.
Source: BURDEN Constructed Variable: Z1. The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always.

Source: Brosnan et al., 2023, Figure 45

14.2 Capacity for caring

Capacity for caring was assessing through measures of carer confidence, competence, preparedness and coping in the population and pre-post surveys, and on a range of similar measures in the CWS.

Confidence and competence

The population surveys assessed carer competence through the Caregiver Competence Scale (Pearlin et al. 1990), which asks: (1) how much they believe that they have learned how to deal with a very difficult situation, (2) how much they feel that all in all, they are a good caregiver, (3) how competent they feel, and (4) how self-confident they feel. The scale consists of four items on a 4-point Likert-type scale ranging from 'not at all competent' to 'very competent'.

In general, 2022 CPA survey respondents tended to have higher feelings of competence in caregiving, with 20% scoring 4 on average on the Caregiver Competence Scale, while Life in Australia^{TM} survey respondents tended to report lower feelings of competence (25% in 2022 for an average score of 2–2.99) (Brosnan et al. 2023, Figure 48).

The proportion of carers who scored 3 and above in the Carer Competence scale increased from 70% in the Carer Gateway pre-survey to 76% in the post-survey (Brosnan et al., 2023, Figure 97).

Comparing carers who had used services with those who had not in the last 12-months, data from the 2022 CWS showed that:

Participation in any Carer Gateway service, assessment and planning, skills building and coaching was associated with an increase in self-reported access to support to help in caring duties. Carers with higher needs for assistance also reported an improvement in this outcome if they accessed respite care while carers with lower needs for assistance improved on this measure if they had accessed practical support.

Participation in the assessment and planning process was also associated with a self-reported increase in an overall ability to care for care recipient/s and the ability to find out about and organise access to services for care recipients for carers with higher needs for assistance.

Participation in skills building and coaching services was also associated with a self-reported increase in overall ability to care for care recipient/s, confidence in ability to be a good carer, and the ability to find out about and organise access to services for care recipients.

Carers with lower needs for assistance who had accessed practical support reported increased access in overall ability to care for care recipients (Schirmer and Mylek 2022, 43-45).

Preparedness

CPA survey respondents reported a slightly lower level of preparedness in 2022, with 21% scoring an average of 3–3.99 on the Preparedness for Caregiving Scale, compared to 26% in 2020. Similarly, those in the general population survey also had a slightly lower level of preparedness in 2022, with 26% scoring an average of 1–1.99 compared to 24% in 2020.

Carers in the Carer Gateway pre-post surveys generally reported a lower level of preparedness, with 12% of carers in the pre-survey scoring an average of 3–3.99 on the Preparedness for Caregiving Scale increasing to 16% in the post-survey (Brosnan et al., 2023, Figure 98).

Coping strategies

The surveys asked carers questions about how they were coping with the answers reflecting different coping strategies. In general, the overarching coping style reported by carers in the population surveys was ‘acceptance’, with 54% of CPA 2022 survey respondents reporting they are ‘doing this a lot’ or ‘doing this a medium amount’. This is comparable to 53% of respondents to the 2020 CPA (Brosnan et al. 2023, Figure 50).

There were no changes in the types of coping strategies reported by carers in the Carer Gateway pre-post surveys with the most common being ‘acceptance’ (used a medium amount or a lot by 53% in pre and post), then ‘planning’ (37% pre and 32% post), and ‘positive reframing’ (30% pre and 31% post) (Brosnan et al. 2023, Figure 99).

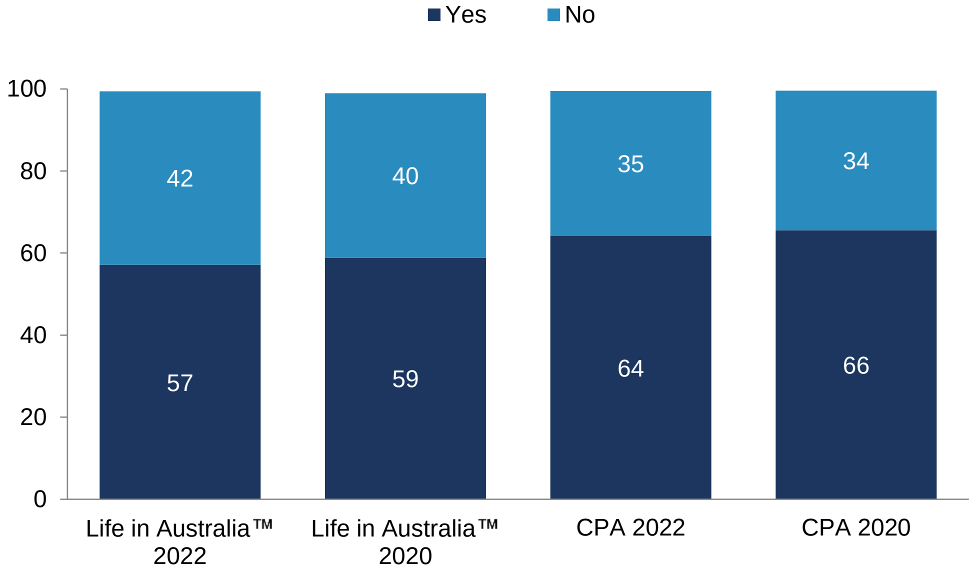
14.3 Social participation and loneliness

Social participation is measured by the types of contact with family and friends that carers do not live with, their desire to have more contact, and whether the carer felt lonely.

Social participation

In 2022, 57% of Life in Australia™ respondents and 64% of CPA survey respondents indicated that they would like to have more contact with family or friends who do not live with them (Figure 13). These results are similar to findings for 2020 (Figure 13 below). More than two in three mental health carers (68%) said they that they would like to have more contact with family or friends who do not live with them. A higher proportion of carers (85%) in the Carer Gateway pre and post surveys indicated that they would like to have more contact with family or friends who do not live with them (Brosnan et al. 2023, Figure 92).

Figure 13 Desire for more contact with family or friends who do not live with them 2020 and 2022 (% All)



Base: All respondents. 2022 Life in Australia™ n=553, 2020 Life in Australia™ n=397, 2022 CPA n=3315, 2020 CPA n=2061. Question not asked of ERC in 2022.
Source: CP6. Would you like to have more contact with family or friends who do not live with you?
Note: Don't know and Refused responses not shown on chart.

Source: Brosnan et al. 2023, Figure 42

The types of contact that were most common were mobile phone for texting (84% Life in Australia^{TM} and 81% CPA), phone or video calls (88% Life in Australia^{TM} and 80% CPA), and face-to-face or in-person visits (83% Life in Australia^{TM} and 71% CPA). Desire for more contact slightly declined between 2020 and 2022 in both surveys.

Loneliness

Loneliness was measured using a composite of a question of whether the carer reported feeling lonely and a question as to whether the carer wanted more contact. A greater proportion of carers in the CPA survey (63%) reported they felt lonely or wanted more contact with family or friends compared to those in the general population survey (44%) (Brosnan et al. 2023, Figure 44). In the Carer Gateway pre-survey 74% of respondents reported that they were lonely compared to 69% in the post-survey (Brosnan et al. 2023, Figure 94). Among respondents who answered both the Carer Gateway pre and post surveys, 63% had no difference in their reported sense of loneliness, 15% reported that they were feeling increased loneliness, and 22% reported feeling less lonely (Brosnan et al. 2023, Figure 102).

In the CWS 2022, analysis comparing carers who had used services with carers who had not identified that participating in the assessment and planning process was associated with lower levels of loneliness for carers with higher needs for assistance (Schirmer and Mylek 2022, 43).

14.4 Economic participation

Participation in employment

Data on carers' employment and the impact of caring on employment was collected in the population surveys, the Carer Gateway pre-post surveys, and the CWS.

In the 2022 Life in Australia^{TM} survey, 54% of respondents (aged 18 years and over) were currently employed on a full-time or part-time basis (Table 20), which is similar to the 2018 ABS SDAC estimate of 53.6% of carers aged 15 years and over (ABS 2019). The CPA survey showed an increase in the proportion employed over time; 33% of respondents were employed in 2020, and 39% were employed in 2022 (Table 20).

Impact of caring on employment

Findings relating to the impact of care on employment, outlined in Table 20, show:

- For Life in Australia^{TM} respondents, 29% of carers in 2022 and 28% in 2020 needed time off work for their caring role. For CPA respondents, the proportion of carers who needed time off work for their caring role had increased to 72% in 2022 from 58% in 2020.

- In 2022, 29% of carers from the CPA survey and 26% from the ERC survey needed to leave their job for 3 months or more to provide care. Fewer respondents to Life in Australia^{TM} (12%) reported they needed to leave their job for 3 months or more to care. For both Life in Australia^{TM} and CPA surveys, there has been minimal change since 2020 (10% Life in Australia^{TM} and 26% CPA).

- Of those Life in Australia^{TM} respondents in 2022 who were not working, 45% were working before they commenced their current caring role (in 2020 this was 43%). Among 2022 CPA respondents, 60% were working before their caring role (in 2020 this was 57%). Approximately half (51%) of ERC respondents in 2022 were working before they commenced their current caring role.

- For those who relinquished employment, 31% of Life in Australia^{TM} and 74% CPA respondents said caring was the main reason they left their job. This was similar to respondents in 2020 (36% Life in Australia^{TM} and 71% CPA). In the 2022 ERC survey, 92% indicated they needed to leave their work to provide care.

Table 20 Employment and the impact of caring on work (% All)

	Life in Australia™ 2022	Life in Australia™ 2020	CPA 2022	CPA 2020	ERC 2022
Employed (full-time or part-time)	54% n=301	-	39% n=1287	33% n=1005	29% n=23
Do you often need time off work because of your caring role?	29% n=88	28% n=67	72% n=921	58% n=556	-
Have you ever needed to leave your job for a period of 3 months or more to provide care?	12% n=37	10% n=23	29% n=385	26% n=263	-
Did you work in a job just before you began your current caring role?	45% n=114	43% n=77	60% n=1280	57% n=1190	51% n=26
Was providing care the main reason you left your job?	31% n=35	36% n=30	74% n=964	71% n=826	92% n=24

Base: D_EMPL: All respondents. 2022 Life in Australia™ n=553, 2022 CPA n=3315, 2020 CPA n=3061, 2022 ERC n=79. Question not asked of Life in Australia™ in 2020. W1: Respondents who are employed. 2022 Life in Australia™ n=301, 2020 Life in Australia™ n=222, 2022 CPA n=1287, 2020 CPA n=1005. Question not asked of ERC in 2022. W2: Respondents who are employed. 2022 Life in Australia™ n=301, 2020 Life in Australia™ n=222, 2022 CPA n=1287, 2020 CPA n=1005, 2022 ERC n=23. W3: Respondents who are not employed. 2022 Life in Australia™ n=252, 2020 Life in Australia™ n=175, 2022 CPA n=2028, 2020 CPA n=2056, 2022 ERC n=51. W4: Respondents who are not employed but were working prior to starting their role as a carer. 2022 Life in Australia™ n=114, 2020 Life in Australia™ n=77, 2022 CPA n=1280, 2020 CPA n=1190, 2022 ERC n=26.

Source: D_EMPL Constructed variable: P_WORKEDLASTWEEK. In the last week, did you do any work at all in a job, business or farm?, P_WORKEDFAMILYBUSINESS. In the last week, did you do any work without pay in a family business? and P_WORKEDFAMILYBUSINESS. In the last week, did you do any work without pay in a family business? W1. Do you often need time off work because of your caring role? W2. Have you ever needed to leave your job for a period of 3 months or more to provide care? W3. Did you work in a job just before you began your current caring role? W4. Was providing care the main reason you left your job?

Change in ability to participate in work or study

Data on changes in employment and study for carers who accessed services was collected in the Carer Gateway pre-post surveys and the CWS. The employment rates for carers in the Carer Gateway pre-survey (39%) and the Carer Gateway post-survey (36%) were not significantly different (Brosnan et al. 2023, Table 41). Among carers who responded to both the pre-post surveys, 90% had the same employment status at both time points, 6% were no longer employed, and 4% had changed from not being employed to being employed (Brosnan et al. 2023, Figure 100).

The CWS compared outcomes for carers who had received Carer Gateway services in the last 12 months with those who had not in 2022 and 2023. The CWS also analysed longer term outcomes for carers who had used services in 2021 in the 2023 survey.

In 2022 and 2023, the analysis found no statistically significant differences in self-reported improvement in the ability to participate in paid work or the ability to progress education/studies between carers who had used any Carer Gateway service and those who had not (Schirmer and Mylek 2022: 51–52, Mylek and Schirmer 2023a, 57 Figure 24). In 2023, the more robust findings in CWS data relating to specific services indicated that:

Among all carers, those who had received support to participate in education and training were more likely to report improvement in being able to progress their study (Mylek and Schirmer 2023a: 55).

Among carers providing support for people with low assistance needs:

- Those who had used respite care were more likely to report the ability to work or study than carers who had not (Mylek and Schirmer 2023a: 56).
- Those who had used practical support were more likely to report improved ability to work (Mylek and Schirmer 2023a: 56).

The CWS 2023 analysis also examined carers engagement with work and study and found that:

Among carers aged 13–64 years providing support for people with *high or very* assistance needs, those who had used respite care were more likely to be studying than carers who had not (Mylek and Schirmer 2023a, 58, Table 4).

Among carers aged 18–64 years providing support for people with *low* assistance needs, those who had used respite care were more likely to be employed than carers who had not (Mylek and Schirmer 2023a, 59, Table 5).

Financial Stress: Impact of the rising cost of living

The 2023 CWS identified that a higher proportion of carers (85%) than the general population (74.7%) reported their household expenses had increased more than their income (Mylek and Schirmer 2023b: 34). Cost of living challenges identified by carers related to difficulty affording groceries (59.8% had difficulty a few or many times), transport (49.7%), and medications (27.7%) (Mylek and Schirmer 2023b: 34). Changes to save money included cancelling, delaying, or reducing medical appointments (46.6%), and cancelling or reducing carer support services (24.1%) (Mylek and Schirmer 2023b: 35).

14.5 Resilience

The approach to resilience in the ICSS Outcomes Framework (see Appendix B) is to increase carers' resilience through effective preventative support services. Key elements of resilience as conceptualised in Carer Gateway are: whether carers are able to access support in a crisis, whether they are supported in a crisis, and whether they are able to continue caring post-crisis.

Barriers to entry or access

The Carer Gateway half yearly performance monitoring reports examine barriers to entry or access to services in the program. Variations in barriers to entry in specific regions may also affect program reach across different geographical locations. Table 21 reports on key statistics identified in these reports across the duration of the ICSS program which are discussed below.

Table 21 Data on barriers to entry (Carer Gateway half yearly performance monitoring reports 2020–2022)

	July to December 2020	January to June 2021	July to December 2021	January to June 2022	July to December 2022
Average telephone wait times (seconds)	65.4	89	140	242	117
Abandoned calls average (*highest reported from a single provider)		10%	*17%	*20%	*13%
% of carers interacting with the Carer Gateway who go on to complete a Carers Star™			73%	69.5%	82.1%
Time to Carers Star™(days)	13	8	12	12	9
Time from Carers Star™ to Receive Services (days)	25.4	20	20	23	26
Time to Service Review from service receipt (days)	87	110	93	98	103
% who have had a Service Review of those receiving services		34	40	55	54

Sources: Accenture 2020:20–24; Accenture 2021 a: 19–22; Accenture 2021b:15–19; Accenture 2022a: 14–18; Accenture 2022b: 15-18.

Telephone wait times**:**

- The average wait time has generally increased since the first year of the program from an initial wait time of 65 seconds to around 2 minutes or more in the period from July 2021 to December 2022.
- In the most recent reporting period (July to December 2022) 50% of calls were answered within 61 seconds, and 80% were answered within 2 minutes (Accenture 2022b: 15).

Abandoned calls:

- In January to June 2021, 10% of calls were abandoned. Since that time the reports have included data relating to the highest percentage of calls abandoned based on data from a single provider in each 6-month period. The highest value in this case was that 20% of calls were abandoned in the January to June 2022 period.

Completing a Carers Star™ assessment**:**

- In July to December 2022, 82.1% of carers who interacted with Carer Gateway completed a Carers Star™ assessment. This percentage has increased relative to the previous two periods.

Time to receiving Carers Star^{TM}:

- The average time to complete Carers Star^{TM} varied between 8 and 13 days across the reporting periods. It is noted that there is a lot of variation across the program with 50% completed within 3 days, and 90% within 26 days (Accenture 2022b: 17)

Time to receive services:

- The average time to receive the first service after Carers Star^{TM} is also increasing and stands at 26 days in July to December 2022 (Accenture 2022b: 17), with longer average times for carers living in regional and remote areas and for some service types (carer support and material goods and specialist support (funded through tailored support packages)). Around 93% of carers have a Carers Star^{TM} assessment before receiving their first preventative service (Accenture 2022b: 17).

Time to service review:

- In July to December 2022, the average time to service review from receiving the first service was 103 days, and 54% of carers receiving services had a service review (Accenture 2022b: 18).
- Across the program to December 2022, of the 134,715 carers who had registered, 71% had had one Carers Star^{TM} assessment and 34.6 % had recorded a second Carers Star^{TM} assessment, which is below the program benchmark of 50% (Accenture 2022b: 18).

Effective preventative services – service mix

Key issues identified in the performance monitoring reports about the service mix are:

- In July to December 2022, among clients who accessed emergency respite, 34% also received a preventative service before or after (Accenture 2022b: 19).
- The average wait time to receive emergency respite was 6 days (to June 2022), with 50% receiving it within 1 day (Accenture 2022a: 20).
- The average number of emergency respite sessions used across the program is 10 (Accenture 2022b: 20).
- In the July to December 2022 period, the number of days between emergency respite sessions is 50 for carers who do receive a preventative service and 25 for carers who do not (Accenture 2022b: Figure 16, 20).

The impact of ICSS on continuity of caring (as indicated by receipt of Carers Allowance).

A key aim of Carer Gateway services is to support carers' ability to continue caring. This section reports on the analysis of the relationship between exit from Carers Allowance and the receipt of services over the 2015 to 2022 period. This analysis tests whether people are more likely to continue caring (as indicated by continued receipt of Carer Allowance) if they are receiving different carer support services. Specifically, this seeks to identify whether continuity of care has changed since the introduction of the ICSS program (compared to the earlier carer support programs).

The estimation method tests whether the probability of continuing caring is lower for those people receiving ICSS services (compared to earlier services and no service receipt). More details of the analysis are included in Appendix F.2.

Prior to the introduction of ICSS, carers who had received any carer support services in the previous year were less likely to exit from Carer Allowance and therefore more likely to continue caring. This could be because either those carers and carers with greater needs were more likely to both receive support services and also more likely to continue to stay on Carer Allowance, OR because the support services assisted them to continue to care longer and hence remain on the payment. While we cannot distinguish between these two explanations, we are able to test whether this overall relationship between exit and support has changed since the introduction of ICSS.

Overall, we find no overall change in this relationship between the period before and during the ICSS operation. We then explore whether different components of the ICSS program were associated with changes in exit from Carer Allowance. The ICSS interaction terms for counselling and ‘review’ services are not significantly different from zero – indicating that their impact on exit is no different than for similar services existing before the introduction of ICSS. Other services, such as intake, and importantly, respite have negative interactions. This indicates that exit from carer allowance for people receiving these services is now lower since the introduction of ICSS. On the other hand, the interaction terms for information and other high-cost services are positive, indicating that they led to higher exit rates from Carer Allowance.

In interpreting these results we have to consider that many of the services will be provided in combination. Intake and information services, for example, would often go together, with offsetting effects.

In summary, compared to the pre-ICSS service model, there is no overall impact of the receipt of Carer Gateway services on exit from Carer Allowance and therefore on the probability of continuing to provide care. However, there is evidence that receiving respite services from Carer Gateway is associated with a lower rate of exit from Carer Allowance (i.e. a greater probability of continuing to care), compared to the pre-2020 respite programs. However, the opposite applies for the other high-cost services, which are associated with a lower probability of continuing to care.

14.6 Stakeholder perspectives

Stakeholders were somewhat cautious to comment on program outcomes and the program logic. Several stakeholders talked about the need for more consistent and comprehensive data collection, monitoring, and reporting to determine whether the program is in fact meeting its intended outcomes.

There were mixed views about whether the shift in design is, or will be, effective in providing early intervention services and supports to carers. As noted earlier, some stakeholders were optimistic that the shift in program design was positive and that it will meet the needs of carers over time.

Others felt that the current design was not meeting immediate needs, compared with the previous carer supports, and therefore was having a negative impact on carer wellbeing.

Stakeholders acknowledged the different approaches that providers have in terms of assessing and identifying carer needs, where some try to ensure carers get what ‘they’re entitled to’ (i.e. maximizing tailored support packages), while others are more focused on identifying carer needs in the present and planning for the future. In the latter case, stakeholders talked about the potential for Carer Gateway as a whole to build the resilience and long-term wellbeing of carers.

Wellbeing

Stakeholders talked about the program design and its logic in supporting carers’ wellbeing; however, they usually referred to evaluations or specific data to say whether or not they thought the program was meeting these outcomes. As discussed elsewhere, many stakeholders still believed that it was too early to know whether the program was achieving its intended outcomes, including around wellbeing. Some examples of this are included below:

> So, this is one way I think as the program matures, we’ll see more about that. Look, you can see the measurement of wellbeing I think is a really nice tool and it’s showing a lift in wellbeing and prevention. So, it feels and the data sort of indicates that it’s heading on the right track, but I think it may be too early to conclude exactly what’s happening there. That’s something I’d really love to see out of the evaluation, but early results feel like we’re on the right direction to increases in wellbeing, greater sort of preventative bolstering’s and that sort of sandbagging against some of the issues that impact on people. Yeah, but I want to watch that space. (Other stakeholder 12).
>
> But then it's interesting because if you look at effective, if you define effectiveness by doing a pre and post evaluation on how accessing a service has impacted a carers wellbeing, I know from the very few people that have done carer coaching, they've reported that they've had really positive impacts and outcomes from that service. (Service provider 10)
>
> But in terms of what we’re seeing about the types of supports and services being accessed, there is a spread – some of, lower than others – but it is showing that some more effort is going towards that early intervention and prevention to support carers. I think it’s one of those things that we’re not really going to see whether it’s achieving its intended outcomes until 10 years down the track – until we see those actual changes in carer participation in community, in employment, in those types of things, to see if those early intervention services are working. (Other stakeholder 8)

Social connection

Several stakeholders talked about the importance of social connection as contributing to the wellbeing of carers and, ultimately, the sustainability of their caring role. Stakeholders explained different ways social connection is, and can be, achieved through Carer Gateway. Other stakeholders talked about the social connection that is achieved through the services and packages, often for specific cohorts. For example, providing camps for young carers was identified as an important service to help with social connection, as were retreats, in-person peer support, and bush picnics for Aboriginal and Torres Strait Islander carers.

Resilience

As reported earlier, several stakeholders believed the new Carer Gateway model is more preventative and designed to build capacity, as opposed to providing immediate respite (Service provider 10). In this way, stakeholders implied the program has the potential to improve resilience for carers. However, they were cautious to make any conclusive statements about whether these outcomes have been realised within the short timeframe of the program. As with other outcome areas, stakeholders often referred to the need for consistent data and monitoring to track these outcomes.

14.7 Aboriginal and Torres Strait Islander carer perspectives

There were mixed responses about whether Carer Gateway was achieving the intended outcomes for Aboriginal and Torres Strait Islander carers.

Wellbeing

Some carers talked positively about the benefits of immediate support (i.e. respite) they received and the impacts on their wellbeing and stress (Carer 35, metro). Others, however, were more neutral or negative about the services making a difference, indicating that they would access emergency respite, but they would then go back to the stresses of their everyday caring role (Carer 34, metro).

> Well, it’s helped me do my doctor’s appointments and get all the appointments and that because I had no phone. So, they gave me a phone so I can do Skype and all that. So, I haven’t missed no appointments since that. (Carer regional)

Other carers reflected on the benefits of receiving support but noted that it was time limited.

> The first year I was involved in it, they were supportive; the lady that was there, she was very good at what she was doing. She was very inclusive of everybody. She had lots of supports there and there were a few workshops that I attended, and the psychologist. The support I received for that year I’d had a lot of anxiety and depression problems, and I was really down and out. I’d seen their psychologist, and they were really, really good. Then I got a package from them that I could do yoga and meditation. But then after that year they stopped that package – I haven’t been back– I didn’t see that there was any other help that they could give me. (Carer regional)

Capacity for caring

A number of carers noted that Carer Gateway had provided them with information about services, and skills to help them in their caring role and to support their mental health. For example:

> They just made me understand a little bit more of the services that were available if I did need extra services, which I didn’t know were available and now that I know they’re available and if I do need them, at least I know that I can go to them. (Carer metro).
>
> One of the questions in the Star was about my own mental health and stuff like that. It made me sort of sit back and think when she asked me if I had time for myself. Which the answer is no I don’t have time for myself. So I've made it a thing when the kids go back to school,

> then I'm going to have to find time for myself. Even if it's just meeting up with my friends to go for a coffee and cake. Yeah, it needs to be done. Because it was helping me with my mental health. Like I said, even just five minutes out of the house (Carer metro).

Economic participation

Although several carers spoke about their respite needs not being met, one carer provided an example of how respite can support economic participation. The carer worked part-time and said that receiving respite enabled her to continue to work. However, the carer wanted more respite so she could have a break from caring apart from when she went to work. The carer commented:

> I think I need more respite – because it's just 24/7 with my [child]. The only break I get is when I'm virtually at work. I just need more respite. At least I can come to work, and I think well, at least somebody is with [my child] for four hours. (Carer regional)

Other carers were helped financially through referrals to services that subsidized the cost of food.

