



Public consultation on the draft Service Delivery Model: Summary Report

An overview of the feedback and core considerations

April 2017 | FINAL

© Commonwealth of Australia 2016
Department of Social Services
Tuggeranong, Canberra ACT



With the exception of the Commonwealth Coat of Arms, all material presented under a Creative Commons Attribution 3.0 Australia licence (www.creativecommons.org/licenses/by/3.0/au).

The details of the relevant licence conditions are available on the Creative Commons website (accessible using the link provided).

This document must be attributed as:

Department of Social Services. 2017. Public consultation on the draft Service Delivery Model: Summary Report, Australian Government, Canberra.

Contents

1 Introduction	5
Background	5
A word of thanks	5
How this feedback will be used	5
About the consultation	6
About this report	6
2 Submission Outcomes	7
Submissions received	7
Feedback on the consultation process	7
3 Feedback	8
Development of the draft Service Delivery Model	8
Objectives and direction of the service	8
Access to services	9
Carer Choice	10
Funding	10
Regional Hubs	11
Relationships between national, regional and local services	12
Connections with other areas in the support sector	12
Condition specific support	13
A centralised carer record	13
Referral to existing services	14
Awareness	14
Information	15
Education	15
Peer Support	16
Coaching and Mentoring	16
Counselling	17
Respite	17
Needs Identification	18
Financial support	19
Support through the carer journey	19
Transition issues	19
Outcomes	20
Importance of governance and quality	21

Other issues	22
4 Carer Survey	24
About the sample.....	24
Demographics	24
About their caring role.....	26
Using technology and the internet	27
Carer views on the model	28
Support earlier in the caring journey.....	28
Website	29
Education and training.....	30
Peer support	30
Carer coaching	32
Carer counselling.....	32
Carer App	34
Additional comments.....	35
Issues relating to the survey	36
APPENDIX A: Public Submissions	38
APPENDIX B: Carer Survey Questions.....	40
GLOSSARY	45

1 Introduction

Background

In recognition of the need to support and sustain the vital work of unpaid carers, in 2015 the Australian Government committed \$33.7 million over four years to design an Integrated Plan for Carer Support Services (the Plan). The Plan is being developed to reflect the Australian Government's priorities for carers, and outlines actions to improve access to information and services specifically for carers.

The Plan has two key stages. The first stage was the design and implementation of Carer Gateway.

Carer Gateway launched in December 2015, and established a website (www.carergateway.gov.au) and national contact centre, dedicated to the delivery of carer-specific information. Its purpose is to provide a recognisable source of clear, consistent and reliable information to help carers navigate the system of support and services.

The second stage of the Plan has involved working with the sector, over the past 18 months, to design an integrated system of carer-specific supports and services that could better assist carers in the future.

The Plan is intended to complement the significant investment made in the reforms in other sectors, including aged care and disability, aimed at providing better support for many Australians.

The draft design of the proposed new integrated carer support service system is outlined in two key documents, both of which were co-designed with input from the sector and carers. The first is a draft Service Concept which identified a range of supports shown to be effective at supporting carers.

The second is a draft Service Delivery Model, which outlined the proposed services for carers, and how they would be delivered.

The draft Service Concept is available on the Department of Social Services' public consultation platform, DSS Engage, along with a report on the outcomes at www.engage.dss.gov.au.

The draft Service Delivery Model was released for feedback through the DSS Engage platform between 6 November and 16 December 2016. This report summarises the responses received as a result of the public consultation process on the draft Service Delivery Model.

A word of thanks

The Department of Social Services (DSS) would like to thank all who responded to the draft Service Delivery Model consultation paper. It is essential that the design of a future integrated carer support service system continues to be a co-design process and informed by a broad range of perspectives.

How this feedback will be used

The feedback received through the consultation process will inform further refinement of the Service Delivery Model for the integrated carer support service system, which will in turn be put to the Government for consideration.

While DSS endeavours to ensure that all feedback is considered, it may not be possible to adopt all suggestions and feedback received. This may occur where:

- there is a lack of consensus in the views received on a particular issue;
- including a particular feature or issue is not feasible; and/or
- the proposed changes do not align with other government policies or priorities.

About the consultation

The draft Service Delivery Model was released for public consultation through the DSS Engage website, between 6 November and 16 December 2016. The DSS Engage website enabled respondents to provide comment and upload supporting material.

In previous consultations, feedback was received regarding the suitability of the consultation documents and the feedback mechanisms for different audiences. Carers reported that reading a lengthy document and writing a comprehensive submission was too time-consuming.

For this reason, the draft Service Delivery Model was structured into sections, which could be read individually, and accompanied by a set of Frequently Asked Questions. These were designed to enable readers to more easily gain answers to some questions they may have had.

Carers were also able to provide their thoughts on the draft Service Delivery Model through a survey specifically targeted for carers. This survey was available on the DSS Engage website.

Respondents who made a submission were able to indicate whether or not their response should be made public. For this reason, not all of the submissions received have been made publicly available.

A list of the respondents who provided submissions, with consent to publish their submission is available at [Appendix A](#).

To view the publicly available submissions, please visit www.engage.dss.gov.au.

DSS acknowledges that while there has been significant feedback on the draft Service Delivery Model, it is likely that some carer cohorts may not have been aware of, or contributed to, the consultation process. This may be because they do not yet identify as carers (hidden carers) or that they may not currently interact with the carer service system, and were therefore less likely to be aware of the consultation process. DSS will continue to engage with key stakeholders to develop effective strategies to reach and engage with this audience during detailed design work on the integrated carer support service system.

About this report

This report has two sections:

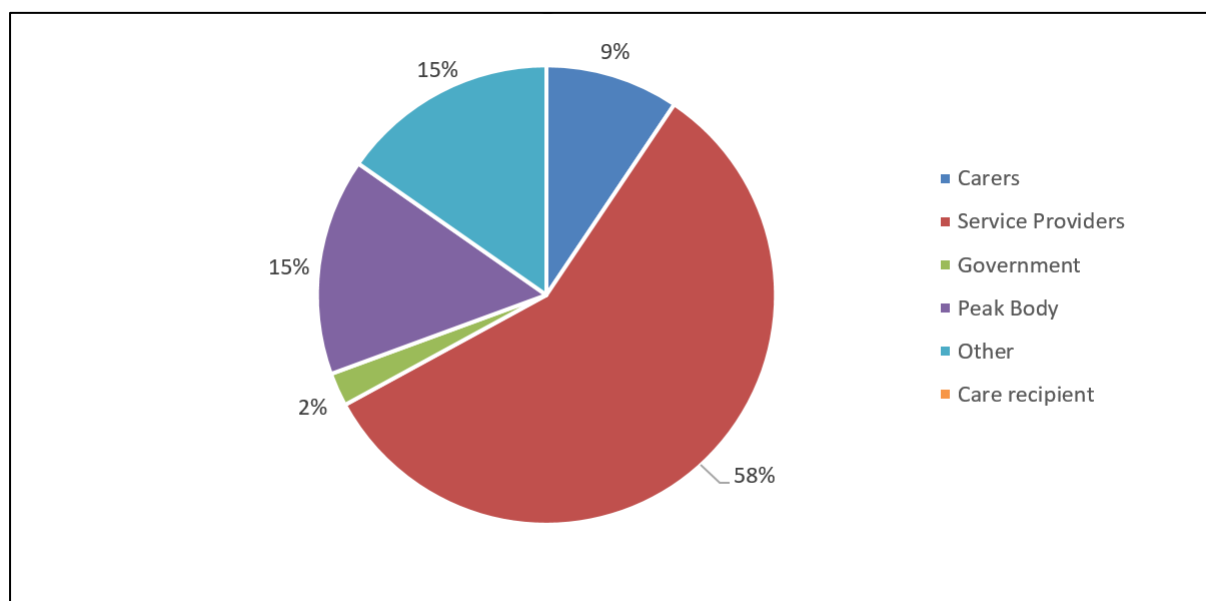
- Outcomes of the open submission process: an overview of the key themes of feedback; and
- Outcomes of the carer survey: an overview of the responses received through the carer-specific survey.

2 Submission Outcomes

Submissions received

A total of 85 submissions were received as part of the public consultation process. Most responses were from service providers (58 per cent), peak bodies (15 per cent) and other individuals and organisations (15 per cent).

Submissions were also received from carers (10 per cent) and other government departments (2 per cent).



Feedback on the consultation process

Feedback from providers and other organisations is that, overall, the document was comprehensive. There was some criticism that the document does not provide enough detail about the services and the structure of the proposed new service system. It should be noted that the intent of the model is to provide enough detail to form the basis of a submission to Government. In-line with the iterative design approach used to date, further detailed design of the services will be undertaken as part of any implementation efforts.

In contrast, some carers felt the document was too long and too technical in its language and style. Some organisations also raised this as an issue on behalf of carers.

3 Feedback

The consultation process was not prescriptive in any way. Respondents were not required to provide feedback on particular topics and were able to provide whatever comments they felt necessary and important. The draft Service Delivery Model discussion paper does however, include a number of optional discussion questions, seeking views from the sector on specific elements of the model, or garnering information on how to proceed with further work.

All submissions received through the consultation process were critically analysed to identify themes and issues raised. The themes and issues are discussed in the following sections.

- | | |
|---|--|
| • Development of the draft Service Delivery Model | • Awareness |
| • Objectives and direction of the service | • Information |
| • Access to services | • Education |
| • Carer choice | • Peer Support |
| • Funding | • Coaching and mentoring |
| • Regional hubs | • Counselling |
| • Relationships between national, regional and local services | • Respite |
| • Connections with other areas in the support service | • Needs identification |
| • Condition-specific support | • Financial support |
| • A centralised carer record | • Support through the carer journey |
| • Referral to existing services | • Transition issues |
| | • Outcomes |
| | • Importance of governance and quality |
| | • Other Issues |

The following discussion includes an assessment of the commonality and whether or not the views represented a consensus.

Development of the draft Service Delivery Model

The draft Service Delivery Model was developed through research and co-design activities involving carers and representatives from the sector. Several submissions commented on this process, expressing satisfaction with the work to date, their involvement and DSS' responsiveness in incorporating feedback and suggestions (where appropriate).

Three submissions expressed dissatisfaction with the process. Two organisations felt they had not been sufficiently involved, and three felt their feedback had not been fully addressed as part of the draft Service Delivery Model.