> She sent me a card to go to [name of service] and believe me, you would not believe how much that helped me get through. It was a blessing. I mean, there’s one that I got $50 where I didn’t pay, but then on the next visit which I paid for it but what I bought would have cost me a fortune in the shop. You know what I mean? I’ve got one more visit left that I’m hanging onto dearly for just before I do go into hospital and then I can use my last visit and get stuff for the house and hoping that we get through until I can get back on my feet again (Carer metro).

14.8 Non-Indigenous Carers

Many carers perceived the supports and services they accessed through Carer Gateway to be very beneficial in terms of their wellbeing and resilience. Some carers experienced multiple benefits from the different support.

Wellbeing

Although some found it difficult to organise time to attend coaching sessions, carers who accessed coaching indicated that it provided positive self-care strategies that supported both their wellbeing and confidence. Carers also gained tools to help manage their stress leading to improvements in wellbeing.

Counselling services helped carers to manage their caring responsibilities by giving them strategies to manage their care and support their health. One carer commented:

> So that was good [counselling], she gave me some really good strategies on how to actually set that in motion and implement that on a daily basis. So that was one of my main goals. That was really good, and then the follow-up a month later we talked about how it had gone that previous month, and it was good because I knew that I had that appointment with her, so it made me do my half an hour a day because I didn’t want to have the appointment and then say, oh, no, I haven’t done this. (Carer 4 regional)

Another carer noted that access to counselling support impacted positively on the way they provided care. They said:

> So at one point when I had counselling with them, I was really angry, and I was angry about the fact that - just the fact that my life was literally pivoting around this one role, and everything comes back to that. So how much I can work, how much money I can make, my life then in that respect, all that. So, and I think that was just an accumulation of stuff. So it impacts (sic) the way that I cared for my mother because it changed that focus for me. (Carer 4 metro)

Capacity for caring

Access to Carer Gateway programs helped some carers better manage their stress at difficult times or when in a crisis. Carers could access and learn about tools to manage stress through counselling and online forums. These tools helped carers not feel guilty about their responsibilities to their care recipient and helped them understand that they should take care of themselves. For example, Carer Gateway services helped the carer to better acknowledge the impact of the caring role on them, the time it took, and the associated exhaustion. One carer noted that through counselling she had a better understanding of her feelings and of ways to communicate with her parent around the impact of being a carer and the importance of collaboration. The carer commented:

> I think it’s given me a break so that I can be a better carer. Don’t know whether it’s increased my skills or my knowledge, but it’s definitely afforded me to have that bit of time to myself so that you can just rejuvenate and feel like you’ve had a break, so that you can – yeah, be better at your caring role. (Carer 4 regional)

Access to counselling had increased carers’ knowledge and skills they needed to manage their caring role. One carer provided an example of attending the Carer Retreat. The activities at the retreat provided them with information about Carer Gateway, as well as self-care strategies that supported mental health and assisted them to continue to provide care. Access to practical help, such as a support worker once a month, alleviated some of the pressure associated with caring responsibilities. Some carers found undertaking the Carers Star^{TM} increased their knowledge about caring because it helped them to reflect on and assess their daily caring role.

Social participation

Carers with access to respite indicated that it enabled them to continue caring and be a better carer. Respite provided a break and the time to connect with others and do things they enjoyed.

Economic participation

One carer (Carer 7 regional) found a computer course she attended was very useful. Through the course she was able to develop computer skills which gave her more control over her life and increase her independence. As a result of attending the course, her confidence improved, and she became involved with voluntary work. This helped her to understand her role as a carer – especially during times of crisis. Since then, she has tried to be a spokesperson and help other carers in her community.

A number of carers were employed but it is difficult to associate this outcome with support provided by Carer Gateway. The most common situations for carers in terms of economic participation was that it was difficult for them to maintain employment while providing high levels of care. A number of carers worked part-time due to their caring responsibilities. At least three carers had left work to provide care. For example, a now full-time carer for his wife had accepted redundancy in 2020. His wife's level of disability had increased during 2020, so given he had left work, was nearing retirement age, and could receive Carer Pension, it seemed reasonable for him to focus on the care of his wife as she now relied on him for everything. Carer Gateway supported his transition from work and applying for their pensions. He was guided through managing financial worries around caring responsibilities. The couple was helped to set up their pensions, via a counsellor. This carer stopped accessing support, as circumstances at home changed and his wife's health improved and found life more manageable.

Resilience

Several carers indicated that services such as online peer support and counselling accessed via Carer Gateway during a specific time had provided them with the support they needed. For example, a carer used online peer support and counselling when his wife was hospitalised for over 6 months. During this time he felt lonely and depressed. He valued getting a professional opinion 'outside of his bubble' and talking to someone who could help with him deal with emotional issues and motivate him to care for himself. After his wife returned home, he found he no longer needed support.

Another carer (Carer 5 regional) noted that although she was not accessing supports at present, she was reassured that if her circumstances changed, she would be able to access the necessary help through Carer Gateway. The supports she had previously accessed, such as counselling, had improved her wellbeing by teaching her strategies for self-care and skills to manage her caring role; this strengthened her resilience through the use of effective preventative support services.

14.9 Summary

Overall, carers score lower on **wellbeing** measures than the non-carer population. Among carers, some aspects of wellbeing (general health, K10, carer burden) have worsened between 2020 and 2022. Carers receiving Carer Payment or Carer Allowance or accessing Carer Gateway had lower wellbeing (general health, K10, carer burden) than carers generally, which may reflect these groups of carers having higher needs than those not accessing income support or services. Changes in wellbeing cannot be attributed solely to Carer Gateway services and the analysis is limited by small samples sizes. Among carers who had used services, the majority of wellbeing outcomes remained the same. However, some changes were recorded in the data:

- 35% reported a positive change on Carers Star^{TM} and 10% reported a negative change (DEX program data).
- 23% reported positive changes on PWI and 13% reported a negative change (pre-post surveys).
- K10: 19% had lower stress levels and 24% had higher stress levels (pre-post surveys).

- Burden: the proportion of carers reporting they felt extremely burdened reduced from 14% of carers in the pre-survey to 7% of carers in the post-survey (pre-post surveys).

- Carer Distress: participation in the ICSS program was associated with an *increase* in the likelihood of being prescribed one of the prescription drugs in 2022. This may be due to selection effects.

- The CWS analysis found that use of some services (assessment and planning process or skills building and coaching) was associated with increased wellbeing (as measured by the PWI and K10) for carers caring for a person with higher support needs.

Carers in the Carer Gateway pre-post surveys improved their scores on measures of competence and preparedness and therefore their **capacity for caring**. The CWS 2022 and 2023 analysis found that a number of Carer Gateway services were associated with improvements in carers' overall ability to care, confidence in ability to be a good carer, and ability to find out about and organise access to services for care recipients.

In terms of **social participation**, the majority of carers indicated they would like to have more contact with family or friends who do not live with them. A large proportion (85%) of carers who were accessing Carer Gateway services reported wanting more contact. Loneliness was higher amongst Carer Payment/Carer Allowance recipients (63%) and carers accessing services (74% pre-survey and 69% post-survey) compared to 44% in the general carer population. Among Carer Gateway pre-post survey respondents, most reported no change, 15% reported they were feeling increased loneliness, and 22% reported feeling less lonely.

The **economic participation** of carers is lower than the general population. Carers have lower levels of employment than non-carers, with carers in receipt of Carer Payment or Carer Allowance having lower employment levels overall, reflecting that these are income-tested benefits. The impact of caring on employment was similar in 2020 and 2022. Small changes may relate to the impact of COVID-19 pandemic. The majority (90%) of respondents in the Carer Gateway pre-post surveys reported no change in their employment status.

Barriers to entry to the program include telephone wait times and the wait times to complete a Carers Star^{TM} and receive services. Program data indicates that carers who receive preventative services have a longer duration between emergency respite use episodes. Among Carer Allowance recipients, receiving respite care is associated with a lower rate of exit from Carer Allowance, which may be a proxy for being able to continue to care and therefore demonstrates **resilience**.

Overall, carers identified the benefits of receiving support such as respite on reducing stress and improving wellbeing, although these outcomes could be short-term. Access to information and courses helped carers to continue to care and provided them with skills to assist in their caring role. Services such as counselling and peer support contributed to carers positive outcomes in terms of wellbeing, resilience, and social participation. Carers were also supported financially by taking courses that helped them secure employment, and regular respite that enabled a carer to remain in part-time employment.

15 Question 7a: Unintended outcomes

Evaluation Question 7a: Have there been any unintended program outcomes?

15.1 Stakeholder perspectives

Most stakeholders did not identify any unintended consequences. The few examples of positive or negative unintended consequences identified related to carers' interaction with Carer Gateway rather than outcomes specified in the program logic.

A couple of stakeholders talked about an unexpected outcome being the social connection that carers experienced from ongoing communication with care planners. As one stakeholder explained:

> The real challenge we actually have is we've got these amazing care planners who have got these big hearts full of empathy and they don't want to sort of go, okay, it's time to go, time to go. But I guess that's probably a bit of unintended consequences, that sort of pseudo counselling sort of role that the care planners come into. We just see our numbers of people that connect and they're growing year on year on year and it's not – I don't think it's because the services are growing, I think it's because people are connected. (Service provider 11)

A couple of stakeholders identified other associated negative unintended consequences, either in relation to the lack of respite services due to broader workforce shortages, which were exacerbated by the timing of the rollout, changes to the NDIS, and the impacts from the COVID-19 pandemic. Note that as discussed above, these factors were not caused by Carer Gateway but are reflections of broader care workforce issues and the pandemic.

15.2 Carer perspectives

Some carers talked positively about their conversations with the intake team members when they first contacted Carer Gateway. Although for carers this was an unexpected outcome, it was part of the program design. Carers were provided with connections and knowledge about what services might be available to support them in the future. One Aboriginal carer explained:

> Well, there was just the people that I called when I was in the most stressed-out moments and I didn't know what to do, just the person on the phone saying we can help with this. They offered different services and told me everything that was available and then it was up to me to choose. Just talking to them in that moment was actually more beneficial than the counselling session. (Carer 35, metro)

Other Aboriginal and Torres Strait Islander carers identified unintended consequences, in that the 1800 number acted as a point of contact to ask questions:

> Yes. They are helpful. They're a good resource just to have there as far as, you know, if I get stuck, I can ring them and say, hang on a minute, can you please explain this to me? (Carer 45, regional)

> But other than what the Carer Gateway could do by listening to me and supporting me emotionally and that, there was not much else that they could do about that particular situation. (Carer 46, regional)

Non-Indigenous carers also commented on the positive impact of having someone listen to them and understand their needs when they spoke to intake teams or when undertaking an assessment. For some carers this was the first time their caring work had been acknowledged and valued. Another unexpected consequence for some carers was information about and help to navigate administrative and service systems. While Carer Gateway is designed to focus on preventative services, many carers first engage with Carer Gateway when they reach a point of crisis; in these cases, intake workers may act as de facto counsellors and help carers navigate systems during periods of crisis.

> I think the biggest thing I got from the Carer Gateway, is the assistance to get around the red tape as you can imagine, it's really, really difficult, and I found that that was the most challenging thing. I'm in my 50s, mid-50s, and even though I so grew up on computers and stuff like that, to get around the government departments, even though we had duties of care with powers of attorney and all this stuff, it was really difficult. It was really on me, and it was really, really challenging (Carer 19 metro).

Although carers' experience of contact with Carer Gateway should be a positive experience and their questions should be responded to, this was in some ways unintended in the sense that the participants did not expect such a positive experience when making their initial contact.

15.3 Summary

There were very few positive or negative unintended consequences. The inconsistent use of Carers Star^{TM} assessments for emergency respite is potentially a negative unintended consequence, but this can also be considered a 'teething problem' faced by a new initiative and is something that will be relatively easy to resolve. Most of the positive changes were intended as part of the program. The assessment process for some carers was the first time they had talked about their caring situations in detail and had been listened to. Carers also identified Carer Gateway as a touch point and source of information to help them find appropriate support in different services systems. Although these are intended processes and outcomes of Carer Gateway they were unexpected from the point of view of the carers.

1 Question 7b: Factors affecting program outcomes

Evaluation Question 7b: What factors have contributed to or detracted from the achievement of outcomes (intended and unintended)?

15.4 Stakeholder perspectives

COVID-19

Almost all stakeholders identified the COVID-19 pandemic as impacting the implementation and outcomes of Carer Gateway. Impacts were talked about both positively and negatively. Some of the negative aspects for Carer Gateway included: workforce shortages; inability to engage with carers to deliver in-person services (counselling, coaching, in-person peer support); increased mental health issues for carers and their recipients; and complex caring arrangements due to restrictions and isolation requirements, particularly where care recipients were living in residences or receiving medical services (Other stakeholder 1, Service provider 3). Some stakeholders also talked about COVID-19 as a barrier to achieving their KPIs[15] because it was harder to engage with carers. Some stakeholders explained how the pandemic impacted the capacity for Carer Gateway to operate as a preventative model.

> The Carer Gateway, fundamentally, is designed to be a capacity building model. It's designed to get carers before they reach crisis point. It's designed to reach hidden carers. But because we went live during COVID-19, it meant that people were just surviving, and carers were really struggling. We had carers ringing us looking for support when they were in dire straits and there was just no capacity within that two years to think about taking that preventative approach because everyone's just in survival mode. So, it was reacting to the carers most urgent needs and providing a lot of crisis support and immediate support. (Service provider 10)
>
> That’s had a big impact and now as we’re coming out of COVID-19, we’ve got to try and – our providers have got to try and re-educate our – the carers about what is actually – the program is about. I think that was that crisis, immediate needs support of carers during COVID-19 which has skewed the intent of the program. (Other stakeholder 8)

Stakeholders also talked positively about some aspects of COVID-19, particularly the way that DSS and providers responded and adapted to the pandemic to meet carers’ needs. This included shifting to provide services online and by phone; being flexible with how respite packages could be used; and extending packages in extenuating circumstances. Many providers were very proud of what they had achieved to support carers through COVID-19. Some stakeholders noted that online services were normalized and became more popular and accessible to some cohorts of carers who otherwise may not have engaged at all (Other stakeholder 3).

---

[15] Note the Carer Gateway does not set KPIs for services, although they may have KPIs from their own organisations.

Workforce shortages

The National Skills Commission (NSC) estimated that the demand for care staff would increase by 40% by November 2025 and that this could not be met by working-aged Australians. The growth and demand for care workers will occur at the same time as a decrease in working-aged Australians. At present there are four working age persons for every person aged 65 years and over; this compares to 6.6 people in 1984 (NSC 2021, 2021a).

Workforce shortages were regularly identified as a barrier to achieving the intended outcomes of Carer Gateway (Service provider 1, Service provider 9). CGSPs had different service models, with some having direct employees for counselling and coaching, while others subcontracted to other services. It is understood that for providers relying on subcontractors, in particular, it was often very difficult to find workers to deliver the services that carers were assessed for under Carers Star^{TM}. Thus, carers often waited a long time to receive services – or did not receive them at all. This was especially challenging in regional and remote areas where it is particularly difficult to recruit workers. In some locations, CGSPs were competing for a local workforce where NDIS and aged care workers were paid higher wages. One stakeholder explained they would welcome greater consistency in conditions of these workforces.

> This is the harmonisation approach, which is trying to get the systems like NDIS, aged care and DVA, which are the three main ones, to better talk to each other. Regulation around all these other bits and pieces and the Fair Work Commission decisions that are being made recently on minimum awards and the aged care work case, will help in terms of attracting staff. (Other stakeholder 11).

Workforce and skills shortages were identified for counsellors for carers of people with mental health and alcohol and other drug issues (Service provider 14).

Rural and remote

Workforce shortages are especially pronounced in regional and remote locations due to thin markets in those areas.

> I think the thing that we're hearing most at the moment is the difficulty finding respite care in rural and remote areas and we have so many people begging and all we can do is follow up with their local provider and let them know that they're really upset about it. (Service provider 13)

In addition to workforce shortages in rural and remote communities, some stakeholders also identified the added cost of getting staff, services and products into remote communities, which is not accounted for in the tailored support packages (Service provider 4).

Carers Star^{TM} assessment

Several stakeholders viewed the Carers Star^{TM} assessment as a barrier to accessing Carer Gateway services, which included both real and perceived barriers. For example, some providers indicated that they did not call it an 'assessment', but rather referred to the Carers Star^{TM} process as a planning session to ensure carers did not think they needed to be at a certain 'level' to receive support (Service provider 15). Others saw the Carers Star^{TM} as a real barrier in that carers said they did not have time to complete the Carers Star^{TM} with a staff member and so they would not access any services.

> The Carers Star^{TM} in essence should be – there should be lots of time to provide that, to introduce it, to give people information and then give people information to digest that and work through it individually before they come together with an assessment worker to work through the whole process together. But the reality I think is quite different on the ground, because to actually put services in place you need to have completed that Carers Star^{TM} and then have a corresponding action plan with whatever services you identify. Carers Star^{TM} is probably more of a case management tool. (Service provider 9)
>
> Whilst it is a really comprehensive assessment tool – and I think that it's fantastic, that it actually does look at a carer's life and their needs very holistically – it is something that does take a lot of time for carers. I think they find it very invasive. Particularly if they are also accessing other assessments for the person they care for to receive, whether it be Aged Care or disability type care services. It's yet another comprehensive assessment that they have to go through. (Service provider 12)
>
> I do think too – it would actually enable us to be more efficient if we were to have a less complex assessment tool. … it would make the whole assessment and review process much more attractive for the carers. It would actually improve their journey with our organisation too. So, I definitely think that's a benefit. (Service provider 12)

Lack of awareness

Another factor stakeholders identified as a barrier to achieving outcomes is the lack of awareness among carers and the broader community. Many stakeholders explained that client numbers have been slow to increase because carers do not identify as carers and/or they are not aware of Carer Gateway. Some stakeholders thought COVID-19 impacted the latter and because the national communications campaign was delayed (Service provider 5, Service provider 8, Service provider 11, Other stakeholder 9).

Stakeholders had mixed views about the effectiveness of the recent communications campaign that commenced in October 2022. Some indicated that the volume of carers has increased, while others did not think the campaign made much of a difference.

The lack of awareness was experienced differently across carer cohorts. For example, stakeholders indicated young carers were not aware because there is not enough targeted campaigns and outreach to schools. While for Aboriginal and Torres Strait Islander carers, it is understood that there are cultural barriers to recognizing themselves as carers because kin structures mean there are family obligations to care, and so it they don't view themselves as 'carers' (Service provider 4). Similar comments were made about carers from culturally and linguistically diverse communities.

It is expected that recent specialist communication for targeted groups of carers, including Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse communities, will address some of these barriers (Other stakeholder 7).

> [They think that Carer Gateway is] for people on the Carer Payment or the Carer Allowance. Again, it's that perception that to be a carer that needs help from the government at this level, you have to be on something like that, whereas the Gateway's more preventive and

> available. There’s information for everybody. So, that’s a bit difficult as well that a lot of carers think, well, I wasn’t eligible for the payment so I’m not going to be eligible for the Carer Gateway stuff. It’s a government system (Other stakeholder 5).

Some stakeholders also commented on the need for greater community awareness to facilitate referrals into Carer Gateway (Other stakeholder 7). As one stakeholder said:

> So, it really is about that community-wide approach, and that bigger community piece around, if you see a carer, or you know a carer, then you might encourage them to phone Carer Gateway, or you might phone for them, or you might refer them to Carer Gateway. I think it's just that broader understanding (Service provider 5).

Digital access

A few stakeholders talked about digital access as a barrier to accessing Carer Gateway and achieving outcomes (Service provider 4, Service provider 5, Service provider 12, Other stakeholder 3). This included carers living in rural and remote communities who did not have access to a telephone or internet, as well as carers who had low levels of digital literacy. Conversely, digital access was identified as a facilitator for some carers who would otherwise, due to geographic isolation or COVID-19, not access any services. On balance, it could be concluded that digital services are an important part of the Carer Gateway model to facilitate access, but there must also be alternative options to access Carer Gateway and its services to ensure that some carers don’t miss out. In this way, digital access is both a solution to reaching carers in regional and remote locations, but a barrier for others. Carers in regional and remote locations can be doubly disadvantaged where there are also workforce shortages, plus there are often challenges of ensuring services are culturally appropriate (Other stakeholder). As one stakeholder said:

> It's what services are actually available out there, that’s the biggest limit and also whether the models actually are culturally appropriate. The access to telephone counselling or online counselling – for traditional Aboriginal people – I'm not saying that people couldn't benefit from counselling, but it would have to be culturally appropriate. (Service provider 2)

15.5 Aboriginal and Torres Strait Islander carer perspectives

Aboriginal and Torres Strait Islander carers noted several factors that contributed to or detracted from the achievement of outcomes.

Carers experiences of contacting Carer Gateway varied. Several carers had positive interactions when speaking with workers conducting the initial intake or assessment process. Factors that contributed to carers’ increased knowledge of available services and access to support to help them continue to care included: feeling comfortable when speaking to workers, being listened to, information being provided in a manner they could understand and being referred to appropriate support. Carers commented:

> I felt quite comfortable with the people that I talked to, most definitely. If I didn’t understand, I’d ask them what they meant, they’d explained it really well. When I need them, they seem to be there for me all the time. I get their advice on what I need. They’re very, very good. (Carer, metro)

> Yes, they referred me onto their services. So, I did some telephone counselling, and something else as well. It was good as far as finding out what was available, but, as far as getting referrals onto those services, that's when I kind of found more difficulty with the requirements. (Carer regional)

However, other carers did not access the support they needed through Carer Gateway. Some carers expressed frustration about not receiving support after contacting services or being spoken to in a rude and condescending manner.

> Sometimes you just give up, because it's just promises and you're not getting anywhere, so you just give up ringing and that. (Carer metro)
>
> I applied for one of their services – like a getaway just overnight sort of thing and that. Apparently, I'm not entitled to it. She was very rude about that as well – the way she spoke to me – this woman. She's also rude. I said, well why did I have to be recognised [as a carer], and she says, well you have to bloody be. More understanding about Aboriginal people. And the way they speak to them as well – like speak down to them. (Carer metro)

Another carer found the number of reviews they had to undertake problematic and commented:

> To make it better - I reckon their services should– stop giving reviews every time, because that is humiliating to me because they want to know the ins and out. They're not giving the services I really need and there's money sitting there. (Carer metro).

Another factor identified by carers that detracted from achieving outcomes was the variable quality of support provided by services. One carer commented:

> Everything keeps changing and the staff keep changing, and my [child] is just so stubborn that when they have a change of staff, it takes her a while to get used to one [staff] member and then when they change her to another… we're back to square one. We just keep taking backward steps (Carer regional).

Some carers perceived there to be differences between their previous experiences with Commonwealth Care Link and Carer Gateway.

> I rang to ask them about the differences between Commonwealth Care Link and them [Carer Gateway] – When I asked for respite before, Commonwealth Care Link used to help us with that like paying our board or travel expense and everything. But now with [Carer] Gateway it's different. They don't do that anymore. (Carer regional)

15.6 Non-Indigenous carer perspectives

Carers identified several factors that contributed to the achievement of outcomes. Friendly, well trained front-line staff, who understood the issues they faced, and supported them through the registration and assessment processes helped them to access needed services. Timely follow-up calls after the registration and assessment and streamline referrals to high quality services also helped them to gain support that could impact on outcomes. However, being placed on a waiting list, particularly in a crisis, dealing with multiple people from different organisations and a lack of services to cover carers when they attended information or training courses created barriers to accessing support. One carer commented:

> I think they've all been helpful in different ways, to be honest. I couldn't really say one over the other, because the retreat was really, really good, their monthly support is really good, and I also found the coaching quite beneficial. So, yeah, I think they all definitely have really good merits on their own. Well, it's given me more grey hairs dealing with them, but the services that they offer - it's worth the input from me because the services that they can offer are really, really beneficial. I just wish that they were easier to deal with. (Carer 4 regional)

15.7 Summary

A range of factors have been reported by stakeholders and carers to affect outcomes. In summary these include external factors, in particular COVID-19 and its impact on care service systems, as well as aspects of Carer Gateway itself which have limited access to services for some groups of carers, as is reported elsewhere. The workforce challenges which affect the availability and timeliness of services are considerable barriers for many carers to improve their wellbeing. On the positive side, the more streamlined service, positive relationships, and good communication between DSS and service providers, and the use of the Carers Star™ assessment have contributed to continuous improvement of service provision. Factors that facilitated Aboriginal and Torres Strait Islander carers achieving outcomes included interactions with staff who treated them with respect, staff who actively listened to them, and having access to or being provided with information that met their needs. Non-Indigenous carers identified well trained staff who could help them to access appropriate support by streamlining the referral process to high quality services contributed to positive outcomes.

16 Question 7c: Carers who have benefited most

Evaluation Question 7c: What are the characteristics of carers who have benefited most from the program and why? To what extent have outcomes differed for the following demographic groups (where applicable):

(i) Aboriginal and Torres Strait Islander carers
(ii) female carers
(iii) carers with disability
(iv) regional or remote carers
(v) young carers (aged less than 25 years)
(vi) older carers
(vii) carers of older persons
(viii) Culturally and Linguistically Diverse carers
(ix) mental health carers.

16.1 Changes in Carers Star™ scores by demographic group

This section uses DEX data to examine outcomes for different groups of carers[16]. Outcomes are examined using changes in the first and last SCORE, for the 46,653 carers (one third) who had more than one Carers Star™ assessment recorded by the end of 2022.[17] In most cases, the first and last scores recorded were collected at intake and review, but in some cases the two scores were both initial intake scores.

All demographic groups improved their average score. Overall, the average increase was 0.29 score points, with 33.6% having an increase in their score, 55.7% showing no change and 10.7% a decrease.

Increases were lower than the average increase for those carers aged under 26 years and over 65 years, Aboriginal and Torres Strait Islander carers, carers with a disability, those living in remote and very remote regions and those who reported their primary income source as government payments (though there were many carers who did not report their income status).