Objectives and direction of the service

Most submissions received reflect broad support for the draft Service Delivery Model. A small number of submissions reflected disappointment with the proposed model, which on analysis, may be related to the interpretation of how the model would work in practice. In contrast, others provide support for the model in its entirety.

The draft Service Delivery Model includes four primary objectives:

- encourage and normalise earlier uptake of services proven to help carers in their caring journey;
- help more carers;

- deliver a service carers will value; and
- provide a service carers find easy to access and use.

A discussion question was included in the paper, which asked respondents to consider whether or not they believed the objectives, outcomes and delivery principles are appropriate for the services required to be delivered under the defined programs.

In terms of the objectives specified in the model, most respondents felt they are appropriate and strongly supported them. However, there is a prevailing view that further objectives are required, specifically relating to the need to support carers to maintain their own health and wellbeing. Some submissions went further, stating that the integrated carer support service system should aim to help carers participate more fully in the community, education, employment and social opportunities.

Coupled with this, was feedback from some organisations and carers that the objectives should be reflective of all principles within the *Carer Recognition Act 2010*.

There is majority support for a shift towards an early-intervention, empowerment-based model for carer support. However, one provider did not think the model reflects this aim and some sector organisations raised concerns that by limiting supply of certain services, an early-intervention model may not be successful.

A small number of submissions supported a philosophical shift towards an early-intervention approach, but questioned if broad changes to the current provider base is required in order to achieve this.

Respondents also identified a number of other benefits that could be realised under the model, including:

- a more coherent national approach, using agreed best practices;
- less local fragmentation;
- improved coordination and access to support; and
- improved community awareness and uptake of supports.

Access to services

There was consistent support for the principle of 'no wrong door' for carers to access services under the proposed model. Submissions from both providers and carers supported this principle, with the general sentiment that this was essential to encouraging carers to access support earlier in their caring journey.

On the whole, there is overarching support for carers to access support through multiple channels (e.g. phone, online, in person). There are concerns that the model appears to rely too heavily on online and phone-based supports as a way of reducing costs. A number of providers and carers highlighted that their preference is to access assistance face-to-face.

Seven submissions interpreted the model to include a centralised contact centre, and four of these assumed carers would be required to first undergo eligibility testing or screening as a pre-requisite to support. **It is important to note that the draft Service Delivery Model does not include a national contact centre.** It does however, propose a single 1800 number that would connect carers directly to *the regional hub* in their area, with the intention of connecting carers as quickly as possible with trained and experienced staff in their area.

Similarly, many submissions viewed the website, and the proposed self-service supports, as being a mandatory entry point. For example, some submissions incorrectly assumed that carers would be required to request coaching support through the website, prior to subsequently engaging with their regional hub. It is important to note that this would not be the only channel to provide access to services for the different cohorts of carers.

Several providers also identified that self-service supports often rely on a carer being able to identify themselves as a carer and therefore, felt that these types of supports may not be suitable for all cohorts. The draft Service Delivery Model does not specify self-service supports as a compulsory entry point. Their use was envisioned to minimise barriers to entry and promote uptake of these effective services for those whose preference is to access self-service supports.

It is important to note the draft Service Delivery Model includes a number of services that do not rely on self-service e.g. targeted financial support, coaching, counselling and respite.

Carer Choice

A number of submissions supported the concept of carer choice, and enabling carers to choose whether or not to participate or access services. The draft Service Concept released in May 2016 outlined a multi-component support package, which would require participation in multiple services in order to access financial support. This is predicated on evidence that suggests that combining some supports together, particularly the group proposed, is more effective.

Previous feedback from the draft Service Concept indicated that carers should be able to choose what supports they access. In response to this feedback, carer choice has been acknowledged within the draft Service Delivery Model, and no service combinations are mandatory.

Funding

A significant proportion of the responses emphasised the need to ensure the proposed integrated carer support service system would be adequately funded for implementation. Some organisations raised concerns that the model could not be effectively implemented within the existing funding envelope. The transition of funding for some existing DSS carer services to the National Disability Insurance Scheme (NDIS), for example, the Mental Health Respite: Carer Support program transition to the NDIS, was cited a number of times.

Of particular concern for many respondents was the need to ensure the regional hubs are adequately funded to deliver the services specified in the draft Service Delivery Model. There was a view across submissions from service providers that for regional hubs to be viable and provide the services specified, block funding would be required.

The draft Service Delivery Model does not provide details regarding proposed funding; however, it does identify that two of the proposed programs (the National Counselling Program and the National Education Initiative) could potentially be delivered as a fee-for-service arrangement. Some responses interpreted 'fee-for-service' funding model as a 'user-pay' arrangement. The fee-for-service arrangement proposed in the draft Service Delivery Model involves the provision of a service unit for a defined price, not a user-pay arrangement.

One organisation questioned what demand management strategies would be used, particularly where programs are funded on a fee-for-service basis.

Regional Hubs

Location and Coverage

The draft Service Delivery Model identified that DSS is undertaking further analysis to determine the proposed optimum locations of regional hubs.

Almost all submissions discussed regional hubs and their distribution. Many highlighted that the effectiveness of the regional hubs would be dependent on the area they would be required to deliver services to. Specifically, if areas are too large, it may limit the:

- effectiveness of the regional hubs to build relationships with local services and providers and, therefore, reduce referral channels; and
- ability of the regional hubs to undertake outreach to specific carer communities.

Many submissions noted that existing standardised regions should be considered to enable improved coordination of Government supports, such as alignment with Primary Health Networks (PHNs) and/or Local Government Areas. Many submissions did not make a recommendation but provided guidance on how DSS should determine the appropriate placement of the regional hubs. Suggestions included analysis of carer population data for the purpose of geographical location and age, for example. DSS will undertake this analysis, using all suggested techniques and a range of available datasets.

Staffing

A consistent theme throughout the submissions was for DSS to ensure that all elements of the proposed integrated carer support service system, especially regional hubs, be adequately staffed, with a skilled workforce. Most respondents felt the example of certification level provided in the draft Service Delivery Model (Certificate III) was not appropriate to ensure adequate expertise and quality in supporting carers. Many responses also identified the need for specialist knowledge and experience in assisting:

- carers from Culturally and Linguistically Diverse (CALD) backgrounds;
- young carers;
- Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) carers; and
- carers who are immigrants or refugees.

There was a strong view from the sector that it would be important for carers to have an ongoing relationship with a regional hub, preferably with an individual staff member. This is the intention under the draft Service Delivery Model.

There was a mix of views on the use of volunteers and/or staff with a lived experience as carers. Respondents were supportive of the use of staff with lived experience and, to some extent, of volunteers. Some cautioned that volunteers:

- may not be available in all regions;
- may not have the necessary skills to assist; and/or
- may impede effective relationships being established where there are high turnover rates.

A small proportion of submissions highlighted the need to ensure there are not lengthy wait times on the phone to engage with regional hubs.

Functions

There was support for the proposed functions of the regional hubs. Under the draft Service Delivery Model, regional hubs are envisioned to be the primary mechanism by which carers would be

connected to supports in their area. Support for the proposed regional hub functions was closely related to discussions about the number of regional hubs required.

One function that received attention in multiple responses was the need to separate needs assessment from service provision. This has not been identified as a major concern in preceding consultations; however, it has received more attention in this consultation process, most likely due to the further detail provided of the proposed structure.

It was also identified in some submissions that the regional hubs should operate as a network, to improve efficiency through the sharing of key learnings and resources.

Relationships between national, regional and local services

There were questions raised regarding the relationship between the proposed national, regional and local services. Specifically, respondents sought to understand how the three levels of services would assist carers, whilst ensuring that the support provided is not disjointed. Several respondents indicated this could be achieved through clear boundaries and guidelines.

The draft Service Delivery Model does not specify operational detail, with these relationships/connections proposed to be designed and developed as part of implementation.

Connections with other areas in the support sector

The need to connect with other support sectors was discussed by most respondents, particularly in relation to My Aged Care, the NDIS and PHNs. This was in acknowledgement of the overlaps in terms of contact with carers, the information collected, and support provided.

Submissions identified the importance of ensuring that the connections extended across levels of the service system, including:

- between national infrastructures (e.g. the My Aged Care contact centre);
- between national infrastructures and regional organisations; and
- between regional organisations.

Submissions highlighted the need for networking across the three levels of the proposed integrated carer support service system. There was a particular focus on the need for the integrated carer support service system to work closely with the NDIS Local Area Coordinators, the My Aged Care Regional Assessment Services (RAS) and Aged Care Assessment Teams (ACATs). One provider suggested there was a need to analyse the boundaries between these programs and identify potential gaps in eligibility for care recipients and their carers.

Closely linked with this theme was the need to share information between service systems. This was viewed as a way to prevent carers from repeating their story and encouraging improved service coordination for both carers and the person(s) they care for. One provider highlighted the need to educate other sectors about carers, and noted the National Disability Insurance Agency (NDIA) and My Aged Care among those requiring this. One provider also raised a concern about the lack of input carers had into the NDIS plan for the participant they were caring for.

One organisation suggested that improved cooperation could be achieved through the co-location of carer supports with that of other government services, such as the NDIS.

Several providers enquired to how the integrated carer support service system would interface with the supports provided by state and territory governments. One provider expressed concern that, should the model be implemented, there could be a perception that the integrated carer support

service system would be considered a replacement for state-based services and, therefore, state and territory carer support may be diminished.

Condition specific support

A significant number of submissions highlighted concern regarding the lack of support for specific cohorts of carers. For example, several mental health organisations felt that the draft Service Delivery Model would not include mental health specific support. They raised the unique challenges faced by carers of people with mental illness including:

- difficulties relating to continuity of employment or other activities in light of the episodic and changing nature of the condition;
- the stigma associated with mental illnesses, and the need to gain support from organisations and individuals without judgement or fear; and
- difficulties accessing assistance when the person they care for does not recognise them as fulfilling a caring role.

Similar concerns were raised around carers of people with Alzheimer's disease and autism.

It is intended that the model would include support for carers in different cohorts and, based on the research to date, a range of opportunities for this have been identified. Further design of the specific nature of these supports will be undertaken should the Government decide to proceed with the implementation of the model.

A centralised carer record

Central carer record

There is support for a central carer record. The sector and carers viewed this as a mechanism that would negate the need to repeat their information, for example, if they were to relocate and come under the responsibility of another regional hub.