In Section 18 and Appendix F.3, we also report the results from a regression which predicts the change in average score as a function of services received and demographic characteristics. The impact of demographic characteristics while controlling for services and other characteristics is broadly the same as in Table 22, however, there are some differences. In particular, the increase in score for Aboriginal and Torres Strait Islander carers is not significantly different from the

---

[16] As DEX only contains information about the carer, not the care recipient, analysis cannot distinguish carers of older people or mental health carers.

[17] While around a third of carers overall had more than one assessment, this was also the case for each demographic group. Between 30–40% of each demographic group examined had two scores recorded, though the very remote and not stated categories had lower percentages.

average when controlling for these other factors. This could reflect their different service use patterns and their location in very remote locations.

The Half Yearly Monitoring reports confirm that there are no significant differences in wellbeing changes by different demographics. With regard to remoteness, the majority of carers were assessed as maintaining wellbeing. In this analysis very remote carers and outer regional carers are *less* likely to experience a positive wellbeing change, as indicated above, these regions have a smaller group of carers responding and therefore the data is more sensitive to outliers.

Table 22 Mean pre and post SCORES by demographic characteristics

	First score	Last score	Mean increase in score	% with			
	Mean	Mean		Decrease %	No change %	Increase %	N
All	**3.43**	**3.72**	**0.29**	**10.7**	**55.7**	**33.6**	**46,653**
Gender							
Male	3.57	3.86	0.28	9.9	57.0	33.1	10,092
Female	3.40	3.68	0.29	10.8	55.4	33.8	36,366
Not stated/ other	3.26	3.36	0.11	20.5	48.2	31.3	195
Age							
<26	3.41	3.65	0.24	12.4	55.6	32.0	2,855
26-49	3.14	3.44	0.30	11.1	54.1	34.7	12,587
50-64	3.44	3.75	0.31	9.9	55.2	34.9	14,537
65-79	3.64	3.90	0.26	10.8	57.2	32.0	12,915
80+	3.70	3.96	0.26	10.3	58.1	31.6	3,759
Indigenous Status							
Yes	3.25	3.51	0.25	12.8	54.2	33.0	1,671
No	3.44	3.73	0.29	10.6	55.9	33.6	43,861
Not stated	3.32	3.61	0.29	12.1	52.0	35.9	1,121
CALD Status							
Not CALD	3.45	3.73	0.28	10.7	55.7	33.6	43,473
CALD	3.25	3.55	0.30	10.0	55.6	34.4	3,180
Disability Status							
Yes	3.55	3.77	0.21	12.4	58.3	29.2	6,780
No	3.41	3.71	0.30	10.4	55.3	34.3	39,741
Not stated	3.29	3.70	0.41	8.3	47.0	44.7	132
Client Remoteness Area							
Major city	3.41	3.69	0.28	10.6	56.2	33.2	30,828
Inner regional	3.49	3.81	0.32	9.7	55.0	35.3	10,896
Outer regional	3.47	3.72	0.25	12.4	54.8	32.8	4,232
Remote	3.55	3.74	0.19	16.8	51.8	31.4	541
Very remote	3.45	3.53	0.08	18.6	55.8	25.6	156
Income Source							
Employee salary / wages	3.45	3.78	0.33	9.2	56.0	34.8	6,836
Government payments / pensions / allowances	3.50	3.76	0.26	10.8	57.5	31.7	14,725
Other income including superannuation and investments	3.66	3.95	0.28	9.1	58.8	32.0	2,369
Self-employed (Unincorporated business income)	3.45	3.87	0.42	7.2	53.3	39.5	587
Unknown/ Nil	3.36	3.64	0.28	11.3	54.1	34.6	22,136

Source: Authors analysis of DEX data for the period April 2020 to December 2022. Note. Population: Clients who had two or more scores recorded. Excludes scores recorded in association with digital counselling (which uses a different scoring system). Client characteristics as at first session recorded.

16.2 Summary

All the demographic groups appear to have benefitted from the ICSS and there were few significant differences between different demographic groups. However, there were lower increases in wellbeing based on wellbeing score analysis for carers aged under 25 years and over 65 years, Aboriginal and Torres Strait Islander carers, carers with disability, those living in remote and very remote regions and those who reported their primary income source as government payments (though there were many carers who did not report their income status).

17 Question 7d: ICSS services contributing most to carer outcomes

Evaluation Question 7d: For the ICSS evaluation: Which ICSS services have contributed most to carer outcomes?

17.1 Changes in Carers Star™ scores by service types

Table 23 shows the changes in mental health, wellbeing, and self-care score by service type for all carers who had more than one Carers Star™ assessment. On average, these assessments were 225 days apart (median 150) and increased by 0.29 points. Those who had received respite services had the largest increase in the score (0.37 points), with emergency respite having a similar association. Indeed, all service categories except for education and skills training and mentoring/peer support had above-average score increases. Note that about one-quarter of carers who received two DEX scores are not recorded as having received any of the services listed in the table between their two assessments. For example, they might have approached services for two initial assessments, but on both occasions not wished (or been able) to receive further services.

Table 23 Increase in mental health, wellbeing and self-care score between first and last assessment: Clients who have received at least some of each service

	First score	Last score	Mean increase in score	% with		Days between assessments		N
	Mean	Mean		Decrease	Increase	Mean	Median	
Carer support	3.27	3.52	0.25	15.5	35.7	360	327	1,293
Material Goods	3.23	3.50	0.27	13.5	35.8	325	270	1,884
Specialist support	3.27	3.60	0.33	11.3	37.6	294	223	10,246
Respite	3.28	3.65	0.37	10.9	40.1	267	197	10,392
Emergency Respite	3.19	3.54	0.36	12.7	40.1	266	189	2,999
Counselling	3.20	3.52	0.32	12.0	37.8	299	238	8,594
Education and Skills training	3.27	3.52	0.24	13.3	33.1	306	239	2,344
Information/advice/referral	3.45	3.72	0.26	12.9	33.3	272	207	21,666
Mentoring/Peer Support	3.41	3.61	0.20	15.3	31.6	369	328	3,800
All	3.43	3.72	0.29	10.7	33.6	225	150	46,654

Population: Clients with at least two assessments between April 2020 and December 2022 (excluding assessments recorded in association with digital counselling). Support sessions are counted if they lie between the first and last assessment dates +/– one day

In part, these differences reflect variations in the initial situation of clients and tendency for the most disadvantaged groups to be brought closer to the average. Across the different service categories the gap between the highest and lowest first score average was 0.26 points, while this gap narrowed to 0.22 points for the last score.

Table 24 reports on changes in the mean mental health, wellbeing and self-care SCORE data for digital counselling clients. The DASS-21 is used to assess the wellbeing of clients receiving digital counselling and scores from the DASS-21 are translated into the five-point mental health, wellbeing and self-care SCORE scale. The measure and outcomes thus differ from the Carers Star^{TM} used to assess changes in outcomes in the other Carer Gateway programs. The analysis shows that the average increase in means SCOREs was 1.13 and that 70.9% of digital counselling clients improved their scores, while for 7%, their scores decreased and 22.1 recorded no change.

Table 24 Change in mean mental health, wellbeing and self-care (circumstances) SCOREs for digital counselling clients 2020–2022 (DEX)

				Change in score					
	First score	**Last score**	**Increase in score**	Decrease	No change	Increase	**Days between assessments**		
	(mean)	(mean)	(mean)	%	%	%	(mean)	(median)	N
Digital counselling	2.25	3.37	1.13	7.0	22.1	70.9	109	77	3,493

Source: Authors' analysis of DEX data April 2020- 2022. Notes: Digital counselling commenced in 2019 so this analysis does not include all clients.

These associations with receipt of services, do not, however, take account of the fact that people receiving one type of service might also be receiving other services. For example, there is a tendency for people receiving emergency respite to also receive ordinary respite services. Counselling, training, information and mentoring/peer support services also tend to be associated with each other.[18]

To address this, Appendix F.3 presents the results from a regression analysis, predicting the increase in score as a function of whether the person had received each of the services and other demographic characteristics. The first parameter in the model describes the impact of the services alone and shows that, for clients who did not receive any services, the SCORE increased by an average of 0.27 points. This increase could reflect changing patterns of scoring the instrument over time or possibly clients being more aware of the program and hence being more interested in seeking help when their needs were less severe on the second occasion. It could also indicate that they received services from sources outside Carer Gateway or that the initial information and advice was sufficient for them to improve their wellbeing.

To look at the impact of particular services on the Carers Star^{TM} scores, we can combine the effect of each service with this overall impact – though the appropriateness of this depends on the reasons for the increase for people who do not receive any services. If the initial information and advice helped improve outcomes, then it might be appropriate to add them together when considering the overall impact of the program. On the other hand, if this base increase represents changing measurement, or other factors from outside of the program, then it would be most appropriate to only consider the incremental impact of each program (the parameter estimate as presented in Appendix F.3).

In this estimation, respite is associated with the largest increase in score (0.12 points higher than the score for those without any services, or an increase of 0.39 in total), while specialist support, emergency respite and counselling have increases of about half this amount. These results are

---

[18] Correlations in the binary indicator variables of 0.11 to 0.17.

similar when the analysis controls for demographic characteristics. However, even though these observed characteristics are controlled for, it is possible that these patterns could reflect different characteristics of people receiving different services. For example, some services might be more likely to be associated with care recipients whose needs might be increasing over time and thus more likely to lead to a decrease in scores.

17.2 Summary

Carers were provided with services to meet their specific needs, and therefore, the combination of these services influence outcomes. DEX data, which draws on Carers Star^{TM} assessment data, indicated that carers who accessed respite had the largest increase in scores over time, around double those among carers who accessed specialist support, emergency respite and counselling. Some services were associated with *decreases* in mean score outcomes compared to those who received no services (training, advice, and mentoring/peer support), and other services were associated with no significant change (support and material goods). Digital counselling, which uses the DASS-21 to assess changes in outcomes, recorded positive changes for 70.9% of clients.

Part C: Efficiency

Part C presents findings relating to the efficiency of the program. This is informed by:

- Survey data (the population and emergency respite surveys, and the CWS)
- Interview data (carer and stakeholder interviews), and
- DEX data used for 6-monthly reports.

Methods used to answer each question are reported and then triangulated in a summary at the end of the question. The analysis indicates that Carer Gateway is cost-effective and that, using different analyses, the Carer Gateway costs are less than the benefits accrued to the government through carer wellbeing and participation and also replacement of formal care for care recipients. The analysis indicates that high-cost services represented the majority of service offerings from the Carer Gateway, but that, over time, the proportion of high-cost services is declining, indicating that the transition has been cost-effective.

18 Question 8: Interactions and Referral Pathways

Evaluation Question 8: To what extent do interactions and/or referral pathways between the Carer Gateway, the YCBP [Young Carer Bursary program] / YCN [Young Carers Network], and the TCVO [Tristate Carer Vocational Outcomes Pilot/Your Caring Way] contribute to achieving outcomes across the respective programs?

18.1 DEX data on carer support programs

The DSS provided data from DEX on which programs recorded in DEX carers accessed as their first and second activities. Appendix F4, Table 25 summarises some key numbers from this data for five categories of programs. Note that the flows between programs described here are based on data recorded in DEX and for carers with a SLK linkage in the DEX data. See other caveats and explanations in the notes below. The YCBP/YCN and TCVO programs are relatively much smaller than the Carer Gateway, and there has therefore been a low proportion of Carer Gateway clients accessing these programs, although a high proportion of clients from both programs have accessed Carer Gateway.

Key points to note based on this data are:

- Of the 3715 carers recorded in the YCBP in this data, 405 (10.9%) had accessed the ICSS Carer Gateway Providers prior to accessing the YCBP and 171 (4.6%) accessed the Carer Gateway after the accessing the YCBP. (Noting also that YCBP has spanned a period prior to the commencement of Carer Gateway) (Total of 576 carers (15.5%) in both programs).
- Of the 1407 carers in the TCVO, 535 (38%) had accessed ICSS Carer Gateway Providers before the TCVO and 175 (12.4%) had accessed the Carer Gateway after the TCVO (Total of 710 (50.5%) carers in both programs).

18.2 Stakeholder perspectives

Stakeholders generally considered the interactions between the different components of the ICSS to be working well, but noted the overall complexity of the service system, including its relation to the NDIS, My Aged Care, and other state funded services. Generally, service providers attempted to help carers access the most appropriate services irrespective of who they were funded by.

> There’s quite a number of state-funded agencies that do have state funded carer support funding and then there’s the Gateway. So, I think that would probably be quite conflicting for a carer to know which will suit what I need, which one do I go to and why. I guess when they come into us and we might provide some counselling through the Gateway, but we might provide some practical support through our state funded program, we don’t explicitly say to the carer, we’re using this bit for this and this bit for this. I don’t see the point. As long as their goals are identified and addressed, I don’t think it matters to tell them where the funding has come from. But I think maybe for referral sources too, there is confusion around

> do I refer to the Gateway or do I refer to state funded agencies or both? I think there’s still probably confusion there. (Service provider 14)

Some stakeholders, however, noted that it could be a challenge referring on to Carer Gateway services due to waiting times or identifying the correct referral pathway to Carer Gateway services as described below:

> I guess having the right pathways for us to know to, I think with each Carer Gateway, they obviously operate slightly differently too, in terms of their service delivery times, how long carers are waiting to be helped. (Service provider 20)

Stakeholders further discussed how referral pathways could be improved including expanding referral pathways through a continuous improvement process (service provider 20) and building relationships with services they refer to. (Service provider 20, 21)

> It would just be then looking at our existing relationships with who the Carer Gateway would be, you know, to be able to make sure that it is smooth for the carer. (Service provider 18)

The parameters around TCVO and YCBP (referred to simply as the ‘Bursary’ by participants) also created some barriers, in that TCVO was only available in three states, and applications for YCBP need to be made at certain times of the year. However, these were not perceived to be significant barriers or particularly problematic.

> [The] bursary is not accessible to all the young carers, but the carer directed packages [are]. Bursary require process of locations and it’s only open once a year. So, that creates a lot of gaps. So, when we inform the young carers, we say – we separate between the Carer Gateway services and bursary and we deliver to them saying that Carer Gateway service is available but based on their needs while [the] bursary give them more flexibility around how they want to spend for their education, yeah. So, that we would see for a lot of good feedback. Support with time for themselves. That’s also another area where young carers find it really helpful. (Service provider 4)

> We were lucky in that, in the early days of Your Caring Way, we actually had someone sitting within our office. Those referral pathways were built really early around that connection across, and then coming back, but they were enhanced by the ability to have some conversation to around, okay I’ve got this situation what do you think, as well. I think we were actually really lucky in that sense. We saw no barriers. We did work in the very beginning, smoothing out. There were little hiccups as there always is when something’s new, but we smoothed those out really quickly and I think we had good referral pathways in both directions. (Service provider 17)

Stakeholders from TCVO in particular emphasised that it was important to have good personal relationships and clear communication pathways with the Carer Gateway and that these facilitated referrals in both directions.

The data shows that 15.5% of YCBP Clients also accessed Carer Gateway, noting also that YCBP has spanned a period prior to the commencement of Carer Gateway, so the YCBP participants may have accessed other DSS carer support services.

18.3 Summary

The YCBP/YCN and TCVO programs are much smaller than the Carer Gateway. There has therefore been a low proportion of Carer Gateway clients accessing these programs and they have had very limited overall impact on the Carer Gateway outcomes. On the other hand, a high proportion of clients from both programs have accessed Carer Gateway. As of June 2022, 38% of TCVO clients had their first session of TCVO after a Carer Gateway session and 12.4% of TCVO clients had their first TCVO session before a Carer Gateway session. Stakeholders generally considered these interactions to be positive and that carers accessing YCBP and TCVO were provided with adequate Carer Gateway services when needed.

The Your Caring Way (TCVO) evaluation found that referrals to and from TCVO and Carer Gateway were helpful to the carers who accessed the program.

19 Question 9: Cost-effectiveness of the program

Evaluation Question 9: How cost-effective is the program?

The economic value of informal care is typically measured as either: (1) the replacement value, estimated as the cost of providing the equivalent formal care[19] based on the market cost of buying services, or (2) the opportunity cost, estimated as the amount of time spent caring relative to forgone earnings.

The anticipated benefit of Carer Gateway is that informal care will be sustained, and replacement costs will be minimised. The cost-effectiveness analysis estimates the money saved by providing services to carers via Carer Gateway by placing an economic value to observed changes in behaviour and wellbeing of carers receiving services.

The approaches used to estimate the cost-effectiveness of the program are presented in Appendix G.

19.1 Cost of Carer Gateway

The cost of Carer Gateway is approximately $130m spent on grants in 2022 (DSS data). This cost is attributed to an estimated 5% of carers who access Carer Gateway each year.[20] The cost-effectiveness of the program considers the cost of different services provided to each client as the unit of observation.

As a starting point, services are categorised into ‘low’ and ‘high’ cost using the categories supplied by DSS, although the actual unit costs and the relative differences between low- and high-cost services are not known. This approach relies on the assumptions that:

- the differences between low- and high-costs are sufficiently large, e.g. more than 20% or 30%
- such differences might cover both fixed and variable costs, and
- sessions can only be low-cost or high-cost with no variation within a category – i.e. all sessions in the low-cost (or high-cost) category have similar financial cost and cost structure regardless of the service provider and the location where the service takes place. If this were not the case, the analysis and conclusions below could be quite different.

The services are categorised as follows:

- **low-cost**: Counselling; Education and skills training (in person coaching); Mentoring/Peer support (in person peer support).

---

[19] Note that carers may provide care in excess of what would be provided in formal care arrangements.

[20] Note in Section 11.5, the figure 6% of carers represents the proportion of carers who have *ever* accessed Carer Gateway.

- **high-cost**: Carer support; Emergency respite; Material goods; Respite; Specialist support.[21]

Table 25 indicates the numbers of occasions of service provided in each 6-month period from January 2021–December 2022. The table shows that the numbers of occasions of service have risen in each 6-month period since the start of ICSS. Of note, emergency respite services have recorded an upward trend until mid-2022 but then fell in the last half of 2022 from a high of 25,200 to a low of 14,123. Planned respite has increased in each period other than January to June 2022 when there was a slight drop.

Table 25 Services in each period April 2020–December 2022

	Apr–Dec 2020	Jan–Jun 2021	Jul–Dec 2021	Jan–Jun 2022	Jul–Dec 2022
Carer support	2,378	2,527	2,284	2,416	3,761
Counselling	19,440	19,019	24,778	24,183	30,701
Education and skills	565	929	3,856	8,661	10,325
Emergency respite	18,226	21,844	24,159	25,200	14,123
Information	42,444	39,228	58,369	79,986	93,102
Intake assessment	74,938	82,434	92,376	80,514	85,765
Material goods	623	774	1,333	1,400	1,510
Mentoring	7,314	9,277	15,045	16,210	25,424
Respite	27,003	35,168	43,280	40,830	44,787
Service review	8,909	14,849	20,660	21,534	27,199
Specialist support	12,984	22,180	22,593	22,946	24,143
Total	214,824	248,229	308,733	323,880	360,840

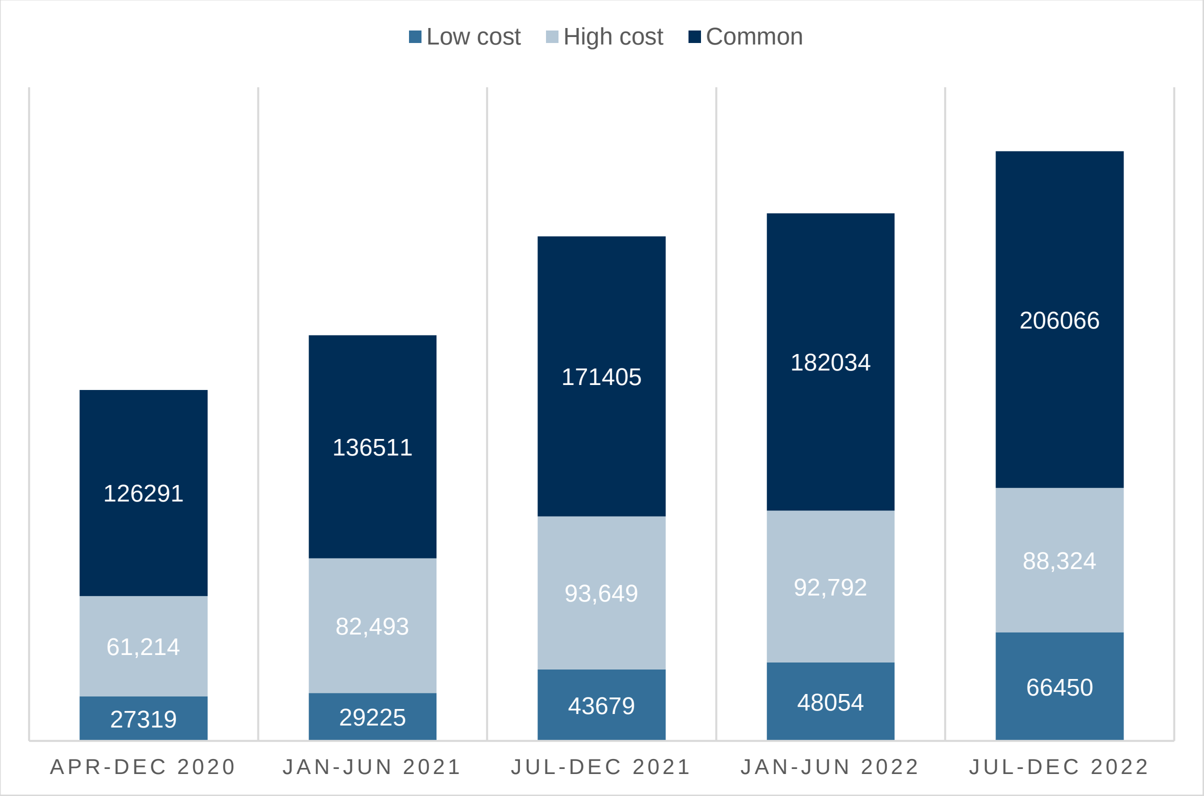
Source: Authors' analysis of DEX data

Figure 14 shows the number of services provided in each 6-month period in 2020 to 2022 by cost category. Intake, assessment and information, and service review are indicated separately as they are provided in relation to both high- and low-cost services. If these are excluded, the analysis indicates that low-cost services represented 26.1% of services in the first half of 2021, rising to 42.9% of services in the last half of 2022. Thus, most services provided by Carer Gateway were high-cost throughout this period, although the proportion of low-cost services has been rising over time.

---

[21] See Appendix C for details of these service types.

Figure 14 Number of high- and low-cost services, 2020–2022



Source: ICSS by cost type, DEX data 2020–2022 (supply 3). Data exclude carers enrolled in the Tristate Carer Vocational Outcomes Pilot and Young Carer Bursary Program. Note that the first period is longer as it covers 6 April 2020 to 31 December 2020. Low-cost services include: counselling, education and skills, and mentoring. High-cost services include: carer support, emergency respite, material goods, respite, and specialist support. Common services include: information, intake assessment, and service review.

19.2 Benefits of Carer Gateway

Carer Gateway is anticipated to impact carers:

- directly, through the hours of care they provide and changes in their wellbeing, participation and resilience, and
- indirectly, through impacts on the care recipient, in terms of reduced need for formal care.

Identifying the direct and indirect effects is complicated by the fact that carers are unlikely to start or stop caring because of an intervention – most carers are intrinsically motivated to provide care or do so because formal care is not available or too expensive. In addition, supports provided to carers may influence behaviours that are unobserved (e.g. the nature of care provided) rather than observed and measurable variables such as the number of hours worked. This suggests the economic benefits of providing carers with supports are likely to be observed through effects on the care recipient through the avoidance of formal care.

19.3 Estimating cost effectiveness

Three different components were identified as contributing to the overall cost-benefits of Carer Gateway. The detailed method and assumptions behind each component are presented in Appendix G.

The traditional approach to cost-benefit analysis involves the identification of the differences that the program generate relative to a world without such the program. We have identified three components: the first is the likely effect of Carer Gateway on the decision, the activity, and the effect of caring on both the carer and person cared for. From here we can estimate the economic value of such effects relative to the cost of providing Carer Gateway services (a1). In addition, we calculate the proportion of caring that can be attributed to Carer Gateway (based on program costs) relative to the overall value of care provided (a2). Finally, we include the indirect effects of the program: namely the avoidance of hospitalisation for the people cared for (a3). The sum of these three components provides a more accurate estimate of the overall benefits of Carer Gateway.

(a1) ***Effect on the decision to provide care***

This analysis focuses on the extent to which carers receiving Carer Gateway support remain in employment or take up employment.

Using the Deloitte (2020) estimate that 17.7% primary carers had given up employment to care full-time, we suggest that it is unlikely that Carer Gateway services will facilitate a return to work for this group. Our prior assumption is confirmed by the pre-post survey findings reported in Section 14.4.3, which indicate 90% of carers did not change employment status. The opportunity cost of working can be approximated by average weekly earnings $1753/week ($91,000/year) while the value of Carer Gateway support is estimated to be $1100/year (using median earnings leads to the same conclusion).

For the 82.3% of primary carers who remain in employment, the question is whether receiving Carer Gateway support of $1100/year has an impact on their choice to remain in employment or whether they would give it up to be a full-time carer. This possibility is also unlikely, as Carer Gateway support is about 1% of the value of earnings when calculated on an annual basis (i.e. $1100/(52 x $1753)) – an unlikely amount to trigger a large behavioural response in the sub-population of interest.