Some questions were raised regarding the privacy of carer records with concerns as to how consent to access the record would be appropriately managed.

There were views to the contrary however, with some respondents indicating that a record would not solely guarantee carers would not need to re-tell their information. It was suggested that an ongoing relationship with an individual coordinator would be a more efficient way of achieving this.

It is the intention that carers would maintain a relationship with a regional hub and preferably with a support worker who is familiar with their circumstances. However, it is an operational reality that individual support workers may not be consistently available, due to absences, leave and other considerations.

Responses from the sector also highlighted that a central carer record would provide an opportunity to collect an improved dataset, to inform future service and policy development.

Emergency care plan

There was consensus that including an emergency care plan within a central carer record would be beneficial. However, several issues were raised. These include:

- the need to assist some carers, particularly those caring for persons with a mental illness, to develop an emergency care plan;
- associated privacy concerns with the amount of care recipient information captured within the emergency plan; and

- potential overlaps of information capture between the carer record and the information stored as part of the care recipient-focussed service systems (i.e. My Aged Care, NDIS).

Referral to existing services

The draft Service Delivery Model seeks to connect carers to existing services within the community. This is in acknowledgement of the current service system where carer services are funded and delivered under a diverse suite of funding arrangements. For example, the Department of Health provides significant funding for the mental health sector, including peer support programs, education programs and counselling for carers of people with mental illness.

Almost all submissions included commentary on this issue and highlighted this as a risk as it is not possible to guarantee that these services will exist on an ongoing basis. Respondents cited that the transition of carer specific funding, including the Mental Health Respite: Carer Support program, to the NDIS could potentially result in these services not being available in the future. Their rationale also included the broader reform agendas currently being implemented such as the NDIS, has seen the shift of funding being allocated to providers, to the service users (consumer directed).

Awareness

The draft Service Delivery Model proposes a national and regional approach to awareness-raising. This was identified as a key way to identify hidden carers, reach carers earlier in their caring journey, and promote carer support at the regional and local level.

There was support throughout the submissions regarding the need to raise awareness of carers. The majority of respondents were in support of a national awareness approach, and some highlighted that a national campaign would enhance the awareness-raising efforts of regional organisations. Respondents also thought a national brand/campaign would enable the broader community to more easily identify the integrated carer support service system. There was also agreement with the need for regional hubs to undertake awareness-raising efforts; however, coupled with this were questions regarding the size of the regions.

A small number of organisations were not supportive of national awareness-raising. One organisation felt that if regional hubs were to operate under a national brand, there would be a lack of individuality in regional promotion efforts. Their concern was that a regional level of service would not be apparent to consumers.

Two organisations suggested that national efforts alone would not be appropriate and that a community development approach was required. One provider felt there would be no opportunity for regional outreach.

One organisation felt the draft Service Delivery Model would rely upon carers self-identifying, rather than viewing awareness-raising as a mechanism for identifying carers in the broader community.

Some responses drew attention to possible strategies that could be utilised, to raise awareness and subsequent uptake of services, including:

- developing relationships with schools to reach young carers;
- offering financial incentives for health professionals to identify and refer carers for support;
- development of community relationships in order to reach specific cohorts such as Aboriginal and Torres Strait Islander carers;
- ensuring the marketing includes multiple messages to effectively target particular cohorts;
- and

- the development of connections with other organisations carers interact with, such as Centrelink, the My Aged Care RAS etc., with an emphasis on the acute health sector and specialist medical practitioners.

Information

The draft Service Delivery Model identifies the delivery of information through a national website and via phone by regional hubs.

The submissions reflected support for the delivery of online and phone-based information for carers. In regards to online delivery, numerous organisations stated that some carers will not access or have access to information online. Others reflected support for the channel as part of a 'no wrong door' approach, and recommended that Carer Gateway be expanded for this purpose. One organisation recommended a mobile (phone) first strategy as part of this, and the need to ensure that the platform was compliant with accessibility standards. Other submissions highlighted that the site needs to be user-friendly and contain simple and culturally appropriate content.

A key consideration for the delivery of phone-based information was the need for skilled staff, with regional knowledge. Several organisations highlighted that it would be necessary to provide service coordination support (i.e. low level, informal advocacy) for carers.

Two organisations did not feel that coordination support would be sufficient, recommending more formal advocacy services for carers. Many of the respondents from the mental health sector discussed the value of case management-style support for carers. They highlighted that assistance to navigate and coordinate supports was highly valuable to carers, and dedicated individual support coordinators could be included within regional hubs.

Education

The draft Service Delivery Model proposes the delivery of education for carers. This is aimed at helping carers to obtain skills to:

- care for the person they are looking after;
- build resilience to enable them to maintain their caring role;
- increase their capacity to communicate with health professionals, and navigate and access service systems (e.g. NDIS); and
- attain care-related qualifications (certificate level) should carers wish to enter or return to the workforce in a care-related field.

The overarching view in the submissions reflected strong support for carer education. The submissions reflected there was value in providing these supports through multiple means.

Concerns were raised about access to face-to-face education services. The draft Service Delivery Model identifies there is a need to provide some face-to-face education and the service would also link carers to existing programs in the community. This was challenged on the basis that some of the programs may not be available due to the impacts of other reforms, specifically those in the aged care and disability sectors. These areas have undergone significant reform over the preceding years, with a shift towards consumer-directed funding. The premise of consumer-directed funding is that consumers have more say in determining how individualised funding is disbursed to providers. A potential adverse effect of moving to fully consumer-directed models is that those providers with low demand may no longer be viable or cease offering services that are unprofitable.

A small number of providers referenced the limited amount of education available under the NDIS. One provider from the mental health sector noted there is an existing database of mental health education programs.

There was a mix of opinions on the value of obtaining care-related qualifications should carers wish to enter or return to the workforce in a related field. There was some support for this initiative; however, other respondents did not feel there would be value in this. The concept of providing training and education to enable carers to enter or re-enter employment was supported however, this was generic rather than focussed on care-related qualifications.

Other feedback included:

- the need to provide training regarding assistive technology that may be available for carers; and
- that some carers would require access to transport and/or short-term respite to participate.

Peer Support

The draft Service Delivery Model proposes delivery of peer support through: (a) a national online platform; and (b) through local groups, coordinated and supported by regional hubs.

The submissions reflected support for the delivery of peer support through these means with the majority of the commentary dedicated to the latter form of delivery. Organisations and individuals highlighted that face-to-face forms of peer support have additional benefits such as reducing social isolation, providing a 'respite like' break and learning from peers.

Some submissions reflected upon the coordination of such groups, identifying the need for dedicated funding through regional hubs, and skilled facilitators/peer leaders. It was also highlighted that peer leaders require training and support to be effective in the role.

One submission identified that the term 'peer support' is not easily translatable for carers from CALD backgrounds, and that the service would need to be communicated in a culturally effective way to reach these populations.

Coaching and Mentoring

Included within the draft Service Delivery Model is a coaching program, spanning six to 10 weeks in duration, involving assistance from either a professional or a peer worker. Coaching as a service was supported.

One submission indicated dissatisfaction with the term 'coaching' but did not offer an alternative. Further, it did not support a mandatory application of the program over a six to 10 week period, noting the fluctuating nature of caring and this may not suit some carers.

There were some concerns raised in relation to the utilisation of peer workers in this program and questions regarding the detail of the service itself. Regional hubs were considered as the most appropriate point for the coordination for the coaching program (noting earlier the uncertainty about the number of hubs and their coverage).

One organisation also questioned whether coaching would be considered a replacement for informal advocacy that is currently delivered by existing carer support providers. Informal advocacy involves assisting carers who may be encountering difficulties in dealing with, or accessing support from, an organisation or party. The draft Service Delivery Model describes this role as 'Service Coordination Support'.

Counselling

The draft Service Delivery Model proposes counselling to be delivered through online and phone channels, with face-to-face counselling available to those carers with a specific need.

There was support for counselling, delivered through multiple channels. Respondents viewed this as a way of reaching different groups of carers; however, there was a preference for more face-to-face options for counselling. Some organisations were critical of the model as they did not consider enough emphasis on face-to-face counselling for carers, which has particular benefit for carers with cultural needs or communication difficulties.

Some other concerns were raised in relation to counselling including:

- the need to ensure that online and phone counselling would be provided by qualified counsellors;
- a focus on online and phone-based counselling could increase social isolation; a common issue for many carers; and
- a lack of carer-specific counselling, particularly if delivered through a brokered arrangement by regional hubs.

Respite

Short-term and emergency respite

The draft Service Delivery Model includes the delivery of emergency and short-term respite.

There was consensus that short-term respite should be offered as part of the integrated carer support service system. There were several providers however, who did not agree with the proposed purpose of short-term respite, that being to assist carers to participate in capacity-building activities. It was commonly raised that respite should be available to enable carers to look after their own health and wellbeing needs or have a break.

Providers also raised the lack of retreats for carers. Their view was that retreats enable carers to have a break, while accessing other supports such as educational sessions, peer support and social activities.

Emergency respite was also viewed as an essential component. However, there were questions about what would be deemed as an emergency.

Planned Respite

The draft Service Delivery Model indicates that the integrated carer support service system would connect carers to, but not directly fund, planned forms of respite. This is in-line with reforms in the aged care and disability sectors where access to respite-type supports is determined primarily on the assessed need of the care recipient.

There was a strong view in the submissions that the integrated carer support service system should play a primary role in the delivery of planned and flexible forms of respite, with a focus on supporting the carer. Many submissions sought the funding for planned respite to be transitioned to the integrated carer support service system.

The submissions raised a range of issues regarding access to planned respite in the current environment. A key concern for many was that, in their view, there is limited access to planned forms of respite under the NDIS and My Aged Care. A smaller group of providers also highlighted that not all cohorts of carers have access to planned forms of respite, for example carers of persons with chronic illnesses are not eligible under the NDIS.

One response noted that there would be significant practical challenges associated with transitioning responsibility for planned respite to the integrated carer support service system, as much of the infrastructure required is provided under the aged care system.

Some submissions highlighted that, at a minimum, the integrated carer support service system should assist in the coordination and booking of residential respite. This was predicated on the significant administrative burden involved in coordinating this, which carers may not have time to undertake.