Even if marginal cases existed (that is, where people switch from working to caring or vice-versa) the resources allocated to Carer Gateway support seem very small relative to weekly earnings to impact, alone, on the decision to work or provide care.[22] The effect in one direction (e.g. from

---

[22] Brosnan et al. (2023) Figure 100 indicates that around 10% of carers accessing Carer Gateway have changed employment status: 4% are now employed and 6% have given up employment. In the most extreme of cases, whereby the extreme reference group from which to enter/exit employment is unemployment, the existence of Carer Gateway has generated a net reduction in the hours of labour supplied (–6% exits + 4% entries = –2% x about 130,000 carers x 35 hours/week x 52 weeks/year = about 4.732m hours of labour), and a corresponding increase in the number of unemployment benefits being paid as there are now more unemployed than before the program was introduced (i.e. 2% x 130,000 = 2,600). This could represent a net annual cost of $243.71m (i.e. 4.732m hours x $37/hour + 2,600 new

working to caring) is likely to be compensated by the opposite effect (i.e. from caring to working). We propose to follow a conservative approach and hence **set to zero** the effect of Carer Gateway on the decision to move from employment to providing care.

(a2) *Effect on caring activity*: the prevention of, or reduction in, burnout and mental health issues among carers (estimated in the lower use of medication and associated health costs).

Effect on caring activity: the literature identifies two possible effects of carer support programs. The first is the prevention of, or reduction in, burnout and mental health issues among carers. This effect is at times estimated in the lower use of medication and associated health costs (Arksey et al, 2002).

A conservative approach is to limit the positive effects of Carer Gateway to those using services that have a high-cost ('high-cost'). Based on DEX-DOMINO data for 2021 and 2022 (i.e. the more recent years and the period when the program could be considered as getting closer to its desired regime) about 28% of cases are high-cost sessions (carer support, emergency respite, respite, material goods, and specialist support). The most conservative analysis assumes that all risk is accounted for by the wellbeing of the carer, and that use of Carer Gateway lowers such risk but only for carers accessing high-cost services. As shown in Table 25 and Figure 14 there were 357,258 high-cost sessions in total in 2021–2022, or 178,629 on average for each of the two years.

Multiplying the number of sessions by the cost of non-admission hospital services (mainly mental health services) of $317 (the Australian Institute for Health and Welfare; AIHW, 2023) allows us to estimate the total savings associated with receiving Carer Gateway support (mental health) of $56.625m in each year (i.e. 178,629 x $317). This is a conservative measure as the number of high-cost services over time has been rising.

The second effect of providing carer supports is the increase in wellbeing impacting on the productivity of carers who remain in employment. Fakeye et al. (2023) estimate a 30% productivity loss of carers who continue to work while caring. Carer support programs can reduce such a loss.

From Table 23, the average increase in mental health and wellbeing of carers receiving Carer Gateway is 0.29 on a first score of 3.43. This corresponds to an improvement of 8.5%, which is assumed to be reflected in higher productivity for carers who are in employment. As productivity underpins earnings, such improvement is assumed to generate a corresponding increase in average earnings.

---

unemployment benefits of $510/week x 52 weeks per annum based on the maximum Carer payment - https://www.servicesaustralia.gov.au/how-much-carer-payment-you-can-get?context=21816). In a more realistic case, exits from employment are from intermediate stages of employment like part-time or casual (9-15 hours/week) to provide some hours of care, while entries likely raise substantially the hours of work, including the case of full employment at 35 hours/week, as they may be related to the relocation or death of the person cared for. For instance, exits (6% of 130,000 = 7,800 carers) working on average 15 hours less per week would reduce hours of work supplied in a year by 6.084m units (7,800 x 15 hours reduced x 52 weeks) while entries would add about 6.67m (4% x 130,000 x 25 additional hours x 52 weeks) resulting in a net gain of about 676,000 hours or $25.012m (if valued at the average of $37). These numbers and nature of assumptions suggest using a conservative approach with no tangible effect arising from this component of cost-benefit

The productivity improvement resulting from this effect of Carer Gateway support **is therefore valued** as:

- 8.5% (higher productivity) x $1,753 (weekly earnings) x 52 (weeks/year) x about 75,000 carers (for each of the years 2021 and 2022) x 28% employment rate = **$162.71m** per year.

If the 30% productivity improvement is applied (rather than 8.5%), as found by Fakeye et al. (2023), the result above increases to $574.28m per annum.

The value of component (a2) based on 8.5% higher productivity is $56.625m + $162.71m = $219.33m

(a3) *Indirect effect*: Preventing or delaying hospital admissions or avoiding outpatient services for the care recipient

Indirect effect: This analysis includes the effect on the care recipient when the carer accesses Carer Gateway. One approach is to assume that Carer Gateway services delay or prevent hospital admissions (in the most serious cases) or avoid outpatient services (in the least severe cases) for the care recipient. The value of this effect is estimated to be $661.7m for 2022 (see Appendix G.2 for the approach used).

The resulting benefit-cost ratio (BCR) for these three components is 7.6 (actual expenditure). Thus Carer Gateway appears to be cost effective as the costs are about 13.1% (expenditure) of the benefits generated.

Even if indirect benefits are excluded[23], the total amount of benefits associated with Carer Gateway is equal to $219.33m, or about 1.89 times the expenditure of the program ($116m on an annualised basis over 2021-2022, based on DSS information), and 1.67 times using 2022 expenses.

For each of the components identified above, the Carer Gateway provides greater benefits than costs with the most robust benefit-cost ratio (BCR) being 7.6 (or 6.72 using 2022 expenses).

19.4 Summary

Three different effects were identified to estimate the cost-benefits of Carer Gateway. Based on the data available for this evaluation, Carer Gateway is a cost-effective program.

(a1) *Effect on the decision to provide care*: this analysis focuses on the extent to which carers receiving Carer Gateway support remain in employment or take up employment.

(a2) *Effect on caring activity*: the prevention of, or reduction in, burnout and mental health issues among carers (estimated in the lower use of medication and associated health costs.

---

[23] Cost-benefit analysis should conceptually include indirect benefits.

(a3) *Indirect effect*: Preventing or delaying hospital admissions or avoiding outpatient services for the care recipient

All three effects suggest that the benefits of Carer Gateway exceed the costs with a benefit-cost ratio (BCR) of 6.72–7.60 times (actual expenditure).

20 Question 9a: Cost-effectiveness of restructure

Evaluation Question 9a: To what extent has the ICSS restructured investment in carer support increased cost-effectiveness?

20.1 Effect of the restructured investment in carer support

This section analyses the DEX-DOMINO data which indicates the service use of carers on Carer Payment, comparing service use before and after the implementation of Carer Gateway. Examination across the range of services reveals the lower likelihood of accessing high-cost services such as respite and specialist support (‘respite’ and ‘other high-cost’). In contrast, there is no statistically detectable change in accessing counselling and only a small drop in the likelihood of accessing information services. Combined, the findings indicate that carers who access Carer Gateway are more likely to access low-cost services (and less likely to access high-cost services) than carers who accessed services prior to the implementation of the Carer Gateway. Since Carer Getaway was found to be cost-effective overall (see Section 20), the restructuring has resulted in more demand for services that are cheaper to deliver and are cost-effective.

To better understand whether these effects are driven by sub-groups of the population of carers, the analysis explores various demographic characteristics to highlight whether some sub-groups were more or less likely than others to access services following introduction of the Carer Gateway (see Appendix G,

Table 42).

This additional analysis (presented in Appendix G, Section G.3) provides additional insights. Namely, after the implementation of the Carer Gateway:

- The proportion of male carers accessing services (other than counselling) is higher compared to the period before the implementation of Carer Gateway.
- Services are more likely to have been accessed by carers in the 27–49 age group since Carer Gateway was implemented compared to carers in the older age group (50+).
- Aboriginal and Torres Strait Islander carers appear to have become less likely to access services. This may reflect differences in accessing information and/or services and is consistent with some of the findings of the qualitative analysis.
- The analysis indicates that there appear to be changes in the delivery of services across Australian states and territories, with a higher probability of accessing Carer Gateway services in NSW and in Victoria and South Australia with respect to respite and other high-cost services. More counselling and information were instead accessed in Western Australia, Tasmania, Victoria, and South Australia.

20.2 Summary

The restructured investment does appear to have increased the cost-effectiveness of carer services in Australia in that it helped shift use away from high-cost services such as respite and specialist counselling, towards low-cost services such as information. This effect is more marked for particular sub-groups: male carers, carers in the 27–49 age group, and carers in Western Australia, Tasmania and South Australia.

Part D: Aboriginal and Torres Strait Islander carers

Part D presents key findings related to Aboriginal and Torres Strait Islander carers from the analysis of Appropriateness (Part A) and Effectiveness (Part B) of Carer Gateway in this report.

21 Aboriginal and Torres Strait Islander carers

21.1 Introduction

This section brings together evaluation findings to provide an overview of the specific issues related to the appropriateness and effectiveness of Carer Gateway for Aboriginal and Torres Strait Islander carers. This is informed by analysis of DEX and DEX-DOMINO data, population surveys and the CWS, and interviews with stakeholders and Aboriginal and Torres Strait Islander carers.

Sections 22.2–22.7 report on the appropriateness of the program, and Sections 22.8–22.14 report on the effectiveness of the program for Aboriginal and Torres Strait Islander carers.

21.2 Appropriateness

Aboriginal and Torres Strait Islanders were considered by stakeholders to be one of the groups served least well by Carer Gateway. Aboriginal and Torres Strait Islander carers had different experiences of Carer Gateway, with some having positive experiences whereas others indicated their cultural needs had not been met. Some Aboriginal and Torres Strait Islander carers and service providers expressed concerns that the Carers Star^{TM} assessment is not culturally safe for some Aboriginal and Torres Strait Islander carers and similarly that some of the services are not culturally appropriate or accessible for this population, particularly those who live in regional and remote areas.

Some service providers adapted the engagement and assessment processes to better reflect the needs of Aboriginal and Torres Strait Islander carers. A consistent finding across different data sources related to the interface between the Carer Gateway and the NDIS; Aboriginal and Torres Strait Islander carers found the task of navigating these different schemes very challenging. Stakeholders also reported challenges for service providers and carers in negotiating this interface, given the different policy and funding settings of the two schemes. Some Aboriginal and Torres Strait Islander carers were uncertain about which services were provided by the NDIS and which were provided by Carer Gateway. This made it difficult to determine whether Carer Gateway services were accessible or effective. This confusion suggests a lack of awareness about Carer Gateway which may prevent it reaching more carers and achieving the intended outcomes of the program. In contrast, Carer Gateway was reported by stakeholders and carers to work well with My Aged Care.

Stakeholder perspectives

Stakeholders identified cultural barriers to accessing Carer Gateway, both in terms of language and geographical remoteness. Service providers explained how program design and service offerings were not appropriate for some Aboriginal and Torres Strait Islander carers, including accessing Carer Gateway through a 1800 number rather than through a trusted relationship or connection to an existing service or individual. Other service providers talked about how respite looked different for Aboriginal and Torres Strait Islander carers, who may prefer to stay in community and have access to practical supports rather than leave community to access respite from caring.

Some stakeholders talked positively about how they adapted certain elements to better meet carers' needs; for example by setting up Aboriginal and Torres Strait Islander outreach teams, ensuring assessments were able to be conducted face-to-face rather than by phone or online, and using some discretion to let tailored support packages be used to purchase tools or appliances where services simply did not exist in communities (i.e. a washing machine or lawn mower when there were no cleaners or gardeners to do the work). Aboriginal engagement teams were talked about positively by the service providers as a way to address some of the program design challenges and to better reach and connect with Aboriginal and Torres Strait Islander carers.

Carer perspectives

The experiences of Aboriginal and Torres Strait Islander carers appeared to differ across locations/providers. Importantly, interviews with Aboriginal and Torres Strait Islander carers indicated many were uncertain about what Carer Gateway consisted of. Carers were more likely to refer to an individual or a service provider they were connected to, which in some instances appeared to be an NDIS or other service provider and not necessarily related to Carer Gateway.

Data in the CWS 2023 indicated that Aboriginal and Torres Strait Islander carers were less satisfied than all carers with some aspects of Carer Gateway including: the phone service (47.1% vs 63.3%), and the friendliness (59.9%) and helpfulness (57.1%) of staff (Schirmer and Mylek 2022:23–5). The CWS analysis also found that Aboriginal and Torres Strait Islander carers were:

- Less likely to be satisfied with the Carer Gateway printed information (Mylek and Schirmer 2023a:34).
- More likely to be satisfied with the Carer Gateway website overall and the information available on the Carer Gateway website (Mylek and Schirmer 2023a:34).

The only service consistently identified and discussed by Aboriginal and Torres Strait Islander carers interviewed was emergency respite. Emergency respite was accessed to address immediate needs and helped carers prevent a crisis from occurring or supported them to continue in their caring role.

Aboriginal and Torres Strait Islander carers talked about regular/scheduled respite, particularly in circumstances where they had children with a disability. However, it was unclear whether this respite was provided through Carer Gateway or the NDIS. In some instances, respite was not accessible or suitable for Aboriginal and Torres Strait Islander carers.

Respite care, housework, gardening, rubbish removal, and transport to medical appointments were the most common services that carers wanted better or more access to. Some carers expressed frustration after being referred to services due to the costs or not being able to access supports they felt they were entitled to. Other carers indicated they did not access any supports or services, but they found it helpful to know who to ring if they needed it.

21.2.1.1 Appropriateness of Carers Star^{TM}

In addition to being seen as time consuming to administer, some stakeholders considered the Carers Star^{TM} to be inappropriate for Aboriginal and Torres Strait Islander carers, given the need to build trusting relationships before expecting carers to share information about themselves and their families. Several providers talked about adapting the Carers Star^{TM} when working with Aboriginal and Torres Strait Islander carers or finding alternative approaches to identify their needs and services. Some worked closely with local clinics and mobile services where workers already had established trusting relationships with carers and could help to identify and refer to them to appropriate services and supports.

Many of the questions in the Carers Star^{TM} were also identified as culturally inappropriate for Aboriginal and Torres Strait Islander carers. For example, respite for Aboriginal and Torres Strait Islander carers might look very different to respite for non-Indigenous carers, as discussed above. One stakeholder commented that respite sometimes required taking them away from their care recipient and community, which was often not what they wanted.

Overall Aboriginal and Torres Strait Islander carers were happy with the registration and Carers Star^{TM} assessment process, indicating they felt comfortable with the person they spoke with, and felt they provided the information and referrals they needed at the time. However, many said that they were unclear about what the Carers Star^{TM} assessment was, as they tended to view any contact and communication with the service provider as part of the process of identifying needs and services. The Carers Star^{TM} itself did not appear to be either meaningful or very valuable for carers themselves to identify their needs.

As with the initial registration/intake phone call, there were differences across the locations/providers in terms of whether staff members asked carers if they identified as Aboriginal or Torres Strait Islander and whether they would prefer to talk to an Aboriginal or Torres Strait Islander staff member. There were mixed experiences about the length of time the Carers Star^{TM} assessment took, which is likely an indication of providers adapting the Carers Star^{TM} to improve the cultural appropriateness for the carer and their needs.

21.2.1.2 Carers’ needs and wellbeing

Data recorded in DEX up to December 2021 showed that Aboriginal and Torres Strait Islander carers were assessed with higher levels of need on their initial Carers Star^{TM} compared to all carers (note lower score = higher need) (Accenture 2021b: 27). As shown in **Error! Not a valid bookmark self-reference.**, 14% of Aboriginal and Torres Strait Islander carers scored 1 or 2 (i.e. high levels of need) on the Carers Star^{TM} compared with 10% of all carers, while 47% scored 3 compared with 37% of all carers (Accenture 2021b: 27).

Table 26 Carers Star^{TM} score for All carers and Indigenous carers to December 2021

Score	All carers %	Aboriginal and Torres Strait Islander carers %
1 or 2	10	14
3	37	47
4	42	32
5	11	7

Source: Analysis of DEX in Accenture 2021b: 27.

The DEX data from the Carers Star^{TM} assessments do not provide insights into the specific needs of carers.

Some specific issues are noted in the analysis of the 2023 CWS (Mylek and Schirmer 2023b) which reported that Aboriginal and Torres Strait Islander carers:

- Experienced a greater than average increase in the proportion of carers reporting low wellbeing (as measured by the PWI) from 44.1% in 2022 to 59.1% in 2023 (Mylek and Schirmer 2023b: 7).
- Were less likely to report that their home meets their needs well (Mylek and Schirmer 2023b: 18).
- Were more likely to report 'overall poorer access to telecommunications, devices and private spaces to use those devices' (Mylek and Schirmer 2023b: 19).
- Were more likely to report that 'their ability to engage in paid work was getting better' (Mylek and Schirmer 2023b: 19).
- Were less likely 'to speak to their employer about their caring role' (Mylek and Schirmer 2023b: 29).

21.3 Effectiveness

The intended outcomes of Carer Gateway services for carers, as outlined in the ICSS Outcomes Framework (see Appendix B), are to 'improve carer wellbeing, increase their capacity, and support their participation, socially and economically and reinforce carer resilience'. Effectiveness of the program was examined in relation to program reach and program outcomes. Aboriginal and Torres Strait Islander carers appear to be accessing Carer Gateway in similar proportions to their representation in the carer population, although they are under-represented in the Carer Allowance population accessing Carer Gateway which has decreased over time (between 2016 and 2022). Aboriginal and Torres Strait Islander carers were more likely to find out about Carer Gateway from Facebook and family and friends than carer organisations. Data from the CWS suggests they are more likely to access informal support and services than non-Indigenous carers, but Aboriginal and Torres Strait Islander carers also reported less access to respite care since the introduction of Carer Gateway.

Carer perspectives

Aboriginal and Torres Strait Islander carers provided mixed responses about whether Carer Gateway was achieving the intended outcomes.

Some carers talked positively about the benefits of immediate support (i.e. respite) they received and the impacts on their wellbeing and stress. Others, however, were more neutral or negative about the services making a difference, indicating that they would access emergency respite, but they would then go back to the stresses of their everyday caring role.

Other carers reflected on the benefits of receiving support but noted that it was time limited.

A number of carers noted that Carer Gateway had provided them with information about services and skills to help them in their caring role and to support their mental health. Although several carers spoke about their respite needs not being met, one carer provided an example of how access to respite supported economic participation. The carer worked part-time and said that receiving respite enabled her to continue to work. However, the carer wanted more respite so she could have a break from caring apart from when she went to work. Other carers were helped financially through referrals to services that subsidized the cost of food.

Some Aboriginal and Torres Strait Islander carers talked positively about their conversations with the intake team members when they first contacted Carer Gateway. They were provided connections and knowledge about what services might be available to support them in the future. For some carers the 1800 number acted as a point of contact to ask questions.

Carers experiences of contacting Carer Gateway varied. Several carers had positive interactions when speaking with workers during the initial intake or assessment process. Factors that contributed to carers’ increased knowledge of available services and access to support to help them continue to care included: feeling comfortable when speaking to workers, being listened to, information being provided in a manner they could understand, and being referred to appropriate support. However, other carers did not receive the support they needed through Carer Gateway. Some carers expressed frustration after contacting services about the lack of supports available to them or being spoken to in a rude and condescending manner.

Several Aboriginal and Torres Strait Islander carers talked about the transition from previously funded programs for carers to Carer Gateway. In most instances this transition was talked about negatively, referring to the difficulty in accessing respite and the difficulty in being able to contact the Carer Gateway provider when they needed support.

DEX data

The analysis of DEX data for the period 2020–2022 indicates Aboriginal and Torres Strait Islander carers had a lower increase in wellbeing than non-Indigenous carers, as did carers in remote and very remote areas. Interviews with Aboriginal and Torres Strait Islander carers revealed positive and negative views about the outcomes of the services with regards to wellbeing, their capacity for caring, and economic participation. However, carers valued the connection with Carer Gateway and the information, support and resources staff were able to provide. Factors that contributed to carers’ increased knowledge of available services and access to support to help them continue to care included: feeling comfortable when speaking to workers, being listened to, information being provided in a manner they could understand, and being referred to appropriate supports. Challenges identified by carers were staff with inappropriate attitudes or lacking training, the number of reviews required, and the varying quality of services.

Carer Wellbeing Survey

The 2023 CWS data analysis found that Aboriginal and Torres Strait Islander carers were more likely than all carers to have:

- accessed any Carer Gateway services and support in the last 12 months (40.4% vs 27.2% for all current carers) (Mylek and Schirmer 2023a: 25 and Appendix 2), and
- used the following Carer Gateway services:
    - Skills and coaching
    - Peer support/online forum
    - Respite
    - Practical support (Mylek and Schirmer 2023a: 72, Appendix 4).

More generally, the analysis of the 2023 CWS data found that Aboriginal and Torres Strait Islander carers were more likely than the average current carer to:

- access support from friends or family (78.7% vs 61%) (Mylek and Schirmer 2023b: 46, Table 5)
- connect with other carers to share experiences and advice (62.7% vs 32.4% (Mylek and Schirmer 2023b: 46, Table 5), and
- report that they had accessed the following services (although not necessarily from Carer Gateway) in the previous 12 months:
    - Psychological support for carers (55.2% vs 27.9%)
    - Respite care services (51.6% vs 26.8%)
    - Financial support to help in caring role (54.1% vs 29.3%)
    - Carer training and skills courses (51.2% vs 20.8%) (Mylek and Schirmer 2023b: 46, Table 5).

Changes in wellbeing were examined using the Carers Star^{TM} score recorded in DEX. Only one-third of carers in the DEX data had more than one score, so the analysis is limited to that group. The DEX analysis for the period 2020–2022 indicates that Aboriginal and Torres Strait Islander carers had a lower increase in wellbeing, as measured by changes in the first and last Carers Star^{TM} score compared with non-Indigenous carers (0.25 vs 0.29). Table 27 shows that while the majority of carers reported no change on their scores, 12.8% of Aboriginal and Torres Strait Islander carers reported a decrease in wellbeing scores compared to 10.6% of non-Indigenous carers, and 33% reported an increase compared to 33.6% of non-Indigenous carers.

Table 27 Mean pre and post SCORES by Indigenous status characteristics

	Mean First score	Mean Last score	Mean increase in score	% with Decrease %	% with No change %	% with Increase %	N
Indigenous Status							
Yes	**3.25**	**3.51**	**0.25**	**12.8**	**54.2**	**33.0**	**1,671**
No	3.44	3.73	0.29	10.6	55.9	33.6	43,861
Not stated	3.32	3.61	0.29	12.1	52.0	35.9	1,121

Source: Authors analysis of DEX data. (see Section 17.1)

Another factor identified by carers that detracted from achieving outcomes was the variable quality of support provided by services. The analysis of changes in Carers Star^{TM} scores (Section 17.1) showed lower than average increases for a number of groups of carers including Aboriginal and Torres Strait Islander carers and those living in remote and very remote regions.

The analysis in the *Carer Gateway Half Yearly Performance Monitoring reports* (Accenture 2020, 2021a, 2021b, 2022a, 2022b) found there were no significant differences in wellbeing changes by different demographics or by remoteness (Accenture 2022b:12–13).

21.4 Summary of implications for Aboriginal and Torres Strait Islander carers

There are mixed findings in relation to Aboriginal and Torres Strait Islander carers. On the one hand, Aboriginal and Torres Strait Islander carers were accessing Carer Gateway in similar proportions to their representation in the carer population. Aboriginal and Torres Strait Islander carers also improved in their wellbeing after accessing Carer Gateway. Most carers interviewed for this evaluation were happy overall with the service they received.

On the other hand, Aboriginal and Torres Strait Islander carers were under-represented in the Carer Allowance population accessing Carer Gateway and they were accessing services at a lower rate than prior to the implementation of Carer Gateway. Although their wellbeing improved, Aboriginal and Torres Strait Islander carers had a lower increase in wellbeing than non-Indigenous carers.

Stakeholders and Aboriginal and Torres Strait Islander carers identified concerns about access, assessment and service delivery of Carer Gateway for some Aboriginal and Torres Strait Islander carers, and overall it appears that practice is variable, with some services developing innovative methods for engaging with and supporting Aboriginal and Torres Strait Islander carers, while others appear to fall short of culturally safe engagement, assessment and service provision. Aboriginal and Torres Strait Islander carers also expressed concerns about the interface between Carer Gateway and NDIS, indicating a lack of information targeted at Aboriginal and Torres Strait Islander carers about how these schemes should work together.

Overall these findings indicate a need for Carer Gateway processes and services to be reviewed and adapted to meet the needs of Aboriginal and Torres Strait Islander carers, particularly those living in rural and remote areas.

Part E: Discussion and implications

Part E discusses the findings from all components of the evaluation and outlines the implications for demographic groups and the conclusions and implications of the evaluation.

22 Discussion

The overall wellbeing of carers in the population has slightly declined since 2020, particularly because of COVID-19. However, this cannot be attributed (one way or the other) to Carer Gateway, which is accessed by only a minority of carers (around 5% of carers access Carer Gateway each year). In addition, as the national communications campaign only began in October 2022, Carer Gateway could not yet be expected to deliver changes in wellbeing at a population level. However, the evidence overall points towards a positive impact of Carer Gateway on the increasing proportion of carers who access the program.

Most stakeholders were positive about the transition to a more streamlined model of provision. There are clear indications that using low-cost services is associated with less likelihood of using emergency or non-emergency respite and reduces the number of days of respite used. Thus, there are strong indications that the investment in early intervention and support may be resulting in a more cost-effective service system. However, the majority of services provided by Carer Gateway continue to be high-cost services, with low-cost services increasing in the last quarter of 2022. Also, there were some concerns about the flexibility of the Gateway services and their predominantly short-term nature. Many carers require longer term support.

Awareness of Carer Gateway is still low but is increasing. There are indications that the national communications campaign initiated in October 2022 has further raised awareness and engagement with Carer Gateway. Carers accessing Carer Gateway were largely representative of the range of carers in the general population, although carers with a disability and CALD carers were under-represented and Aboriginal and Torres Strait Islander carers were under-represented in the Carer Allowance population accessing Carer Gateway.

There are good interactions and communication between DSS and the service providers, and a strength of the program is that outcome measurement is built into the infrastructure.