One provider also raised the challenges related to delivering respite in the current environment, highlighting that funding for respite does not reflect the operational realities of providing respite on weekends or at other times where staff penalty rates apply. Further concerns were raised regarding residential respite in the current environment including:

- limited ability to book in advance;
- the lack of wrap-around services, such as allied health supports;
- issues regarding security of bookings where care recipients can be deemed as unsuitable by respite providers;
- the need for a restorative approach to respite, with carers anecdotally reporting quality issues and decline of care recipients after their respite stay; and
- challenges in carers accessing respite when the assessment is based upon the needs of the care recipient.

Needs Identification

The draft Service Delivery Model proposes needs identification would be offered in a number of ways. Firstly, as a self-assessment through a website, and secondly, through phone or face-to-face contact with a regional hub.

There were a variety of views in relation to how needs identification should be carried out including support for self-assessment. Respondents felt this acknowledged that carers understand their own circumstances best, rather than requiring a professionally prescribed assessment. In contrast, one provider noted that carers commonly minimise their own needs, and mostly prioritise the needs of the person/s they care for.

There were some considerations raised in regard to the implementation of this service. Several providers stated that online self-assessment should not be onerous and should focus on identifying the primary issues. There is a concern raised by one provider that regimented registration processes may provide a disincentive for some carers to seek, or participate in, supports available.

It is considered appropriate for a more detailed assessment to be undertaken by the regional hub, once they are in contact with the carer. This is particularly when a carer is seeking to utilise a rationed or prioritised service (e.g. financial support). It was also raised that consent to contact the carer would be required.

Concerns were raised regarding the absence of a face-to-face needs identification. The draft Service Delivery Model includes that face-to-face needs identification should only be undertaken where there is a specific need, such as where carers have a cultural or communication need, or they are a young carer. Some organisations felt that an interaction through phone or online would be an impersonal experience and may not build enough trust for the carer to engage.

Financial support

Financial support is included in the draft Service Delivery Model, involving the provision of targeted funding to assist carers to stay in the workforce or participate in educational activities. There was a mix of perspectives on the provision of financial support. The initiative was supported by a range of respondents; however, some respondents did not agree with the shift in the purpose of financial support compared with the intent originally proposed in the draft Service Concept. The draft Service Concept proposed it as a support package (multi-component support), without a specific focus on education and employment. It was viewed that the purpose should be to provide a form of flexible respite.

A common theme associated with the financial support service was that further detail of the service would be required to provide adequate feedback.

Other feedback included:

- assistance from the staff at regional hubs would be required to adequately plan and coordinate services required;
- this assistance would need to be factored into the costing to ensure the service delivery would be feasible;
- the provision of financial support should be accompanied by a realistic assessment of a carer's ability to return to, or continue to, participate in the workforce/education;
- the service should be renamed to a term such as Consumer Directed Respite Care (CDRC) to avoid confusion with income and other financial supports offered by Centrelink; and
- the provision of this support should not impact other entitlements, such as welfare entitlements, available through Centrelink.

Support through the carer journey

A common theme within the submissions was the need to support carers throughout the caring journey. While there was agreement that assisting carers earlier in their journey is important, several submissions raised the need to provide support during changes to, or at the end of, the caring role. Grief counselling and support was also raised in this context.

Transition issues

Almost all submissions included a degree of commentary regarding the implementation of the proposed integrated carer support service system. Many submissions reflected the view that existing organisations should be utilised in the future model, having the skilled staff, capabilities and community relationships to deliver the services required. This was commonly related to the regional hubs.

Many submissions provided advice and considerations for implementation including:

- the need to ensure carers being supported under current arrangements receive clear communication about the implementation; and
- the need to ensure existing providers and the broader sector receive timely, effective communications, through written communication and roadshows.

A small number of providers raised concerns regarding the proposed commencement date for implementation (1 July 2018). One provider also raised the need to use the experience from previous reform programs when planning implementation.

There were concerns about the transition of funding from existing organisations to regional hubs. As identified earlier, there is disappointment with the transition of funding from the Mental Health Respite: Carer Support program to the NDIS. Linked to this were questions about how existing carers would be transitioned to regional hubs for support, and whether they would experience a reduction in support that they currently receive.

It was also identified that the current Young Carer Program, which is transitioning in part to the NDIS, has been funded until July 2019. It was suggested that young carers currently being supported under this program, not be transitioned to the regional hubs until the integrated carer support service system has been established and operational. Another provider also recommended retaining the Young Carer Bursary Program in the future model.

There was a strong response received from organisations within South Australia regarding implementation of the proposed new service system in their state. Their view is that the current South Australian service model is effective and cost-efficient, and have requested special provisions in the event that Government proceeds with implementing the new service system. These included:

- enabling all current providers to continue to be funded under the new model;
- not applying the model in South Australia; and/or
- varying any procurement conditions for South Australia so that the regional hubs in South Australia oversee existing providers delivering carer support services.

Outcomes

Included in the draft Service Delivery Model was a discussion question asking respondents to identify ways in which outcomes could be measured while preserving a good service experience for carers (i.e. by preventing repeated questionnaires).

There was a significant response to this question. Almost all respondents providing commentary on this issue identified the need to include global measures, involving carer feedback on the service(s). It was emphasised that this needed to extend beyond satisfaction, and should cover all aspects of the integrated carer support service system, rather than individual services.