Carers’ experiences using Carer Gateway varied considerably. Several carers commented that they could not find fault with the service and would recommend it to other carers. They found the service to be friendly and provided them with helpful information and support that met their needs. They also indicated that they were confident that Carer Gateway could provide them with any extra help they needed or information about how to access it. Others found it frustrating and challenging to navigate, and that services were difficult to access. Carer Gateway appears to be less appropriate for some Aboriginal and Torres Strait Islander carers, CALD carers, young carers, and mental health carers, and there are some indications that Aboriginal and Torres Strait Islander carers are less likely to use Carer Gateway services than they were to access services before Carer Gateway. However there are no significant differences in outcomes between these demographic groups once they are receiving services.

There were mixed views about the Carers Star^{TM}, with some stakeholders and carers believing that it is a good assessment and outcomes measuring tool that provides the basis for supporting carers appropriately. However, there were some concerns that it is burdensome for some carers, and not culturally appropriate for some Aboriginal and Torres Strait Islander carers, and that many young carers would prefer online interactions with Carer Gateway rather than phone conversations. Some services are adapting assessment to improve appropriateness.

The quality of services provided by Carer Gateway, and which Carer Gateway has commissioned, appear to be variable. In some cases services are provided in a timely manner, but there are significant gaps in the timeliness and availability of services, often due to workforce issues such as competition in areas for NDIS and aged care workers with different wages rates.

One reason is that carer service providers find it difficult to recruit and retain staff and broker services is due to competition with other sectors such as aged care and disability. This is consistent with the findings from the *Carer Workforce Labour Market Study* (National Skills Commission, 2021) which noted a skill gap in the carer workforce nationally and in particular geographic areas.

It is not possible to identify which services are most effective for carers. Selection of services are intended to be tailored to the particular needs of carers and therefore carers access and benefit most from those service types which meet their individual needs. Some carers access multiple services from Carer Gateway and also from other providers. Further, all Carer Gateway services were associated with improved wellbeing. However, respite services showed the greatest improvement in wellbeing overall.

23 Implications for priority groups

This section summarises the implications of the appropriateness and effectiveness of Carer Gateway for different priority groups.

23.1 Aboriginal and Torres Strait Islander carers

See Section 22 for a summary of all findings related to Aboriginal and Torres Strait Islander carers.

23.2 Female carers

The majority of carers are female, and female carers are accessing the range of services available through Carer Gateway and are proportionately represented in Carer Gateway services. Carer Gateway therefore appears to be a suitable resource for female carers. There are no indications that appropriateness or effectiveness of Carer Gateway services is different for female carers compared to male carers.

23.3 Carers with disability

Carers with disability have amongst the highest needs of the carer population, have lower levels of wellbeing than other carers, and are significantly under-represented in accessing Carer Gateway services, to some extent because they find it difficult to access Carer Gateway services. It is important to better understand the needs and service requirements of these carers.

23.4 Regional or remote carers

Service access for Australians living in regional and remote areas is challenging, not only for carers but for all client groups, and the workforce issues and thin markets are particularly acute in these locations. This requires a broader cross-government approach. A particular issue for these carers is that the support packages do not consider the additional costs of providing services and material goods to regional and remote areas.

23.5 Young carers (aged under 25 years)

As with some other carer groups, the Carers Star^{TM} and access to Carer Gateway are perceived as being less appropriate for young carers than for other groups of carers. Young people often prefer virtual and web-based interactions over phone conversations, for example. However young carers appear to benefit equally from Carer Gateway services compared to other ages of carers.

23.6 Older carers

The interface with other service systems is sometimes difficult, but overall appears to be working well, and there are no particular issues in terms of appropriateness or outcomes for older carers. Olde cares are slightly over-represented in accessing Carer Gateway services.

23.7 Carers of older persons

The DEX-DOMINO data set cannot specifically identify carers of older persons. Interviews with carers of older people noted some patchiness of services for carers of older persons. However, the interaction between Carer Gateway and My Aged Care was overall positively experienced by carers and stakeholders.

23.8 Culturally and Linguistically Diverse carers

CALD carers are significantly underrepresented in their access to Carer Gateway, and stakeholders have identified reasons for this, including lower levels of awareness, and the cultural appropriateness of Carer Gateway services. DSS and service providers are addressing this challenge through targeted campaigns in other languages, outreach to local services, as well bilingual staff members for providers servicing areas with high proportions of non-English speaking carers. This population of carers may be targeted in specific ways and that services may need to be tailored so that CALD carers can more easily access and engage with them.

23.9 Mental health carers

Population surveys indicate that they have similar levels of wellbeing compared to carers of other types of care recipients. However, interviews with stakeholders and carers indicate that these carers face several challenges. Stakeholders indicated that mental health carers are more likely to be caring for high needs care recipients and to contact Carer Gateway when they are at breaking point, requiring emergency respite and other high-cost services. Their most significant challenge is reported to relate to accessing the NDIS rather than Carer Gateway, but they still face a range of difficulties engaging and accessing Carer Gateway services due to the nature of their caring roles.

23.10 Summary

Overall the analysis indicates that outcomes for the priority groups were similar and that access to Carer Gateway services was broadly representative of the population of carers in Australia. However, some services and assessment processes were less appropriate for some groups of carers and some providers have made efforts to reach out to priority groups such as young carers and Aboriginal and Torres Strait Islander carers.

24 Conclusion and implications

24.1 Conclusion

The findings from the Carer Gateway evaluation indicate that the transition to Carer Gateway has been beneficial for carers. Most carers are satisfied with services they receive and all service types resulting in improvements in wellbeing of carers who access them. The economic analysis indicates that the benefits of the program outweigh its costs, and that high-cost services are declining as a proportion of overall services, consistent with the program logic. Nevertheless, the need for respite and emergency respite services is still great, and although these and other high-cost services are reducing as a proportion of services, they still represent the majority of services provided by Carer Gateway.

A key benefit of Carer Gateway is the governance arrangements, which include routine outcome monitoring and close liaison between DSS and service providers. This has ensured that Carer Gateway services can be adapted and improved continuously over time.

Carer Gateway has, however, faced several challenges, including delay to the national communications campaign and the COVID 19 pandemic which has exacerbated capacity issues in the carer workforce. Furthermore, the pandemic has resulted in a lowering of wellbeing of many carers in the population as a whole.

A particular innovation of Carer Gateway was the introduction of the Carers Star^{TM} assessment, with the aim to consistently measure outcomes of clients. This has, overall, been a beneficial initiative, and has provided crucial information about how carers have benefitted from different services. However, its use is still reported to be inconsistent, with only about 35% of carers receiving more than one assessment, and the tool does not appear to be appropriate for some Aboriginal and Torres Strait Islander carers, young carers, CALD carers and carers with disability. Although DSS has provided training and guidance to service providers on the use of the Carers Star^{TM}, there were mixed views about when and how the Carers Star^{TM} can be adapted for these groups of carers, indicating the need for further clarity and communication around the use of the Carers Star^{TM}.

A significant challenge for Carer Gateway is the interaction with other services accessed by carers. Many carers live with disability, are aged, are caring for someone with disability or receiving aged care packages or have health issues. Carers find it challenging to obtain the range of services for themselves and for the care recipients that they require, due to issues related to eligibility criteria, service access and funding rules for the various programs. This is compounded by the geographical and other inconsistencies across and between programs. While many services work hard to ensure that their clients receive the appropriate support, and service providers have developed a range of innovative practices to address these challenges, including co-location of services with My Aged Care and NDIS and other forms of collaboration. Nevertheless, there continue to be significant structural barriers and service gaps faced by carers.

With regard to data, analysis of DEX is dependent on the SCORE data which is a single score derived from the seven Carers Star^{TM} domains. This is a considerable limitation to the analysis because it conflates a number of different outcome areas and obscures how carers have changed over time in different domains. Carers may improve their employment or engagement in education or voluntary activities but still feel high levels of psychological distress, and this would not be reflected in the DEX dataset.

24.2 Implications

Client and stakeholder interviews highlighted challenges with the interaction between Carer Gateway and the NDIS. Some, notably Aboriginal and Torres Strait Islander carers, did not distinguish between NDIS and Carer Gateway services. Carers related more to the service provider, not the funding program. There is an opportunity for Carer Gateway policy makers and service providers to improve the interface between the NDIS and Carer Gateway.

Stakeholder and client interviews indicated that the value of tailored support packages was not always sufficient to meet the increased costs of goods and services in regional and remote areas and that there could be more flexibility in the amount provided to carers in these areas.

Analysis of program reach using Data Exchange (DEX) data and Australian Bureau of Statistics (ABS) surveys indicates that culturally and linguistically diverse (CALD) carers, carers with disability and young carers are underrepresented among Carer Gateway clients. Stakeholder interviews indicate that these groups of carers may benefit from more tailored engagement processes

Workforce challenges in regional and remote areas contribute to service access challenges in these areas. Consistent with the *National Skills Commission Report* (2021), stakeholder interviews highlighted workforce challenges, particularly in regional and remote areas. In some locations, Carer Gateway Service Providers were competing with Aged Care and NDIS service providers who offer higher wages than Carer Gateway service providers.

Stakeholder and client interviews indicate the Carers Star^{TM} assessment is not always appropriately tailored for some Aboriginal and Torres Strait Islander carers, young carers, and some CALD carers, and it may be appropriate for the assessment to be tailored specifically for these groups of carers.

The seven domains of the Carers Star^{TM} are averaged into a single score in DEX, which can obscure how carers have changed over time in individual domains. DSS should explore the implications of including all seven domains in the DEX score. While some service providers support a change in program reporting requirements into DEX for ICSS, any change requires considering the following factors: existing and potential data quality and the added value of all Carers Star^{TM} outcome domains for analysing program outcomes; the impact on Carer Gateway Service Provider (CGSP) practice, case management systems, and costs; the impact on DSS reporting and administrative processes and whether existing DEX domains can be used; and the timeline and process for implementing any changes to the ICSS reporting requirements across the program.

References

Accenture (2020) *Carer Gateway Half Yearly Performance Monitoring Report July 2020–December 2020*

Accenture (2021a) *Carer Gateway Half Yearly Performance Monitoring Report January 2021–June 2021*

Accenture (2021b) *Carer Gateway Half Yearly Performance Monitoring Report July 2021–December 2021*

Accenture (2022a) *Carer Gateway Half Yearly Performance Monitoring Report January to 2022–June 2022*

Accenture (2022b) *Carer Gateway Half Yearly Performance Monitoring Report July 2022–December 2022*

Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., & S. Golder. (2002). *Literature review report: Services to support carers of people with mental health problems.* Report prepared for the national coordinating centre for NHS service delivery and organisation R&D (NCCSDO). Mimeo, University of York https://www.york.ac.uk/inst/spru/pubs/pdf/carersMHP.pdf accessed 23 September 2023.

ARTD (2020) *Integrated Carer Support Service: Performance Monitoring Baseline Report* August 2020.

Australian Bureau of Statistics ABS (2023) https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/average-weekly-earnings-australia/may-2023 Australian Bureau of Statistics

Australian Bureau of Statistics ABS (2019) *Survey of Ageing, Disability and Carers*, Available at https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

Australian Government (2021a) *The Data Exchange Protocols: June 2021*, Available at https://dex.dss.gov.au/sites/default/files/documents/2021-06/data-exchange-protocols-june-2021.pdf

Australian Government (2021b) *Program specific Guidance for Commonwealth agencies in the Data Exchange*, Available at: https://dex.dss.gov.au/sites/default/files/documents/2021-08/program-specific-guidance-commonwealth-agencies-data-exchange-august-2021.pdf

Australian Institute of Health and Welfare AIHW (2023) Spending on admitted patients https://www.aihw.gov.au/reports-data/myhospitals/intersection/spending/apc

Australian Human Rights Commission (2013) *Investing in care: recognising and valuing those who care: research report and technical report*, Australian Human Rights Commission, Sydney.

Brosnan, K., Eglentals, A., Phillips, B., (2023). *Surveys of Australian Carers – Final Report*. The Social Research Centre. Melbourne, Australia.

Carer Support Framework (2019) *Integrated Carer Support Services (ICSS),* Canberra.

Carers Australia (n.d.) *Who is a carer*? https://www.carersaustralia.com.au/about-carers/who-is-a-carer/

Carers NSW (2022) *Carers Star^{TM} Review: Draft report,* Unpublished report provided to evaluation team by DSS with Carers NSW permission.

Cass, B, Smyth, C, Hill, T, Blaxland, M and Hamilton, M (2009). 'Young carers in Australia', *Social Policy Research Paper*, No. 38. Commonwealth of Australia, Canberra.

Centre for Change Governance and NATSEM (2021) *Carer Experiences of the Carer Gateway. Findings from the Carer Wellbeing Survey 2021* Centre for Change Governance and NATSEM, University of Canberra, Canberra.

Deloitte Access Economics and Carers Australia (2020) *The Value of Informal care in 2020* https://www.carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020_No-CIC.pdf

Denyer, D, et al. (2008) "Developing Design Propositions through Research Synthesis." *Organization Studies* 29(3): 393–413.

Department of Social Services (DSS) (2018a) *Integrated Carer Support Service (ICSS) Service Blueprint* https://www.dss.gov.au/sites/default/files/documents/12_2018/icss-service-blueprint-version-13.pdf

Department of Social Services (DSS) (2018b) *Integrated Carer Support Service: Carer Gateway Regional Delivery Partner Grant Opportunity Guidelines.*

Department of Social Services (DSS) (2023) *DSS Benefit and Payment Recipient Demographics June 2023 Quarter*, Department of Social Services, Canberra. Available at: https://data.gov.au/dataset/ds-dga-cff2ae8a-55e4-47db-a66d-e177fe0ac6a0/details?q=DSS%20payment%20data [Accessed September 2023]

Edwards, B, Jahromi, M, Lording, R, Cuttriss, S and Biddle, N (2020) *Evaluation of the Integrated Carer Support Service – Baseline Report.*

Engel*, L.,* Ajdukovic*, M.,* Bucholc*, J., &* McCaffrey*, N. (2021). Valuation of informal care provided to people living with dementia: a systematic literature review. Value in Health, 24(12), 1863-1870.*

Fakeye, M. B., Samuel, L. J., Drabo, E. F., Bandeen-Roche, K., & Wolff, J. L. (2023). Caregiving-Related Work Productivity Loss Among Employed Family and Other Unpaid Caregivers of Older Adults. *Value in Health*, *26*(5), 712-720. https://doi.org/https://doi.org/10.1016/j.jval.2022.06.014

Hill, T and Broady, T (2019) *Understanding the social and emotional needs of carers: Final Report*, Social Policy Research Centre, UNSW Sydney, Sydney, http://dx.doi.org/10.26190/5c59202697201

Leu, A and Becker S (2017) A cross-national and comparative classification of in-country awareness and policy responses to 'young carers', *Journal of Youth Studies*, 20:6, 750–762.

McMillan, S, Lethborg, A, Honey, N and Brosnan, K (2023) *Evaluation of the Integrated Carer Support Service: Surveys of Australian Carers Interim report*. Melbourne, Social Research Centre.

IHACPA (2023) The National Hospital Cost Data Collection (NHCDC). A report by the Independent Health and Aged Care Pricing Authority (IHACPA). Available from https://www.ihacpa.gov.au/sites/default/files/2022-08/Round%2022%20Infographic%20-%20Non-admitted%20care.pdf Independent Health and Aged Care Pricing Authority

Mikkola, TM, Kautianen, H, Mänty, M, von Bonsdorff, MB, Koponen, H, Kröger, T, and Eriksson, JG (2021) Use of antidepressants among Finnish family caregivers: a nationwide register-based study, *Social Psychiatry and Psychiatric Epidemiology,* 56, 2209-2216.

Mikkola, TM, Mänty, M, Kautianen, H, von Bonsdorff, MB, Koponen, H, Kröger, T, and Eriksson, JG (2022) Use of prescription benzodiazepines and related drugs in family caregivers: a nation-wide register-based study, *Age and Ageing,* 51, 1-5.

Mylek M, and Schirmer J (2023a) *Carer Experiences of the Carer Gateway. Findings from the Carer Wellbeing Survey 2023,* Centre for Change Governance and NATSEM, University of Canberra, Canberra.

Mylek M, and Schirmer J (2023b) *Caring for others and Yourself: The 2023 Carer Wellbeing Survey,* Centre for Change Governance and NATSEM, University of Canberra, Canberra.

National Skills Commission (2021) *Care Workforce Labour Market Study: Final Report* Canberra, Australian Government, National Skills Commission.

National Skills Commission (NSC) (2021a) *Skills and jobs of the future-the Four Cs*, Australian Government, Canberra.

National Skills Commission (2023) *Care Workforce Labour Market Study* Canberra, Australian Government, National Skills Commission.

Pickard, L. (2004). The effectiveness and cost-effectiveness of support and services to informal carers of older people. London: Audit Commission. https://www.pssru.ac.uk/pub/dp2014.pdf accessed 23 September 2023.

Schirmer, J and Mylek, M (2022) *Carer Experiences of the Carer Gateway. Findings from the Carer Wellbeing Survey 2022* Centre for Change Governance and NATSEM, University of Canberra, Canberra.

Schirmer, J, Mylek, M, and Miranti, R (2022) *Caring for others and yourself. 2022 Carer Wellbeing survey: Full data report,* Report prepared for Carers Australia. Centre for Change Governance and NATSEM, University of Canberra, Canberra.

Schirmer, J and Riyanti, M (2021) *Caring for others and yourself: The 2021 Carer Wellbeing Survey.* Report prepared for Carers Australia. Centre for Change Governance and NATSEM, University of Canberra, Canberra.

Smyth, C and Hamilton, M (2021) Young Carers. In *The Encyclopedia of Child and Adolescent Development* (eds Hupp, S and Jewell, J). https://doi.org/10.1002/9781119171492.wecad41

Urbis (2021a) *Process Evaluation of the Integrated Carer Support Service (Carer Gateway) Interim report.*

Urbis (2021b) *Process Evaluation of the Integrated Carer Support Service (Carer Gateway) Final report.*

Appendix A Evaluation questions

A.1 Appropriateness questions

1. How appropriate is the program design for meeting the needs of Australian carers, including (where applicable):
    i. Aboriginal and Torres Strait Islander carers
    ii. female carers
    iii. carers with disability
    iv. regional or remote carers
    v. young carers (aged less than 25 years)
    vi. older carers
    vii. carers of older persons
    viii. Culturally and Linguistically Diverse carers
    ix. mental health carers
    a. For the ICSS evaluation: Which ICSS services are most appropriate for meeting carer needs?
    b. For the ICSS evaluation: How appropriate is the service provider use of Carers Star^{TM} assessment for assessing and meeting carer needs?
    c. For the ICSS evaluation: How appropriate is the program for carers as an early intervention service, and for carers who are in high levels of need?
2. How has the program interacted with the NDIS and other policies supporting carers and those being cared for?
3. How effectively have governance and funding processes contributed to achievement of program aims?
4. How effectively have the recommendations from previous evaluations been implemented?

A.2 Effectiveness questions

5. To what extent has the program successfully reached Australian carers, including carers from the following demographic groups (where applicable):
    i. Aboriginal and Torres Strait Islander carers
    ii. female carers
    iii. carers with disability
    iv. regional or remote carers
    v. young carers (aged less than 25 years)
    vi. older carers
    vii. carers of older persons
    viii. Culturally and Linguistically Diverse carers
    ix. mental health carers.
6. What has been the impact of the program on the service system for carers?

    a. For the ICSS evaluation: What has been the impact of the ICSS on access to, use of, and satisfaction with respite services for carers?

7. To what extent has the program achieved the intended outcomes in its program logic?
    a. Have there been any unintended program outcomes?
    b. What factors have contributed to or detracted from the achievement of outcomes (intended and unintended)?
    c. What are the characteristics of carers who have benefited most from the program and why? To what extent have outcomes differed for the following demographic groups (where applicable):
        i. Aboriginal and Torres Strait Islander carers
        ii. female carers
        iii. carers with disability
        iv. regional or remote carers
        v. young carers (aged less than 25 years)
        vi. older carers
        vii. carers of older persons
        viii. Culturally and Linguistically Diverse carers
        ix. mental health carers.
    d. For the ICSS evaluation: Which ICSS services have contributed most to carer outcomes?

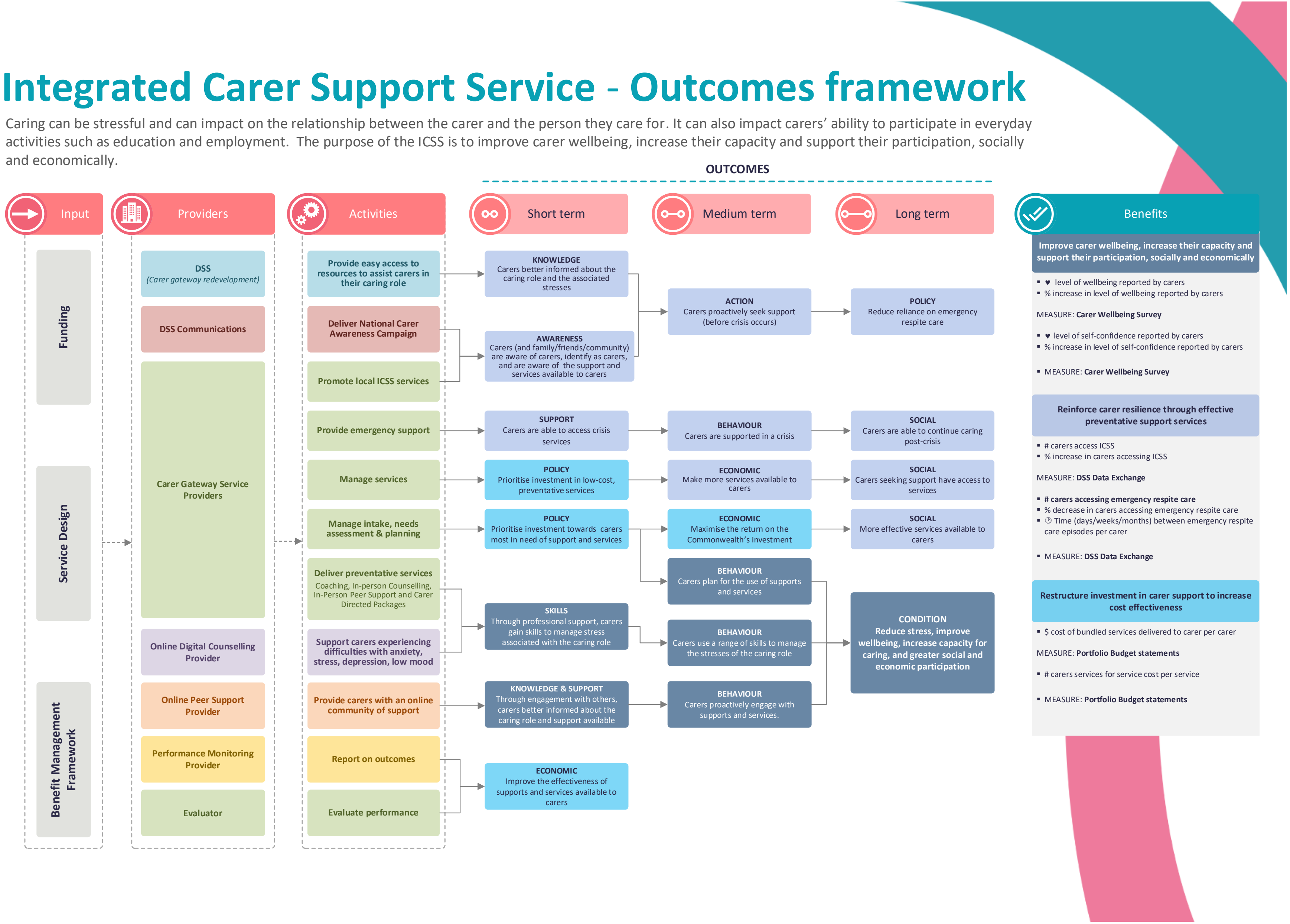
A.3 Efficiency questions

8. To what extent do interactions and/or referral pathways between the ICSS, the YCBP/YCN, and the TCVO contribute to achieving outcomes across the respective programs?
9. How cost-effective is the program?
    a. For the ICSS evaluation: To what extent has the ICSS restructured investment in carer support increased cost-effectiveness?

Appendix B ICSS Outcomes Framework

Figure 15 on the next page presents the ICSS outcomes framework. This is sourced directly from the Benefits Management Plan for the Integrated Carer Support Service (ICSS).

Figure 15 ICSS Outcomes framework



Integrated Carer Support Service - Outcomes framework

Caring can be stressful and can impact on the relationship between the carer and the person they care for. It can also impact carers' ability to participate in everyday activities such as education and employment. The purpose of the ICSS is to improve carer wellbeing, increase their capacity and support their participation, socially and economically.

OUTCOMES

Input

- Funding
- Service Design
- Benefit Management Framework

Providers

- DSS *(Carer gateway redevelopment)*
- DSS Communications
- Carer Gateway Service Providers
- Online Digital Counselling Provider
- Online Peer Support Provider
- Performance Monitoring Provider
- Evaluator

Activities

- Provide easy access to resources to assist carers in their caring role
- Deliver National Carer Awareness Campaign
- Promote local ICSS services
- Provide emergency support
- Manage services
- Manage intake, needs assessment & planning
- Deliver preventative services: Coaching, In-person Counselling, In-Person Peer Support and Carer Directed Packages
- Support carers experiencing difficulties with anxiety, stress, depression, low mood
- Provide carers with an online community of support
- Report on outcomes
- Evaluate performance

Short term

- **KNOWLEDGE** Carers better informed about the caring role and the associated stresses
- **AWARENESS** Carers (and family/friends/community) are aware of carers, identify as carers, and are aware of the support and services available to carers
- **SUPPORT** Carers are able to access crisis services
- **POLICY** Prioritise investment in low-cost, preventative services
- **POLICY** Prioritise investment towards carers most in need of support and services
- **SKILLS** Through professional support, carers gain skills to manage stress associated with the caring role
- **KNOWLEDGE & SUPPORT** Through engagement with others, carers better informed about the caring role and support available
- **ECONOMIC** Improve the effectiveness of supports and services available to carers

Medium term

- **ACTION** Carers proactively seek support (before crisis occurs)
- **BEHAVIOUR** Carers are supported in a crisis
- **ECONOMIC** Make more services available to carers
- **ECONOMIC** Maximise the return on the Commonwealth's investment
- **BEHAVIOUR** Carers plan for the use of supports and services
- **BEHAVIOUR** Carers use a range of skills to manage the stresses of the caring role
- **BEHAVIOUR** Carers proactively engage with supports and services.

Long term

- **POLICY** Reduce reliance on emergency respite care
- **SOCIAL** Carers are able to continue caring post-crisis
- **SOCIAL** Carers seeking support have access to services
- **SOCIAL** More effective services available to carers
- **CONDITION** **Reduce stress, improve wellbeing, increase capacity for caring, and greater social and economic participation**

Benefits

Improve carer wellbeing, increase their capacity and support their participation, socially and economically

- ♥ level of wellbeing reported by carers
- % increase in level of wellbeing reported by carers

MEASURE: **Carer Wellbeing Survey**

- ♥ level of self-confidence reported by carers
- % increase in level of self-confidence reported by carers

- MEASURE: **Carer Wellbeing Survey**

Reinforce carer resilience through effective preventative support services

- # carers access ICSS
- % increase in carers accessing ICSS

MEASURE: **DSS Data Exchange**

- **# carers accessing emergency respite care**
- % decrease in carers accessing emergency respite care
- 🕑 Time (days/weeks/months) between emergency respite care episodes per carer

- MEASURE: **DSS Data Exchange**

Restructure investment in carer support to increase cost effectiveness

- $ cost of bundled services delivered to carer per carer

MEASURE: **Portfolio Budget statements**

- # carers services for service cost per service

- MEASURE: **Portfolio Budget statements**

Appendix C Data sources

C.1 Program data

Program data sources for Carer Gateway include:

Carer Gateway Half Yearly Performance Monitoring Reports for 2020–2022 by Accenture

ICSS Performance Monitoring Baseline Report by ARTD 2020

Urbis Process Evaluation Interim and Final Reports 2021, and

ANU Baseline Evaluation Report 2020 (Edwards et al. 2020).

Google analytics data for website and online services 2020–2022

C.2 Carer Gateway Data Exchange (DEX) data

DEX is the program reporting data for the DSS (Australian Government 2021a). DEX has two components, the mandatory priority requirements, and the extended data in partnership approach (Australian Government 2021a). Service providers in the carer support programs are required to participate in the partnership approach and are expected to report on outcomes for a majority of clients (Australian Government 2021b).

The DEX data analysed in this report were the extracts made available for the Performance Monitoring reports 2020–2022. Future analysis will examine linked DEX-DOMINO and DEX-MADIP data.

DEX data encompasses demographic, service use and outcome measures. The outcome measures include satisfaction and wellbeing data.

The satisfaction measures encompass three domains:

- The service listened to and understood my issues.
- I am satisfied with the services I have received.
- I am now better able to deal with the issues for which I need assistance.

The responses are measured on a scale of 1–5 (1 –Disagree, 2 –Tend to disagree, 3 –Neutral, 4 –Tends to agree, 5 –Agree).

The wellbeing data is recorded through the Carers Star^{TM}

The Carers Star^{TM} is used in Carer Gateway for needs assessment across seven domains (health, the caring role, managing at home, time for yourself, how your feel, finances, work) and is translated into a single mental health, wellbeing and self-care Circumstances SCORE in DEX (Australian Government 2021b).

The Carers Star^{TM} uses five stages that relate to the level of need:

Cause for concern (1)

Getting help (2)

Making change (3)

Finding what works (4)

As good as it can be (5).

The list of services in DEX is not exactly the same as those in the surveys because of the constraints of the DEX program (see Table 28).

The list of Carer Services includes:

Tailored Support Packages – Provision of services under one-off practical support (an instance of tailored support)

Material Goods – Purchase of material goods as one-off practical support (an instance of tailored support)

Specialist support – purchasing services or material goods as part of a tailored support package (an instance of tailored support)

Education and skills training – Coaching service either in-person or over the phone (these services went live from July 2021)

Intake and assessment – The carer has gone through the Carer Support Planning Process, which includes intake, registration, Carers Star^{TM} assessment and completing an Action Plan

Service review – Reviewing a carer's situation, including reviewing or completing Carers Star^{TM} and reviewing or completing an Action Plan

Respite – providing planned respite (direct or indirect) as part of a tailored support package (an instance of tailored support)

Emergency Respite – providing emergency respite to a carer

Counselling – in-person counselling

Mentoring/peer support – in-person peer support groups.

Table 28 DEX and Survey lists of services

List of services used in impact evaluation surveys	Corresponding DEX activity	Corresponding DEX service type(s)
Counselling (in-person)	ICSS Carer Gateway Service Providers (CGSPs) only	Counselling
Counselling (phone/digital)	Chiefly ICSS Digital Counselling, though in practice sometimes ICSS CGSPs also provide a counselling session over the phone	Counselling
Peer support (in- person)	ICSS CGSPs only	Mentoring/Peer support
Peer support (online community forum on Carer Gateway website)	Not applicable – service not recorded in DEX	Not applicable – service not recorded in DEX
Coaching (in-person)	ICSS CGSPs only	Education and skills training
Coaching (self-guided on Carer Gateway website)	Not applicable – service not recorded in DEX	Not applicable – service not recorded in DEX
Tailored support packages (services and support specific to carer needs, such as education supplies, planned respite, or cooking and cleaning services)	ICSS CGSPs only	Material Goods; Carer Support; Respite; Specialist Support
Emergency respite	ICSS CGSPs only	Emergency respite
Online skills courses on Carer Gateway website	Not applicable – service not recorded in DEX	Not applicable – service not recorded in DEX

C.3 Carer Wellbeing Survey

The Carer Wellbeing Survey (CWS) was first conducted by the Centre for Change Governance and NATSEM at the University of Canberra in 2021 and is conducted annually. The survey aims to “build a comprehensive picture of the wellbeing of carers and how it can be best supported” (Schirmer and Riyanti 2021: iv). The survey is administered via online and paper forms. To date the survey has employed five sampling methods for recruitment (University of Canberra, Regional Wellbeing Survey (RWS), care provider organizations, carer representative organisations, social media and Qualtrics panel) and was available in five languages (English, simplified Chinese, Arabic, Italian and Vietnamese). A prize draw incentive was offered in all surveys to encourage participation. Carers had the option of doing a short or long version of the survey. Detailed methods for the CWS are described in Schirmer and Riyanti (2021: 9–13; Schirmer et al. 2022). Appendix 1. This study reviewed the Carer Wellbeing Survey Wellbeing reports and Carer Gateway reports for 2021, 2022 and 2023.

The survey collected information for current carers and past carers aged 14 years and older on:

Caring responsibilities

Carer health and wellbeing (Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale)

Challenging life events in the past 12 months, including financial stress

Quality of time use

Positive and negative experiences of being a carer (including caregiver burden)

Receipt of Carer Payment or Carer Allowance

Finding and accessing formal and informal support

Awareness, access to, need for, and use of services and supports, including Carer Gateway services

Satisfaction with support services

Carer confidence

Carer self-identification

Carer demographics, including employment, education status and employment conditions (Schirmer and Riyanti 2021a:9–10)

In 2022, the questionnaire also included questions about:

Carer Choice

Navigating formal support systems

Health professionals and health records

Peer support groups

COVID-19 impacts

Transport access (Schirmer et al. 2022:66)

The study uses weighting to correct for overrepresentation of groups. Based on analysis of the characteristics of all carers in the Regional Wellbeing Survey (RWS) and carers from the RWS who completed the survey in 2021, the authors consider that the findings are "representative of 'carers with significant caring obligations'. The sample largely excludes those who provide a very small number of hours caring per week" (Schirmer and Riyanti 2021:12). While in 2022, the sample of respondents providing fewer hours of care increased Schirmer et al. (2022) note that the sample composition in this regard is similar to 2021.

In 2023, the survey also asked carers about the rising costs of living and adaptations to address the changing costs. In 2023, 270 respondents completed the Chinese language version of the survey, an increase from 35 respondents in 2022.

Table 29 below outlines sample information for the 2021,2022 and 2023 surveys:

Table 29 Carer Wellbeing Survey sample information

	2021 (24 March to 13 May)	2022 (27 January to 17 April	2023 (13 February- 17 April)
Valid responses	5808	5992	5881
Recruitment source	1,010 previous participant in RWS 2020 1,170 via care provider 1,530 from carer representative organisation 1,005 from social media advertising 530 from Qualtrics online panel 250 other means: information about survey on website, friends, family	1,063 previous participant in RWS or CWS 2021 1,499 via care provider 2,051 from carer representative organisation 1,013 from social media advertising 530 from Qualtrics online panel 684 other means: information about survey on website, friends, family	1,681 previous participant in RWS or CWS 2021 1,033 via care provider 1,609 from carer representative organisation 1,262 from social media advertising 777 other means: information about survey on website, friends, family
Mode of survey completion	99% online 1% paper form (51 respondents)	97.6% online 2.4% paper form (144 respondents)	99% online 1% paper form (31 respondents)
Length of survey completed	Of online respondents: 69% completed long version 31% completed short version	Of online respondents: 64.9% completed long version 35.1% completed short version	Of online respondents: 69.8% completed long version 30.2% completed short version
Composition of sample	Overrepresentation of female carers, Aboriginal and Torres Strait Islander carers, carers aged 45 years and over, and carers caring for more than 40 hours, NILF carers. Oversampling in states and territories with smaller populations.	Overrepresentation of female carers, Aboriginal and Torres Strait Islander carers, carers aged 45 years and over, and carers caring for more than 40 hours, NILF carers	Overrepresentation of female carers, Aboriginal and Torres Strait Islander carers, carers aged 45 years and over, and carers caring for more than 40 hours, NILF carers
Weighting	Weighted to be representative of Australia's carers using following benchmarks: gender, age, state/territory, labour force status, and weekly caring hours, unless otherwise specified (using the CENSUS 2016 and SDAC 2018)	Weighted to be representative of Australia's carers using following benchmarks: gender, age, state/territory, labour force status, and weekly caring hours, unless otherwise specified (using the CENSUS 2016, 2021, and SDAC)	Weighted to be representative of Australia's carers using following benchmarks: gender, age, state/territory, labour force status, and weekly caring hours, unless otherwise specified (using the CENSUS 2016, 2021, and SDAC)

Sources: *Carer Wellbeing Survey User Guide, November 2023*; and also: CWS 2021: Schirmer and Riyanti 2021; CWS 2022: Schirmer, Mylek and Miranti 2022, Appendix 1: Methods; CWS 2023: Mylek and Schirmer (2023).

Appendix D Qualitative methods

D.1 Stakeholder interviews

Sample: The sample for the stakeholder interviews included: CGSPs and DSS Carer policy staff. The profile of participants was co-developed with DSS. The sample included a total of 40 interviews with 57 stakeholders.

Interviews were conducted by telephone or video link to minimise travel costs and time, and to ensure participation could be easily integrated into staff's working day, with minimum disruption.

Recruitment: Recruitment was co-developed with the DSS and involved the DSS circulating information about the study and an invitation to participate in the evaluation to identified service providers and stakeholders. The evaluation team created the recruitment emails for DSS to circulate. Stakeholders and service providers were given the option to contact the evaluators directly or DSS passed on details to the evaluation team.

Interview content: Interviews discussed knowledge and perspectives of impact of the programs on carers and the evaluation questions relating to appropriateness and effectiveness. The interviews took on average an hour to complete.

Analysis: Interviews were audio recorded with interviewees' consent and transcribed verbatim by an external transcription company which has entered a confidentiality agreement with UNSW. An analytic framework was developed based on the evaluation questions. Content was analysed according to the framework using NVivo.

D.2 Interviews with non-Indigenous Carer Gateway program clients

Sample: Semi-structured in-depth interviews of approximately one hour were conducted with 30 non-Indigenous carers (Table 30). Participation in the interviews was voluntary. Program clients were asked to opt-in to the research and contact the researcher, who arranged an appropriate time to conduct the interview. Carers received a $100 EFTPOS card to support their participation.

Interviews were conducted online or by telephone in Metropolitan NSW, WA, ACT and Vic and regional locations in Qld, Vic. And Tas.

Recruitment: Clients of the program were contacted an interview who meet all three of the following conditions:

- live in one of the fieldwork sites
- registered with a service provider
- recorded contact details with the service provider (e.g. email and/or phone and/or postal address)
- consented to participate in follow-up evaluation activities.

The DSS sent information about the evaluation to services providers in the proposed fieldwork sites. The email from DSS asked providers make initial contact with registered clients who met the conditions above on behalf of the SPRC and SRC using an accompanying evaluation invitation. The invitation asked clients if they would like to participate in an interview to register their interest on a registration page (hosted by SPRC). The invitation was sent via letter, SMS text or the email (depending on what contact details the providers have for the carer). As part of the registration process participants answered a few questions about the type of services they have accessed and their basic demographic details.

Interview content: Interviews aimed to capture experiences of program clients accessing and using services, addressing the evaluation questions including engagement with the program, intended and unintended outcomes for carers and the person they care for, positive and negative experiences with services, usefulness of referrals, services that carers using ICSS value most and suggestions for improving the client experience of the ICSS program.

Analysis: Interviews were audio recorded with participants’ consent and transcribed verbatim by an external transcription company which has entered a confidentiality agreement with UNSW. An analytic framework was developed based on the evaluation questions. Content was analysed according to the framework using NVivo.

Table 30 Non-Indigenous Interviewee characteristics

	Total number
Number of interviews	**40**
Location	
Metro interviews	27
Regional interview	13
Characteristics	
Gender	
Female	31
Male	8
Carer age group	
49 years and under	8
50–64 years	15
65 years and over	17
Carer disability	10
LOTE	9
Care receiver age	
49 years and under and 50-64 years	16
50-64 and 65 years and over	24
Carer receiver type of disability	
Dementia	8
Old age-related fragility	18
Autism	8
Other developmental disorder	10
Mental illness	14
Alcohol and other drugs	5
Physical disability	14
Intellectual disability	8
Chronic illness non-terminal	11
Short-term illness	*
Other	7
Carer Gateways services used	
Needs assessment /Carers Star™	22
Peer support online	11
Counselling (phone/digital)	7
In-person counselling	17
CG peer support in-person	7
Coaching (in-person)	12
Tailored support package	12
Emergency respite	*

* Number not reported due to cell size < 5

D.3 Interviews with Aboriginal and Torres Strait Islander ICSS program clients

Ipsos Aboriginal and Torres Strait Islander Research Unit conducted the interviews with carers regarding Carer Gateway. The methods for interviews with Aboriginal and Torres Strait Islander carers involved a number of steps:

recruiting and training the Local Aboriginal and Torres Strait Islander Team Leaders

setting up an Aboriginal and Torres Strait Islander Advisory Committee to ensure that the project has meaningful engagement and advice from Aboriginal and Torres Strait Islander peoples. The Advisory Committee met on 16th May 2022 for the first time. The terms of Reference for the Advisory Committee ensure close oversight of all aspects of the evaluation relating to Aboriginal and Torres Strait Islander data collection, analysis, and dissemination. The Advisory Committee has a close working relationship with UNSW, the Local Team Leaders, and the communities in the demographic groups of interest. The aim was to enlist one person from each site to join the Advisory Committee (total of 4 people). Advice from the Advisory Committee members has been used to obtain the letters of support from the listed communities for the AIATSIS Ethics application. The Advisory Committee will meet three times, the first meeting was face-to-face, and the others will be virtual.

Recruitment: The interviewees were recruited through an opt in process across four sites including metro, regional and remote sites in Qld, NT, NSW and SA. DSS sent information about the evaluation to services providers in the proposed fieldwork sites and asked services providers to generate a list of Aboriginal and Torres Strait Islanders carers in the fieldwork site who met the conditions below:

An Aboriginal and Torres Strait Islander client registered with a service provider

recorded contact details with the service provider (e.g. email and/or phone and/or postal address)

consented to participate in follow-up research.

The list was sent by Secure File Transfer to Ipsos Aboriginal and Torres Strait Islander Research Unit to generate a random sample. The Local Team Leaders contacted the prospective participants via phone/email initially asking if they would like to participate in the evaluation, at this point they were provided a prospective participant an information sheet via email. If the participant agreed to participate, then the Team Leader will organise a time that was convenient for the interview. The interview was conducted face-to-face or by phone depending on the preference of the participant.

Interviews: A total of 29 client interviews were conducted via phone, digital and in-person depending on the preference of the carer and analysed for this report. It is not possible to provide a comparable table detailing the demographic characteristics of the sample as for the non-Indigenous carer sample because demographic characteristics were not collected as systematically due to a different recruitment and registration procedure. Participants received a $100 EFTPOS card to support participation in the interviews. The interviews took approximately one hour. The interviews were audio recorded with permission from participants and provided to the UNSW (SPRC) research team for analysis.

Analysis: SPRC staff analysed the interviews. Interviews were transcribed verbatim by an external transcription company which has entered a confidentiality agreement with UNSW. An analytic framework was developed based on the evaluation questions to analyse the content and emerging themes using NVivo.

Appendix E Population surveys: Methods

A baseline study in 2020 established by the Australian National University (ANU) in collaboration with the Social Research Centre (SRC) provides a robust evidence base for the evaluation of the ICSS and includes two population surveys, the first with a random sample of Australians using the Life in Australia^{TM} and a random sample of carers receiving Carer Payment and/or Carer Allowance. In 2022, the University of NSW (UNSW) in collaboration with SRC repeated these two surveys to determine the impact of the implementation of the ICSS. In addition, a survey of clients receiving emergency respite care was conducted in 2022 to examine their experiences receiving services. Participants were offered the option of completing an online survey or being interviewed over the telephone. Table 31 outlines the key project statistics and mode of completion for all three surveys.

Table 31 Key project statistics and mode of completion for surveys

Key project statistics	Life in Australia™ 2022	Life in Australia™ 2020	CPA 2022 Survey	CPA 2020 Survey	ERC 2022 Survey
Total invitations sent	1,157	397	99,999	99,929	
Interviews completed	553	353	3,315	3,061	79
Response rate	48.20%	88.91%	3.31%	3.10%	N/A
Median interview length (mins)	33.93	20	33.93	22.5	20
% Completed online	524	361	3315	3061	79
% Completed by telephone	29	36	0	0	0

The online surveys follow best practice for making questionnaires as user-friendly as possible for those accessing the survey via mobile phones and tablets. The SRC's online platform adheres to Web Content Accessibility Guidelines (WCAG) version 2.0. Surveys are programmed in English. The SRC uses Unicom Intelligence (previously IBM SPSS Data Collection) for data collection.

E.1 Population survey – Life in Australia^{TM}

The general population of carers survey was drawn from the SRC's probability-based panel, Life in Australia™. An invitation to participate in the survey was sent by the SRC via email to 397 carers in 2020 and 1157 carers in 2022 who identify themselves as "help[ing] or supervis[ing] another member of [their] household or someone outside [their] household who is over 18 years of age and has a long-term health condition or disability or is elderly in an informal capacity". Most of the carers (91% in 2020 and 95% in 2022) completed the survey online, while the remaining 9% in 2020 and 5% in 2022 completed it over the telephone. The number of carers who completed the survey in 2020 is 353 and 553 in 2022. The baseline survey was conducted in January-February 2020 and repeat study undertaken in November 2022.

E.2 Population survey of Carer Payment and/or Carer Allowance recipients

A sample of ~100,000 recipients of the Carer Payment and/or Carer Allowance was drawn from the Services Australia database using a stratified random sample design. An invitation to participate in the survey was sent by the SRC via email to 99,929 in 2020 and 99,999 in 2022. The number of carers who completed the survey in 2020 is 3,061 and 3315 in 2022 identified themselves as “help[ing] or supervis[ing] another member of [their] household or someone outside [their] household who is over 18 years of age and has a long-term health condition or disability or is elderly in an informal capacity. All surveys were completed online. The baseline survey was conducted between June 2020 and repeat study undertaken in November to December 2022.

E.3 Survey of carers who have received emergency respite care

The sample of carers who have received emergency respite care was drawn from service provider records. An invitation to participate in the survey was sent by the service provider via email to maintain the privacy of carers. Service providers sent the invitation to all past emergency respite clients who met the inclusion criteria of accessing emergency respite care between 1 July 2021 to 30 September 2022 and being a carer aged 16 years and over. The exact number of carers who received an invitation is not known. All 79 surveys were completed online. The fieldwork was conducted between September 2022 to December 2022.

E.4 Survey weighting and demographic differences between surveys

Surveys are a commonly used method for making inferences about a population based on responses from just a subset of it. Not everyone invited to complete a survey will do so, however – some may be unable to participate (such as those who do not use the internet, so cannot fill in an online survey, or those who are away during the survey period), some may start the survey but not finish it, some may not be interested in the topic or may not be willing to do the survey, and so on. As a result, the subset of persons who complete the survey may not exactly reflect the underlying population, despite the best possible survey design and data collection practices.

In such situations, it is common to assign a “weight” to each responding case in an effort to align the respondents as closely as possible with the population. The weights are then used in any calculations involving the survey responses. Persons with characteristics that are under-represented among respondents compared to the population get a higher weight in the calculations, whereas persons that are over-represented get a lower weight. For example, males between 18 to 44 years old make up 5.05% of the population but only 2.45% of respondents. Therefore, to align respondents better with the population, respondents who are male and less than 45 years old should be assigned a higher weight on average compared to respondents of other ages or gender.

E.5 Analysis of survey data

The population survey data for the Life in Australia^{TM} and the CPA Survey was tested for statistically significant differences between the baseline in 2020 and the recent survey in 2022. It should be noted that the Covid-19 pandemic commenced in March 2020 and continued to varying extents across Australia while data was collected in 2022. Changes in outcomes over this 2-year period in a cross-sectional sample may not be necessarily attributed to changes in the ICSS program but do give an indication of the impact of caring on Australians over two time points. Where there are differences identified they are discussed in the commentary.

Analysis was also undertaken to determine if recipients of benefits either Carer Payment and/or Carer Allowance have different outcomes to those carers not receiving benefits. Those carers who had used Carer Gateway services were compared to those who had not for statistical differences. Where there are differences identified they are discussed in the commentary.

Subpopulations such as gender of carer, carers with disabilities, Carers with language other than English, and Aboriginal and Torres Strait Islander carers were analysed for statistically significant differences. The sample sizes for some populations at a question level were often too small to detect statistically significant differences.

E.6 Carer Gateway Pre-Post Survey

The sample of carers who have registered through the Carer Gateway was drawn from service provider records (see Brosnan et al. 2023, Appendix 5 for details). An invitation to participate in the survey was sent by the service provider via email to maintain the privacy of carers. Service providers sent the invitation to all registering clients who met the inclusion criteria. It is unknown the exact number of carers who received an invitation. All 479 pre-surveys and 169 post-surveys were completed online. The fieldwork was conducted between October 2022 to June 2023.

E.7 Limitations

There are limitations with the survey data, including:

- A small sample size may cause difficulties in generalising the results, particularly for subpopulations.
- Participants may behave differently than they would in real life.
- Sampling bias may be present in the ERC survey.

Appendix F Administrative data analysis

F.1 Carer distress as proxied by use of antidepressant and benzodiazepine prescriptions

MADIP data were used to examine the association between the use of selected prescription drugs indicating psychological distress and participation in the ICSS program.

The MADIP project links data from several government programs and statistical collections. A master 'spine' list of Australian residents has been created from DSS, Medicare and ATO records, and data from other datasets linked to this. For this analysis, we used data from the DSS DEX data collection, the 2021 Census and the Pharmaceutical Benefits Scheme (PBS).

Following Mikkola et al. (2021, 2022), we look at the usage of three classes of prescription drugs among carers; antidepressants (Anatomical Therapeutic Chemical (ATC) code N06A), anxiolytic benzodiazepines and related drugs (ATC codes N03AE, N05BA and N06CA), and hypnotic benzodiazepines and related drugs (ATC codes N05CD and N05CF).

Mikkola et al. argue that demanding care responsibilities can lead to chronic stress and social isolation, increasing the risk of depression, insomnia and anxiety and, in turn increasing the likelihood of being prescribed these three classes of drugs. In a study comparing family caregivers in Finland (receiving caregivers allowance) with comparable non-caregivers, they find that carers were more likely to be receiving both antidepressants and BZDRD drugs (mainly hypnotic BZDRDs). We identify people who received any of these drugs via the PBS in 2020 and in 2022.

In this analysis, we identify caregivers using the 2021 Census, where people aged 15 years and above were asked if "In the last two weeks did the person spend time providing unpaid care, help or assistance to family members or others because of a disability, a long-term health condition or problems related to old age". Around 2.4 million people indicated yes to this question. Of these, 19.3% were receiving antidepressants in 2020, 5.2% receiving anxiolytic benzodiazepines (aBZDRD), and 3.5% receiving hypnotic benzodiazepines (hBZDRD). The corresponding percentages for medication use in 2022 were similar (20.9, 5.3 and 3.4%).

Participation in any of the ICSS carer support programs between 2020 and mid-2022 was extracted from linked DEX administrative data. The DEX data records 106,000 carers receiving any ICSS services up to mid 2022 (consistent with ICSS monitoring reports). Some 79,000 or 74% of these people were linked to the MADIP spine.[24] This linkage rate is lower than for other MADIP datasets, partly because of limitations in the data available for the linkage.[25] Of these people linked, only 47,000 (59%) were included in the population of Census-identified carers.

---

[24] The overall linkage rate for all DEX records (i.e. including non-carer programs) as recorded in the documentation is lower, at 68%.

[25] Only incomplete name and address information was available for linkage. We also observe that a substantial number (29,000) of the linked records in the DEX database were identified as having multiple links. That is, several people in the DEX dataset were linked to the same person in the MADIP spine. Among ICSS participants, the other linkage was almost always from one of the non-ICSS DEX services. While this could indicate an incorrect linkage for the ICSS client, it might

Timing issues could be responsible for many people receiving ICSS services but not identifying as carers in the Census. For example, they were at some point carers but not in the two weeks preceding the census date. However, we cannot rule out linkage errors as another potential explanation for this. These people receiving ICSS services and identified as carers in the Census comprise 2.0% of the Census carer population.

Using this data on the population of people identified as carers in the Census, we estimate several logistic regressions. Three dependent variables are used; whether using antidepressants in 2022, and whether using aBZDRD and hBZDRD in 2022. For the antidepressant use outcome, we regress separately for two sub-populations; carers who were using antidepressants in 2020 and carers who were not using antidepressants in 2020. Similarly, the other outcomes are estimated for corresponding sub-populations of carers. Predictor variables are whether the person received any ICSS services (from 2020 to mid 2022), and whether they received any of the following categories of service: information, counselling, respite, other high-cost, and other – excluding intake and review services – that is excluding intake and review services. We also control for demographic characteristics: gender, age category, indigenous status, whether a non-English language spoken at home, remoteness, and IRSAD decile. Regressions are also estimated for the sub-populations of female carers and carers aged 65 and above.

Table 32 shows the factors associated with antidepressant use in 2022. The left-hand columns are for the population of carers who were receiving antidepressants at some time during 2020, and the right-hand for those who did not receive antidepressants in 2020. The left-hand columns thus describing the factors associated with continuing with antidepressant use, and the right-hand columns the factors associated with commencement of antidepressant use.

For each model we show the parameter estimate from the logistic regression, the odds ratio for having that characteristic compared to not having it (or for one decile increase for the IRSAD variable) and the estimate divided by the standard error. Absolute values of the latter above 2 are significant at the 5% level.

Being female is associated with both continuing and commencing antidepressant use, while speaking a non-English language at home is associated with both exiting and not-commencing. Living in less advantaged regions is associated with more antidepressant use, but remote areas are associated with less use. Indigenous carers are less likely to continue antidepressants, but more likely to commence use. The same pattern applies to the younger age groups. (i.e. spells of receipt are shorter).

The parameter associated with any ICSS services on its own represents the increase in probability of receiving antidepressants associated with receiving ICSS intake and/or review services, but not any of the other ICSS services. This is positive, indicating an increase in the probability of receipt.

---

also reflect a lack of identity consistency across the different DEX programs (e.g. People with the same name and demographic information were assigned different case numbers in the different programs included in the DEX database). If this is the case, it would be appropriate to ignore the duplicate linkage flags, and this is the strategy that we have adopted here.

The effect is relatively small for those who were already receiving antidepressants (odds ratio of 1.1), but larger for those who were not receiving antidepressants in 2020 (OR 1.5).

To estimate the impact of the other ICSS services, it is necessary to add parameters together. Thus, the estimated impact of someone receiving ICSS respite (plus intake and/or review) is the sum of the Any ICSS and Respite parameters. That is, for those receiving antidepressants in 2020, log odds of 0.085+(-0.016) =0.069, or odds ratio of exp (0.069) = 1.07.

These program-specific parameters are generally either positive or slightly negative (and not significantly different from zero), so that likely combinations generally still imply an increase (or no change) in antidepressant use.

This pattern of greater continued use of antidepressants probably reflects selection effects, with those carers who are most vulnerable most likely to engage with ICSS services and also most likely to continue or commence receiving antidepressants. The bottom panels of the table show corresponding estimates for female carers and for carers aged 65 or more. The estimates also control for the same demographic characteristics, but the demographic parameters are not shown. These patterns are broadly similar to the overall pattern for all carers.

Though the results in this regression appear to be dominated by selection effects, among people receiving ICSS services, those receiving information services and ‘other high-cost’ services tended to be more likely to cease receipt of antidepressants, especially among the older carers – though these differences were usually not statistically significant.

Table 33 shows corresponding estimates for consumption of anxiolytic benzodiazepines and Table 34 for hypnotic benzodiazepines. Again, selection effects seem to dominate, commencement of prescription drug use, in particular, being associated with ICSS participation.

Table 32 Logistic regression of use of antidepressants in 2022 among carers

		Population: Received antidepressants in 2020			Population: Did not receive antidepressants in 2020		
		Estimate	Odds ratio	Est/se	Estimate	Odds ratio	Est/se
All Carers							
Intercept		1.534		116.2	–2.632		–260.6
Any ICSS		0.085	1.1	2.4	0.414	1.5	15.3
Information		–0.048	1.0	–1.1	0.055	1.1	1.5
Counselling		0.051	1.1	0.9	0.281	1.3	6.1
Respite		–0.016	1.0	–0.3	0.128	1.1	3.2
Other high-cost		–0.046	1.0	–0.9	0.064	1.1	1.5
Other		0.109	1.1	1.5	0.033	1.0	0.6
Female		0.339	1.4	42.6	0.463	1.6	76.0
Non-English at home		–0.521	0.6	–49.2	–0.547	0.6	–68.5
Indigenous		–0.160	0.9	–8.8	0.274	1.3	17.8
IRSAD decile		–0.003	1.0	–2.5	–0.043	1.0	–39.4
Age	<25	–1.005	0.4	–58.4	0.293	1.3	24.8
	25–49	–0.515	0.6	–50.5	0.173	1.2	22.4
	50–64	–0.164	0.8	–15.4	–0.120	0.9	–14.8
Inner regional		0.024	1.0	2.5	0.035	1.0	4.7
Outer regional		–0.054	0.9	–4.0	–0.057	0.9	–5.3
Remote/very remote		–0.253	0.8	–7.4	–0.404	0.7	–14.4
Female Carers							
Intercept		1.876		124.2	–2.226		–188.6
Any ICSS		0.077	1.1	2.0	0.389	1.5	12.7
Information		–0.059	0.9	–1.2	0.064	1.1	1.6
Counselling		0.065	1.1	1.0	0.260	1.3	5.2
Respite		–0.032	1.0	–0.6	0.110	1.1	2.4
Other high-cost		–0.041	1.0	–0.7	0.107	1.1	2.3
Other		0.126	1.1	1.6	0.038	1.0	0.6
[demographic controls not shown]							
Carers Aged 65+							
Intercept		1.625		66.3	–2.639		–144.2
Any ICSS		0.124	1.1	1.9	0.437	1.5	9.9
Information		–0.167	0.8	–2.0	0.062	1.1	1.1
Counselling		0.058	1.1	0.5	0.302	1.4	3.5
Respite		–0.033	1.0	–0.4	0.249	1.3	4.0
Other high-cost		–0.145	0.9	–1.3	–0.113	0.9	–1.4
Other		–0.041	1.0	–0.3	–0.031	1.0	–0.3
[demographic controls not shown]							

Notes: Population: unpaid carers as reported in 2021 Census and who were receiving or not receiving antidepressants in 2020 (N=0.46m and 1.94m). ‘Any ICSS’ denotes people who had any ICSS services received (up to mid 2022) and who were linked to the MADIP spine and Census data (N=47,000). ‘Information’ denotes ICSS information services received etc. ‘Other’ does not include intake and review services. Demographic variables are as in the 2021 Census. ‘Non-English at home’ flags people who speak a language other than English at home. ‘Indigenous’ flags people identifying as Aboriginal or Torres Strait Islander. IRSAD is the SEIFA (Socio-Economic Indexes for Areas) decile of advantage and disadvantage for the person’s SA1 of residence (high=advantaged, missing set to 5.5). Reference category for Age is 65+ and for region is Major Urban.

Table 33 Logistic regression of use of anxiolytic benzodiazepines in 2022 among carers

		Population: Received anxiolytic benzodiazepines in 2020			Population: Did not receive anxiolytic benzodiazepines in 2020		
		Estimate	Odds ratio	Est/se	Estimate	Odds ratio	Est/se
All Carers							
Intercept		0.381		19.2	–3.670		–258.4
Any ICSS		0.118	1.1	2.4	0.342	1.4	9.4
Information		0.076	1.1	1.2	–0.029	1.0	–0.6
Counselling		0.157	1.2	1.9	0.224	1.3	3.7
Respite		0.104	1.1	1.4	0.074	1.1	1.4
Other high-cost		0.034	1.0	0.4	0.090	1.1	1.6
Other		–0.087	0.9	–0.9	–0.068	0.9	–0.9
Female		0.018	1.0	1.5	0.467	1.6	53.9
Non-English at home		–0.262	0.8	–15.1	–0.559	0.6	–48.6
Indigenous		0.099	1.1	3.5	0.236	1.3	10.8
IRSAD decile		–0.025	1.0	–11.8	–0.008	1.0	–5.4
Age	<25	–1.067	0.3	–25.2	–0.424	0.7	–20.0
	25–49	–0.365	0.7	–24.7	0.145	1.2	13.7
	50–64	–0.220	0.8	–14.4	–0.058	0.9	–5.2
Inner regional		–0.130	0.9	–8.8	–0.078	0.9	–7.4
Outer regional		–0.249	0.8	–11.2	–0.198	0.8	–12.6
Remote/very remote		–0.448	0.6	–6.9	–0.498	0.6	–11.8
Female Carers							
Intercept		0.435		20.0	–3.206		–202.9
Any ICSS		0.104	1.1	2.0	0.366	1.4	9.3
Information		0.098	1.1	1.4	–0.008	1.0	–0.2
Counselling		0.193	1.2	2.2	0.175	1.2	2.7
Respite		0.081	1.1	1.0	0.071	1.1	1.2
Other high-cost		0.003	1.0	0.0	0.098	1.1	1.6
Other		–0.077	0.9	–0.7	–0.126	0.9	–1.5
[demographic controls not shown]							
Carers Aged 65+							
Intercept		0.344		10.0	–3.676		–143.6
Any ICSS		–0.037	1.0	–0.4	0.320	1.4	5.3
Information		0.083	1.1	0.7	–0.045	1.0	–0.6
Counselling		0.153	1.2	1.0	0.187	1.2	1.6
Respite		0.120	1.1	0.9	0.147	1.2	1.7
Other high-cost		0.041	1.0	0.3	0.046	1.0	0.4
Other		0.266	1.3	1.3	0.042	1.0	0.3
[demographic controls not shown]							

Notes: Population: unpaid carers as reported in 2021 Census and who were receiving or not receiving anxiolytic benzodiazepines in 2020 (N=0.46m and 1.94m). 'Any ICSS' denotes people who had any ICSS services received (up to mid 2022) and who were linked to the MADIP spine and Census data (N=47,000). 'Information' denotes ICSS information services received etc. 'Other' does not include intake and review services. Demographic variables are as in the 2021 Census. 'Non-English at home' flags people who speak a language other than English at home. 'Indigenous' flags people identifying as Aboriginal or Torres Strait Islander. IRSAD is the SEIFA decile of advantage and disadvantage for the person's SA1 of residence (high=advantaged, missing set to 5.5). Reference category for Age is 65+ and for region is Major Urban.

Table 34 Logistic regression of use of hypnotic benzodiazepines in 2022 among carers

		Population: Received hypnotic benzodiazepines in 2020			**Population: Did not receive hypnotic benzodiazepines in 2020**		
		Estimate	**Odds ratio**	**Est/se**	**Estimate**	**Odds ratio**	**Est/se**
All Carers							
Intercept		0.140		6.0	–3.812		–233.9
Any ICSS		–0.009	1.0	–0.1	0.408	1.5	10.2
Information		0.069	1.1	0.9	–0.031	1.0	–0.6
Counselling		0.007	1.0	0.1	0.273	1.3	4.0
Respite		0.007	1.0	0.1	0.104	1.1	1.8
Other high-cost		–0.048	1.0	–0.5	–0.074	0.9	–1.1
Other		–0.132	0.9	–1.0	0.042	1.0	0.5
Female		0.176	1.2	11.1	0.378	1.5	37.1
Non-English at home		–0.114	0.9	–5.5	–0.315	0.7	–23.7
Indigenous		–0.120	0.9	–2.6	0.220	1.2	7.4
IRSAD decile		0.018	1.0	6.9	0.036	1.0	19.9
Age	<25	–2.406	0.1	–25.8	–1.597	0.2	–47.5
	25–49	–1.366	0.3	–69.3	–0.790	0.5	–64.2
	50–64	–0.643	0.5	–39.4	–0.452	0.6	–39.7
Inner regional		–0.067	0.9	–3.5	–0.058	0.9	–4.5
Outer regional		–0.130	0.9	–4.4	–0.128	0.9	–6.7
Remote/very remote		–0.486	0.6	–5.8	–0.403	0.7	–7.7
Female Carers							
Intercept		0.297		11.7	–3.505		–190.5
Any ICSS		0.021	1.0	0.3	0.388	1.5	8.6
Information		0.067	1.1	0.8	–0.028	1.0	–0.5
Counselling		–0.008	1.0	–0.1	0.298	1.3	4.1
Respite		0.009	1.0	0.1	0.094	1.1	1.4
Other high-cost		–0.123	0.9	–1.2	–0.100	0.9	–1.3
Other		–0.124	0.9	–0.9	0.098	1.1	1.1
[demographic controls not shown]							
Carers Aged 65+							
Intercept		0.154		4.7	–3.657		–146.9
Any ICSS		–0.087	0.9	–1.1	0.390	1.5	6.7
Information		0.150	1.2	1.4	–0.001	1.0	0.0
Counselling		–0.001	1.0	0.0	0.072	1.1	0.6
Respite		0.068	1.1	0.6	0.165	1.2	2.0
Other high-cost		–0.147	0.9	–1.0	–0.122	0.9	–1.1
Other		–0.102	0.9	–0.6	0.039	1.0	0.3
[demographic controls not shown]							

Notes: Population: unpaid carers as reported in 2021 Census and who were receiving or not receiving hypnotic benzodiazepines in 2020 (N=0.46m and 1.94m). ‘Any ICSS’ denotes people who had any ICSS services received (up to mid 2022) and who were linked to the MADIP spine and Census data (N=47,000). ‘Information’ denotes ICSS information services received etc. ‘Other’ does not include intake and review services. Demographic variables are as in the 2021 Census. ‘Non-English at home’ flags people who speak a language other than English at home. ‘Indigenous’ flags people identifying as Aboriginal or Torres Strait Islander. IRSAD is the SEIFA decile of advantage and disadvantage for the person’s SA1 of residence (high=advantaged, missing set to 5.5). Reference category for Age is 65+ and for region is Major Urban.

F.2 Continuing to care: detailed regression analysis

This estimation uses data from the linked DEX-DOMINO dataset held by the DSS. The estimation method is a discrete time hazard model estimating the likelihood of ceasing to receive Carers Allowance. Continuing to receive Carers Allowance is thus used as a proxy for continuing to care.

For this estimation, we include one record for every quarter where a person received Carers Allowance (CDA) at any time during that quarter. The last quarter that they received payment is flagged as their exit quarter. We ignore exits that result in a later return to payment. Prior to estimation, we delete all records for Q4 2022, because most of these payment spells end because of the end of our observation window (i.e. are 'censored'). With this data, we estimate a logistic regression model predicting exit as a function of fixed and time-varying characteristics. Because each person has only one exit by construction, we do not need to adjust the estimation to take account of the multiple records per person. We test whether the probability of exit is lower for those people receiving ICSS services (compared to earlier services and no service receipt).

The explanatory variables included in the models are:

- QDuration: Number of quarters since spell commencement. Specified as a fifth order polynomial of (number of quarters – 10)/10. The zero value is thus near the mean duration of 11 quarters. These indicate the 'baseline' hazard. For people with breaks in payment spells we reset this quarter counter to 1 after the break.
- Year (dummy variables). These reflect changing historical time effects (particularly the impact of COVID). (Data from the first three quarters of 2015 are only used to define the service use variables for the fourth quarter onwards).
- AnyServices_Y is equal to 1 if any client DSS carer support services received in the past year (the current and 3 previous quarters).
- ICSS: Equal to 1 if quarter is from 2020Q2 to 2022Q3 inclusive. Used in interaction with service use to flag ICSS services.
- AnyServices_ICSS_Y = AnyServices_Y*ICSS: Identifies ICSS services used in the past year.
- Intake, Information, Counselling, Respite, (other)Highcost, Review, Other. Indicates receipt of each type of service in the previous year. Interaction variables with ICSS also calculated as for AnyServices.
- Female (other and missing are randomly assigned to male or female).
- Age at start of quarter (reference: under 26).
- IRSAD_Dec. Decile of socio-economic advantage/disadvantage. 1 = most disadvantaged areas (reference category: location not recorded).

We estimated four different models and present results for our base preferred model (Model 2).

- Model 1: includes the duration polynomial and year dummies, plus AnyServices_Y and AnyServices_ICSS_Y
- Model 2: as for Model 1, except the different services are entered separately into the model.
- Model 3: as for Model 2, but just carers aged under 50.
- Model 4: as for Model 2, but just for female carers.

Model 1 tests whether receiving any Carer Gateway services (i.e. since 2020 Quarter 2) has an impact on exit from Carer Allowance. In this model (not shown) the AnyServices parameter estimate is negative and significant, implying that prior to the introduction of ICSS, carers who had received any carer support services in the previous year were less likely to exit from Carer Allowance and therefore more likely to continue caring. This could be because either those people with greater needs were more likely to both receive support services and also more likely to continue to stay on Carer Allowance, OR that the support services assisted them to continue to care longer and hence remain on the payment.

The model also includes a term which interacts service receipt with the services being received after ICSS was introduced. This tests whether this relationship between exit and support has changed since the introduction of ICSS. This interaction term is small and not significant – indicating no overall change.

Our preferred model (Model 2) disaggregates by the different categories of support service (Table 35). It also controls for gender, age, and socio-economic status of area (IRSAD decile). Here, the ICSS interaction terms for counselling and ‘review’ services are not significantly different from zero – indicating their impact on exit are no different than before the introduction of ICSS. Other services, such as intake, and importantly, respite, have negative interactions. This indicates that exit from carer allowance for people receiving these services is now lower since the introduction of ICSS. On the other hand, the interaction terms for information and other high-cost (and ‘other’) services are positive, indicating that they led to higher exit rates from Carer Allowance.

Table 35 Discrete time hazard model of exit from Carers Allowance

	Estimate	s.e.	t	p
Intercept	–3.258	0.024	–135.2	<0.0001
Duration (qtrs–10)/10	–0.530	0.008	–65.0	<0.0001
Duration ^2	0.877	0.020	44.1	<0.0001
Duration ^3	0.066	0.013	5.3	<0.0001
Duration ^4	–0.972	0.021	–47.2	<0.0001
Duration ^5	0.406	0.010	42.1	<0.0001
2015	–0.124	0.009	–13.7	<0.0001
2016	–0.356	0.005	–75.8	<0.0001
2017	–0.155	0.005	–33.9	<0.0001
2018	0.020	0.004	4.6	<0.0001
2019	0.213	0.004	50.4	<0.0001
2020	0.034	0.005	7.4	<0.0001
2021	0.181	0.005	40.3	<0.0001
Age 26–49	–0.290	0.003	–96.6	<0.0001
Age 50–64	–0.069	0.003	–22.5	<0.0001
Age 65+	0.150	0.003	49.4	<0.0001
Female	–0.052	0.003	–15.2	<0.0001
IRSAD Decile 1	–0.080	0.004	–21.0	<0.0001
2	–0.086	0.004	–21.2	<0.0001
3	–0.081	0.004	–18.8	<0.0001
4	–0.066	0.005	–14.6	<0.0001
5	–0.056	0.005	–11.8	<0.0001
6	–0.021	0.005	–4.2	<0.0001
7	–0.016	0.005	–3.2	0.0015
8	0.033	0.005	6.2	<0.0001
9	0.087	0.006	15.6	<0.0001
10	0.243	0.006	38.4	<0.0001
Intake	–0.219	0.006	–34.1	<0.0001
Intake*ICSS	–0.051	0.010	–5.0	<0.0001
Information	–0.207	0.006	–34.1	<0.0001
Information*ICSS	0.052	0.011	4.6	<0.0001
Counselling	0.036	0.012	2.9	0.0039
Counselling*ICSS	0.003	0.019	0.2	0.8616
Respite	–0.224	0.006	–34.8	<0.0001
Respite*ICSS	–0.150	0.012	–12.2	<0.0001
Other high-cost	0.021	0.007	3.0	0.0026
High-cost*ICSS	0.169	0.015	11.5	<0.0001
Review	–0.344	0.371	–0.9	0.3546
Review*ICSS	0.298	0.371	0.8	0.4225
Other	0.147	0.011	13.3	<0.0001
Other*ICSS	0.093	0.023	4.1	<0.0001

Source: Authors’ analysis of DEX-DOMINO dataset
Note: Reference category for Year is 2022, age is under 26 and for IRSAD decile is location not recorded. Effect coding is used for these variables and also for the service categories, which means that the intercept represents the value for the unweighted mean case with duration=10 and male. For the shown parameters, this represents the effect of the category compared to the unweighted mean. The estimates for the reference categories are found as the intercept plus the negative of the sum of the other categories.

In interpreting these results we have to consider that many of the services will be provided in combination. Intake and information services, for example, would often go together, with offsetting effects for the interaction with ICSS participation.

Interpreting the quantitative magnitude of these models is not straightforward. Since the estimates come from a logistic regression model, the most natural estimate is the impact of each parameter on the odds ratio of the outcome. So, for example, the negative interaction parameter of (–0.150) for respite services implies that the odds of exit from carer allowance in a given quarter for those receiving respite services since the introduction of Carer Gateway are 74% (0.74 = exp(2 X – 0.150)) of the pre-Carer Gateway value.[26] Another approximation is that the parameter shown will represent the proportionate change in the probability (hazard) of exit in a quarter. So, in this case, the probability of exit is about 30% less.

The results for models 3 and 4 (young carers and female carers, not shown) are very similar to those in Model 2.

In summary, there is no overall impact of the receipt of Carer Gateway services on exit from Carer Allowance (compared to the impact of earlier carer support services). However, there is evidence that receiving respite services since the Carer Gateway program started is associated with a lower rate of exit from Carer Allowance (i.e. a greater probability of continuing to care). On the other hand, the opposite applies for the other high-cost services, which are associated with a lower probability of continuing to care.

F.3 Changes in Carers Star^{TM} scores by service types

This analysis is based on DEX administrative data. Table 37 presents the results from a regression analysis, predicting the increase in Carers Star^{TM} score as a function of whether the person had received services from each of the categories described in Section 18.1 and their demographic characteristics. Model 1 describes the impact of the services alone. The intercept of 0.27 points estimates the increase in score for clients who did not receive any services. This increase could reflect changing patterns of scoring the instrument over time or possibly clients being more aware of the program and hence being more interested in seeking help when their needs were less severe on the second occasion. It could also indicate that they received services from sources outside Carer Gateway or that the initial information and advice was sufficient for them to improve their wellbeing.

The parameter estimates for the receipt of different services need to be added to the intercept to obtain estimates of the predicted change in score associated with each service. For example, the predicted increase for someone receiving respite services, and no other services, is a 0.27+0.12=0.39 points increase. For someone receiving both respite and emergency respite, the predicted increase is 0.27+0.12+0.05=0.44 points. The parameters are significantly different from zero at the 5% level when the absolute value of the t statistic is greater than 1.96. This statistic tests whether the change associated with receiving the service is different from the intercept effect associated with no services received.

---

[26] The multiplication by two is because of the effect coding the variable (the reference category estimate is the negative of the shown category, respite in the ICSS period in this case).

Whether the impact of a service should be represented by its own parameter estimate, or the estimate plus the intercept, depends on the reasons for the increase for people who do not receive any services. If the initial information and advice helped improve outcomes, then it might be appropriate to add them together as described in the previous paragraph when considering the overall impact of the program. On the other hand, if this base increase represents changing measurement, or other factors from outside of the program, then it would be most appropriate to only consider the incremental impact of each program (the parameter estimate as presented in the table).

In this estimation, respite is associated with the largest increase in score (0.12 points higher than the score for those without any services, or an increase of 0.39 in total), while specialist support, emergency respite and counselling have increases of about half this amount. Some services were associated with *decreases* in mean score outcomes compared to those who received no services (training, advice, and mentoring/peer support), and other services were associated with no significant change (support and material goods).

These results are similar when the analysis controls for demographic characteristics (Table 37, Model 2).[27] However, even though these observed characteristics are controlled for, it is possible that these patterns could reflect different characteristics of people receiving different services. For example, some services might be more likely to be associated with care recipients whose needs might be increasing over time and thus more likely to lead to a decrease in scores.

---

[27] The impact of the demographic characteristics shown in Table 37are discussed in Section 17.

F.4 DEX data on carer support programs

Table 36 First and second activity for carers as recorded in the following DEX programs

First activity		Second activity				
		ICSS Carer Gateway providers	ICSS Digital counselling	Young Carer Bursary Program	Tristate Carer Vocational Outcomes Pilot	Other DSS activity (may include historical carer programs)
	N	N	N	N	N	
ICSS Carer Gateway providers	127,140		1,450	405	535	2,305
ICSS digital counselling	5,088	663		n.p.	36	137
Young Carer Bursary Program -	3,715	171	n.p.		n.p.	161
Tristate Carer Vocational Outcomes Pilot	1,407	175	23	n.p.		37
Other DEX DSS Activity (may include historical carer programs)		36,681	1637	717	929	

Notes: The denominator for all percentages reported in the text is the value for the cell in the second column.

Filters: Client type = individual client.

n.p. denotes 'not provided' due to confidentialisation. Only sessions from closed reporting periods are included in this report. Sessions conducted after 31/12/2022 are excluded.

Only individual clients and their sessions are included in this report. Support persons and their sessions, plus group clients and their sessions are excluded.

Only SLKs with a ‘Carer’ activity are included in this report. Whilst information on other DSS activities is included, this information is only included for SLKs with a ‘Carer’ activity.

Within this report, ‘Carer’ activities include: ICSS- Digital Counselling, TCVO and YCBP.

‘Other DSS Activities’ include DEX DSS activity not considered to be a ‘Carer’ activity as defined above. ‘Other DSS Activities’ may include historical carer programs, pre-May 2020.

Counts of SLKs include high quality SLKs only. Low quality SLKs have been excluded. An SLK is considered high quality when the client has a first and last name, the client’s name is not a pseudonym, the clients’ gender is not ‘not stated’, the client’s date of birth is not estimated, and the client is less than or equal to 110 years old at the time of their sessions.

The flow of clients amongst the ‘Carer’ activities ONLY considers a client’s first session within each activity. For example, it shows a client’s flow from their first Carer Gateway session to their first TCVO session. If this client goes back to Carer Gateway after their first TCVO period of service, this second episode of Carer Gateway is NOT included in a client’s pathway within this report. Similarly, only a client’s first session with the; Other DSS Activities; category is included in a client’s pathway within his report.

A single SLK may be associated with multiple Clients IDs and each of these Client IDs may have different client demographic values. When this occurs, the demographics of the client with the most ‘complete’ clients’ attributes in the following list: birth dates estimated flag, pseudonym flag, locality of client’s address, State of client’s address, Indigenous status, country of birth, main language, disability flag are used. When multiple clients have the same demographic ‘completeness’ then the attributes of the client with the latest recency (e.g. details most recently updated) are used. The client chosen, and whose attributes are used, is referred to as the ‘representative client’.

Since the quality of an SLK is determined by a number of attributes tied to the Client ID, it is possible that a singly SLK may be associated with one client with a high quality SLKJ and another client with a low quality SLK, even though they have the same SLK and the same first and last name, but one client may have their name marked as a pseudonym whereas the other client does not have their name marked as a pseudonym. One client therefore has a low quality SLK whereas the other client has a high quality SLK. When this occurs, the SLK itself is considered to be high quality within this report. In other words, if at least one Client ID under an SLK has a high quality SLK then the SLK as a whole is considered high quality.

Data for this report was extracted from DEX on 8 March 2023 8:13:38pm.

Report Version 1 released October 2022.

Table 37 Regression model predicting increase in mental health, wellbeing, and self-care score between first and last assessment

	Model 1: Services received		Model 2: Also controlling for demographics	
	Parameter estimate	t	Parameter estimate	t
Intercept	0.27	46.7	0.27	29.0
Some Carer support	−0.01	–0.3	0.00	0.1
Some Material goods	0.02	1.0	0.02	1.2
Some Specialist support	0.06	7.4	0.07	7.8
Some Respite	0.12	13.1	0.11	12.9
Some Emergency Respite	0.05	3.4	0.05	3.4
Some Counselling	0.07	7.0	0.06	6.7
Some Education and skills training	−0.04	–2.4	−0.04	–2.5
Some Information/advice/referral	−0.06	–7.6	−0.05	–6.2
Some Mentoring/peer support	−0.10	–7.5	−0.10	–7.3
Gender Male			0.01	0.6
Gender Not stated/ other			−0.19	–3.3
Gender Female			0	
Age<26			−0.06	–3.5
Age26–49			−0.01	–1.5
Age50–64			0	
Age65–79			−0.04	–3.7
Age80+			−0.03	–2.3
Indigenous Status Yes			−0.01	–0.3
Indigenous Status Not stated			0.02	0.9
Indigenous Status No			0	
CALD Status CALD			0.02	1.4
CALD Status Not CALD			0	
Disability Status Yes			−0.07	–6.6
Disability Status Not stated			0.14	2.1
Disability Status No			0	
Inner regional			0.04	4.4
Outer regional			−0.03	–2.2
Remote			−0.08	–2.5
Very remote			−0.21	–3.4
Major city			0	
Government payments / pensions / allowances			−0.00	–0.1
Employee salary / wages			0.04	3.9
Other income including superannuation and investments			0.03	1.8
Self-employed (Unincorporated business income)			0.13	4.2
Unknown/ Nil			0	

Notes: Population: Clients with at least two assessments between April 2020 and December 2022 (excluding assessments recorded in association with digital counselling). OLS regression. ‘Some carer support’ is an indicator variable flagging that the person received at least one session of carer support between the first and last SCORE assessment dates (+/– one day). Similarly for the other services listed. The effects for demographic characteristics are relative to the (most frequent) category in each variable – indicated by parameter estimates of zero.

Appendix G Cost-effectiveness methodology

G.1 Common approaches to estimating economic value of informal care

The economic value of informal care is typically measured as either: (1) the replacement value, estimated as the cost of providing the equivalent formal care[28] based on the market cost of buying services, or (2) the opportunity cost, estimated as the amount of time spent caring relative to forgone earnings.

Deloitte's assessment of the economic contribution of care in Australia, in 2020, estimates primary carers spent on average just over 35 hours a week in caring activities and secondary carers spent on average 5 hours a week in caring activities (Deloitte, 2020: iii). Multiplying the number of carers in Australia (ABS data) by 52 weeks/year and the average amount of care given by primary and secondary carers, respectively, Deloitte estimates the total number of 'caring hours' supplied is around 2.2 billion hours per year. The replacement value is estimated using an hourly rate of $36.12 (based on the market rate for carers), resulting in an economic value of $77b per year.

For the opportunity cost method, Deloitte calculates the difference in employment rates between carers and the population in the same age bracket (ABS data). Assuming this ratio is equivalent to the proportion of carers choosing to care full-time, Deloitte (2020) applies this ratio to the number of carers who would have otherwise been in employment. It then multiplies the number obtained by the average weekly earnings (x 52 weeks/year) to estimate the opportunity cost of caring in the year, resulting in an economic value of $11b. Similar approaches and results are found by Ekman et al. (2021), McDaid et al. (2021), Petrillo and Bennett (2022), and Schofield et al. (2019).

These cost estimates are only for one year. Further, caring is likely to have other long-term economic consequences including effects on future income, accumulation of savings (superannuation), consumption, and access to healthcare and other benefits, over the remaining lives of both carers and care recipients (e.g. Furnival and Cullen, 2022).

G.2 Approaches used to estimate cost-effectiveness of Carer Gateway

The anticipated benefit of the Carer Gateway is that informal care is sustained and replacement costs (i.e. where care is provided by formal care services) are minimised. The purpose of the cost-effectiveness analysis for Carer Gateway is therefore to estimate the money saved by providing services to carers via Carer Gateway. In other words, to give an economic value to the observed changes in the behaviour and wellbeing of carers receiving services. The challenge is how to estimate the benefits that can be attributed to Carer Gateway for caring.

The Carer Gateway is anticipated to impact carers:

- directly, through the hours of care provided and changes in wellbeing, and
- indirectly, through impacts on the care recipient.

---

[28] Note that carers may provide care in excess of what would be provided in formal care arrangements.

Identifying the direct and indirect effects is complicated by the fact that carers are unlikely to start/stop caring because of an intervention – most carers are intrinsically motivated to provide care, or they do so care because formal care is not available or is too expensive. In addition, supports provided to carers may influence behaviours that are unobserved (e.g. the nature of care provided) rather than observed and measurable variables such as the number of hours worked. This suggests the benefits of providing carers with supports are likely to be observed through effects on the care recipient, in particular through the avoidance of requiring more formal care.

Given the above, it is unsurprising that evaluations of carer programs focusing on direct benefits tend to yield inconclusive results. For instance, in a review of 204 studies on the effects of carer support, Arksey et al. (2002) find little evidence of direct benefits to carers except from lower psychological stress, whereas observed benefits were reported for the person cared for. Further, of the 204 studies, only 13 provide economic analyses (Arksey et al., 2002: 23). Similar conclusions or implications arise in the surveys of Engel et al. (2021) and Pickard (2004).

The analysis is based on all services received between March 2020 and December 2022, excluding observations related to Information, Intake, and Service review as these are not services. The data have been trimmed to generate the working sample (Table 38):

Table 38 The working sample used for economic evaluation – DEX data

Category	Sessions
Initial observations	1,636,805
of which Individual clients*	1,455,506
of which Carer Gateway service provider	1,429,938
of which are not duplicates	1,175,125
of which have complete information on variables of interest	1,152,395
Working Sample**	611,257**

Source: DSS supply 3. Note: * Do not have different Session_ID for same person and date of service BUT can have different service_types in same date. ** Remaining sessions after removing sessions related to Information, Intake, and Service review

This results in the following several samples as specified in Table 39.

Table 39 Low-cost and high-cost session attendance

Category	Sessions
Working Sample	611,257
only low-cost – clients attend only low-cost sessions	87,641
only high-cost – i.e. clients attend only high-cost sessions	320,805
both low- and high-costs – i.e. clients attend both sessions	202,811
of these, first service is low-cost	97,487
of these, first service is high-cost	105,324

Source: DEX data from DSS supply 3. Note: The working sample has 611,257 Session_ID x Client_ID cases. The working sample includes multiple services received during the same day but excludes sessions related to Information, Intake, and Service review.

Three components are used to estimate the cost-effectiveness of the program:[29]

(a1) Effect of Carer Gateway on the decision to continue providing care

This analysis focuses on the extent to which carers receiving Carer Gateway support remain in employment or take up employment – i.e. whether they continue providing care.

Using the Deloitte (2020) estimate that 17.7% primary carers had given up employment to care full-time, it is unlikely that Carer Gateway services will facilitate a return to work for this group. The opportunity cost of working is estimated to be approximately $1750/week ($91,000/year) while the value of Carer Gateway support is estimated to be $1100/year.

For the 82.3% of primary carers who remain in employment, the question is whether receiving Carer Gateway support of $1100/year has an impact on them remaining in employment. This is also unlikely, as Carer Gateway support is about 1% of the value of earnings when calculated on an annual basis (i.e. $1100/(52 x $1753)).

Even if marginal cases existed (that is, where people switch from working to caring or vice-versa) the resources allocated to Carer Gateway support are too small relative to weekly earnings to impact on the decision to work or provide care[30]. Any effect in one direction is likely to be compensated by the opposite effect (i.e. people in employment choosing to become carers, or vice versa). A conservative approach is to **set to zero** the effect of Carer Gateway on the decision to move from employment to providing care.

In our own analysis, Brosnan et al. (2023) Figure 100 indicates that around 10% of carers accessing Carer Gateway have changed employment status: 4% are now employed and 6% have ceased employment. In the most extreme cases, whereby the reference group from which to enter/exit employment is unemployment, the existence of Carer Gateway has generated a net reduction in the hours of labour supplied (–6% exits + 4% entries = –2%; based on approximately 130,000 carers). This estimate reflects ICSS carers only and excludes carers in the Young Carer Bursary Program and the Tristate Carer Vocational Outcomes Pilot. The net effect on hours of work in a year is obtained as –2% x 130,000 x 35 hours/week x 52 weeks/year = about 4.732m hours of work. In addition to the value of the working hours lost, the social cost has to include the 2% net increase in the number of unemployment benefits being paid, i.e. 2% x 130,000 = 2,600 new unemployed. The combined effect of these two components represents **a net annual cost of $243.71m** (i.e. 4.732m hours x $37/hour + 2,600 new unemployment benefits of $510/week x 52 weeks based on the Single principal carer being excluded from mutual obligation requirements).[31]

In a more realistic case, exits from employment are from intermediate stages of employment like part-time or casual employment (9–15 hours/week) to provide some or more hours of care, while entries to the workforce are likely to substantially increase the hours worked, including the case of full employment at 35 hours/week, as they may be related to the relocation or death of the person

---

[29] If the remaining 95% accessed Carer Getaway and this costed (per carer) what the government is currently funding, the total cost would increase to $2.489b (i.e. 130m x .95/.05) against benefits of between $11b and $77b, leading to a benefit/cost between 4.4 and 30.9 times.

[30] Brosnan et al. (2023) Figure 100 indicates that around 10% of carers accessing Carer Gateway have changed employment status: 4% are now employed and 6% have given up employment.

[31] See https://www.servicesaustralia.gov.au/how-much-jobseeker-payment-you-can-get?context=51411

cared for. For instance, exits from the workforce (6% of 130,000 = 7,800 carers) working on average 15 hours less per week would reduce hours of work supplied in a year by 6.084m units (7,800 x 15 hours reduced x 52 weeks) while entries to the workforce would add about 9,464m hours (4% x 130,000 carers x 35 additional hours x 52 weeks) resulting in a **net annual gain of about 3,380,000 hours or $125.06m** (if valued at the average of $37). The number and nature of assumptions suggest using a conservative approach with no tangible effect arising from this component.

(a2) Effect on caring activity

The literature highlights two possible effects of carer support programs. The first is the prevention of, or reduction in, burnout and mental health issues among carers. This effect is at times estimated in the lower use of medication and associated health costs (Arksey et al, 2002).

A conservative approach is to limit the positive effects of Carer Gateway to those using services that have a high-cost (‘high-cost’). Based on DEX-DOMINO data for 2021 and 2022, about 28% of cases are high-cost sessions. The most conservative analysis assumes that all risk is accounted for by wellbeing of the carer, and that Carer Gateway lowers such risk but only for carers accessing high-cost services.

From Table 26 and Figure 14, there were 357,258 high-cost sessions in total in 2021–2022, or 178,629 on average for each of the two years (high-cost covers: carer support, respite, emergency respite, material goods, and specialist support).

Multiplying the number of sessions by the cost of non-admission hospital services (mainly mental health services) of $317 (the Australian Institute for Health and Welfare; AIHW, 2023) allows us to estimate the total savings associated with receiving Carer Gateway support (mental health) of $56.625m in each year (i.e. 178,629 x $317). This is a conservative measure as the number of high-cost services over time has been rising.

The second effect of providing carer supports is the increase in wellbeing impacting on the **productivity of carers who remain in employment**. Fakeye et al. (2023) estimate a 30% loss in productivity of carers who continue to work while caring. Carer support programs can reduce such a loss.

From Table 22 the average increase in mental health and wellbeing of carers receiving Carer Gateway is 0.29 on a first score of 3.43. This corresponds to an improvement of 8.5%, which is assumed to be reflected in higher productivity for carers who are in employment. As productivity underpins earnings, such improvement is assumed to generate a corresponding increase in average earnings ($1,753; (ABS, 2023 Table 11))[32].

The productivity improvement resulting from this effect of Carer Gateway support **is therefore valued** as:

---

[32] The carers’ employment rate, extracted from Table 15 of the Interim Report (last 4 rows), is 28% (i.e. 6,836/24,517). This is assumed to apply to the number of carers in 2022, as indicated by DSS (74,295).

8.5% (higher productivity) x $1,753 (weekly earnings) x 52 (weeks/year) x about 75,000 carers (for each of the years 2021 and 2022) x 28% employment rate = **$162.71m** per year.

If the 30% productivity improvement in applied, as found by Fakeye et al. (2023), the figure above increases to $574.28m per annum.

The value of the component (a2) is therefore $56.625m + $162.71m = $219.3m

(a3) Indirect effect

As highlighted in the literature above, the cost-effectiveness of interventions for carers should include the impact of the program on the care provided to the care recipient. Therefore we consider the additional effect on the care recipient when the carer accesses Carer Gateway.

One approach is to assume that Carer Gateway services delay or prevent hospital admissions (in the most serious cases) or to avoid outpatient services (in the least severe cases) for the care recipient. This approach uses a conservative 50% ratio for each type of health service used and restricts its application to the number of high-cost services accessed in a given year.

The cost of hospitalisation (AIHW, 2023) and non-admission hospital services (IHCAPA, 2023) are obtained from AIHW and the Independent Health and Aged Care Pricing Authority (IHCAPA), who publish the cost of hospitalisation for each hospital in Australia. A conservative approach is to use the cost of each state's public hospital with the lowest cost – these are typically large public hospitals in each major centre as shown in Table 40 below:

Table 40 Cost of hospital admission by state based on hospital with lowest cost

State	Hospital	Cost per admission 2014–15 ($)	Estimated cost per admission in 2022 ($)
TAS	Royal Hobart	4,900	6,668
ACT	Canberra Hospital	6,000	8,165
SA	Royal Adelaide	5,300	7,213
WA	Royal Perth	5,900	8,029
NSW	Royal North Shore	4,500	6,124
NT	Royal Darwin	5,300	7,213
VIC	Royal Melbourne	4,200	5,716
QLD	Royal Brisbane & Women's	4,700	6,396

Source: AIHW (2023)

Note: 'Cost per admission' is based on costs published by AIHW for 2014–2015. AIHW also reports their average annual increase until 2022 is 4.5% (https://www.aihw.gov.au/reports-data/myhospitals/themes/spending-on-hospitals). 'Cost in 2022' therefore refers to the inflated admission cost by state (2015 costs at 4.5% per annum).

The value of the indirect effect (a3) in 2022 **is**:

50% x inflated admission cost by state + 50% x $317 (non-admission hospital cost) x number of high-cost services by state in 2022 (DEX-DOMINO data) = **$661.7m**

The combined value of the three components a1–a3 is therefore:

0 (decision to care) + \$56.625m (effect on caring activity) + \$162.71m (higher productivity) + \$661.7m (effect on care recipient) = **\$881.04m**

The financial cost to DSS for the Carer Gateway program is \$131.2m in 2022 (actual expenditure) and \$101.1m in 2021. The resulting benefit-cost ratio (BCR) is 7.6 using an annualised expenditure of \$116m and 6.72 using the 2022 expenditure. Thus, Carer Gateway appears to be cost effective as the costs are about 13% (expenditure) of the benefits generated, respectively.

Even if indirect benefits are excluded[33], the total amount of benefits associated with Carer Gateway is \$219.3m, or about 1.89 times the annualised expenditure of the program (or 1.67 times using only 2022 expenses). Carer Gateway is therefore a cost-effective program.

G.3 Approach used to estimate cost effectiveness of restructure

To assess if the restructured investment has been effective, we use a fixed-effects model based on the following specification:

$$y_i=a_0+X_{it}a_1+a_2D+i+t+\varepsilon_{it}$$

Where:

- *y* is an outcome variable, such as the probability of accessing a particular type of service (e.g. respite), for client *i* at time *t* (*t* = 2015–2022). Five different outcomes are used: (i) the probability of accessing respite services; (ii) the probability of accessing another high-cost service, such as specialist supports; (iii) the probability of accessing counselling services; (iv) the probability of accessing information/educational services; and (v) the probability of accessing any support service. Each outcome variable is dichotomous, therefore is equal to 1 if the service is accessed, and 0 otherwise
- *X* is a set of individual characteristics that include gender, age, Indigenous status, country of birth, state of residence, income decile (IRSAD), and carer type
- *D* is a dichotomous indicator identifying the time of Carer Gateway reform (including Digital services), equal to 1 when the Carer Gateway was available (2020–2022), and 0 otherwise (i.e. pre-2020) – these data exclude carers enrolled in the Tristate Carer Vocational Outcomes Pilot and the Young Carer Bursary Program
- *i* and *t* are individual and year fixed-effects (i.e. dichotomous indicators), and
- is an error term capturing unobserved information for each individual at time *t*.

The parameters a_0 (a constant), a_1 and a_2 are estimated based on panel fixed-effect techniques using the linear probability model summarised above. This removes the effect of time-invariant variables, including time-invariant features of each individual, enabling the analysis to focus on changes in outcome *y* associated with changes in the program, which are captured by *D*. The parameter of interest is a_2 indicating the effect of the program restructuring on one of the outcomes

---

[33] Cost-benefit analysis should conceptually include indirect benefits.

y of interest. Statistically significant coefficients at the 1, 5, and 10% levels are indicated with ***, **, and * respectively (Table 41) below:

Table 41 Effect of restructuring use of high-cost services

Probability of à	Any service	Respite	Other high-cost	Counselling	Information
Carer Gateway (a_2)	–0.010*** (0.0001)	–0.0046*** (0.0001)	–0.0095*** (0.0001)	0.0001 (0.0001)	–0.0010*** (0.0001)
N	9,771,464	9,771,464	9,771,464	9,771,464	9,771,464
R^2 within	0.0021	0.0018	0.0015	0.0004	0.0019
R^2 between	0.0024	0.0012	0.0015	0.0002	0.0019
R^2 overall	0.0019	0.0015	0.0015	0.0003	0.0017
F-stat	5,961	5,193	4,305	1,228	5,647

Note: data based on DSS supply 3. ICSS includes digital services but excludes carers who undertook the Young Carer Bursary Program and the Tristate Carer Vocational Outcomes Pilot.

The negative and statistically significant coefficient in the first column findings support the hypothesis that following the implementation of the Carer Gateway, carers are less likely to request ‘any service’. Further examination across the range of services reveals this result is driven by the lower likelihood of accessing high-cost services such as respite and specialist support (‘respite’ and ‘other high-cost’). In contrast, there is no statistically detectable change in accessing counselling and only a small drop in the likelihood of accessing information services.

To better understand whether these effects are driven by sub-groups of the population, the analysis focuses on whether particular demographics were more or less likely to access services following introduction of the Carer Gateway. This examines the effect of the restructuring on the outcome of interest taking into account possible changes in the selection of carers occurring as a result of the restructuring of services. A difference-in-difference (DiD) model is used based on the following specification:

$$y_{it} = b_0 + X_{it}b_1 + b_2D + X_{it}Db_3 + i + t + \eta_{it}$$

Where b_2 is the general effect of the restructuring while b_3 captures the effect of the restructuring on specific carer demographic characteristics. The results are summarised in

Table 42 below.

Table 42 Access to services pre and post Carer Gateway implementation for different demographics

Probability of accessing à	Any service	Respite	Other high-cost	Counselling	Information
Carer Gateway (b_2)	–0.0042***	–0.0011***	–0.0021***	0.0013***	–0.0057***
	(0.0002)	(0.0002)	(0.0001)	(0.00001)	(0.0002)
b_3:					
Males	0.0010***	0.0024***	0.0021***	–0.0010***	0.0025***
	(0.0002)	(0.0001)	(0.0001)	(0.0007)	(0.0002)
ATSI	–0.0017***	–0.0003	–0.0011***	–0.0010***	–0.0006*
	(0.0004)	(0.0003)	(0.0002)	(0.0002)	(0.0003)
Age 50+	–0.0128***	–0.0057***	–0.0071***	–0.0017***	–0.0089***
	(0.0002)	(0.001)	(0.001)	(0.0007)	(0.0002)
Age <26	–0.0063***	–0.0012***	–0.0003	–0.0012***	–0.0028***
	(0.0008)	(0.0004)	(0.0004)	(0.0003)	(0.0006)
ACT	–0.030***	–0.0018**	–0.014***	–0.003***	–0.023***
	(0.0009)	(0.0006)	(0.0005)	(0.0003)	(0.0007)
NT	–0.015***	–0.021***	–0.0016**	0.0022***	–0.022***
	(0.0011)	(0.0006)	(0.0006)	(0.0004)	(0.0009)
QLD	–0.0026***	–0.0011***	–0.0044***	–0.0004***	–0.0095***
	(0.0003)	(0.0001)	(0.0001)	(0.0001)	(0.0002)
SA	0.0037***	–0.0001	–0.0058***	0.0007***	0.0194***
	(0.0004)	(0.0002)	(0.0002)	(0.0001)	(0.0003)
TAS	–0.0037***	0.0006	–0.0228***	–0.0002*	0.0132***
	(0.0006)	(0.0003)	(0.0003)	(0.0002)	(0.0005)
VIC	0.0071***	0.0016***	–0.0047***	0.0032***	0.0100***
	(0.0002)	(0.0001)	(0.0001)	(0.0001)	(0.0002)
WA	–0.0004	–0.0056***	0.0015***	0.0029	0.0015***
	(0.0006)	(0.0001)	(0.0002)	(0.0279)	(0.0003)
N	9,771,464	9,771,464	9,771,464	9,771,464	9,746,632
R^2 within	0.0029	0.0023	0.0027	0.0006	0.0037
R^2 between	0.0007	0.0000	0.0006	0.0002	0.0012
R^2 overall	0.0014	0.0010	0.0008	0.0004	0.0024
F-stat	1,533	1,244	1,440	334	1,995

Note: data based on DSS supply 3. ICSS includes digital services but excludes carers who undertook the Young Carer Bursary Program and the Tristate Carer Vocational Outcomes Pilot. Coefficients other than the one of the main dependent variables (Carer Gateway – b_2) the table are the parameters b_3 of the statistical model (interaction effects).

The results are consistent with those obtained without interactions. However, this analysis provides additional insights:

- Although the number of female carers is greater than male carers, the restructuring of Carer Gateway appears to have attracted a higher number of males to the services relative to the pre-Carer Gateway period, with the exception of counselling services. Whether this is the result of asymmetric changes in the health of the population by gender, or gender-specific screening policies, cannot be established with the data at hand, but it is a relevant policy question for future research.

- Aboriginal and Torres Strait Islander carers appear to have become less likely to access carer services after Carer Gateway was restructured relative to earlier periods. This may reflect differences in accessing information and/or services but is consistent with some of the findings of the qualitative analysis.
- Services are more likely to have been accessed by carers in the 27–49 age group compared to carers in the older age group (50+).
- There seem to be changes in the delivery of services across Australian states and territories, with a higher probability of accessing Carer Gateway services in NSW (the reference group) and in Victoria and South Australia with respect to respite and other high-cost services. More counselling and information were accessed in Western Australia, Tasmania, Victoria, and South Australia after the restructuring of Carer Gateway.

Robustness

The results above remain similar in size and sign when the indicator *D* is restricted to 2021–2022; therefore, removing the ‘mixed’ year 2020 when Carer Gateway was introduced (April 2020). In essence, removing the year 2020 has no effect on the results. This implies the observed effects can be associated with the Carer Gateway program rather than the timing of its implementation.