Some responses reiterated earlier feedback regarding the need to develop program logic to elicit the precise outcomes being sought, as well as how and when they would be achieved. This would further provide a basis for detailed program and evaluation design.

Suggestions were made on evaluation frameworks that could be used for a future service, such as the Results Based Accountability framework and the Carer Outcomes framework from the Victorian Department of Health and Human Services. Many of the submissions reinforce the need for longitudinal data to inform further service development and policy direction.

Numerous suggestions were made in regards to questions and points that any future evaluation should explore. Collectively, these can be summarised as follows:

- measures of **access**, such as the number of carers accessing services through specific channels;
- measures of **cost-effectiveness**, identifying the proportion of funds spent on direct service delivery versus administrative support;
- measures of **satisfaction**, including the perceived value of services or features of the service;

- **demographic** analysis of carers accessing and achieving specific outcomes;
- whether carers are able to **sustain their caring role** and maintain **good health**;
- achievement of **specific outcomes** such as the number of carers returning to work/study has changed;
- **efficiency** and **effectiveness** of the integrated carer support service system's operation and design;
- **service integration**, including the degree of cooperation and inter-service referrals; and
- service **relevance** for carer circumstances.

It was identified by several providers that outcomes measurement could be constructed within the needs identification, planning and service delivery phases of the carer experience. Two providers identified that a standard suite of measures could be built into a tool and utilised at repeated stages throughout the carer's journey.

Alternate evaluation approaches were proposed, such as longitudinal studies of a sample group, rather than attempting to collect data in relation to all carers participating in given service(s). This was viewed as a way of ensuring that carers who provide feedback information have opted to do so, and that support for carers on a broader scale is not disrupted through a focus on measurement.

It was also suggested that the integrated carer support service system enable comparisons of results across regions. Some cautions were offered in relation to:

- using outcomes results in any punitive way; and
- considering carers relinquishing the carer role, as a matter of choice, as a 'fail'. This was on the premise that the integrated carer support service system will seek to assist carers to sustain their caring role.

In a similar vein, several providers identified that it may be challenging to measure outcomes from such initiatives. This would be due to the multi-factorial nature of caring. The caring role may end as a result of decline of the person being cared for, a matter of choice or other factors such as greater family need, or the need to participate in the workforce.

While a central carer record was viewed as a way to capture information to inform evaluation efforts, respondents highlighted that multiple collection methods would be required, particularly for services that do not easily lend support to pre and post-style measures.

One provider recommended these elements be co-designed with the future participants of the integrated carer support service system.

Importance of governance and quality

A discussion question in the draft Service Delivery Model poses that while it would seek to help more carers, it would also be important to ensure quality services would be delivered. Respondents were asked to identify what they viewed as the essential components of a future quality framework.

Many organisations referred to existing health service quality frameworks and standards that could be adapted for use. Examples include:

- Australian Service Excellence Standards;

- Aged Care Accreditation Standards;
- Quality Improvement Council Health and Community Services Standards;
- National Safety and Quality Health Service Standards;
- Common Care Standards;
- Department of Human Services Standards; and
- Australian Safety Quality Framework for Health.

There was a unanimous view that carer feedback was essential for quality evaluation efforts. This, coupled with quantitative methods, was viewed as the best way to evaluate the quality of the services offered. Benchmarking was also raised as a feature that should be incorporated to enable cross-service evaluation.

Suggestions for measures included:

- standard response times;
- integrity of the needs identification undertaken by carer support staff;
- staff with comprehensive knowledge of supports available;
- availability of carer services;
- ease of referral to services, to and from other services; and
- appropriate feedback and complaint mechanisms.

Providers also emphasised the need for streamlined reporting and this extended to quality reporting mechanisms.

Other issues

There were some points of feedback raised in the submissions by one or very few respondents which do not relate to the common themes discussed above.

These included:

- concerns regarding the creation of a 'siloe'd' service within government;
- the integrated carer support service system should be funded through My Aged Care and/or the NDIS, rather than as a standalone service;
- the need to support care recipient's rights in the first instance, and that funding of carer supports should not be at the expense of care recipient supports;
- the integrated carer support service system needs to recognise the gendered nature of caring;
- the future development of the integrated carer support service system must be guided by co-design with carers;
- carers should be prioritised on health waitlists (i.e. medical and surgical waitlists);
- the integrated carer support service system does not acknowledge challenges related to illiteracy;
- the model does not address the longer-term financial outcomes of carers;
- the integrated plan for carer support service system has already caused the closure of some organisations;
- current carer payments are too low, and that accessing support from Centrelink was challenging;
- the need for adequate palliative care funding;
- the need for increased funding for continence aids;

- a desire for future program costings to be made available for review; and
- the integrated carer support service system does not acknowledge siblings of children with disability as a specific cohort, and uses the term 'young carer', which can be viewed as a stigmatised term.

4 Carer Survey

The objective of the carer survey was to collect carer-specific feedback regarding the supports they would consider using under the draft Service Delivery Model, and how they would prefer to access those supports. The survey further provided opportunities for carers to provide views through open comments in relation to the services described, and regarding the model as a whole.

The survey had two parts:

- to capture information about the carer's demographics, caring role and their utilisation of technology; and
- to obtain carer's views regarding the services proposed and preferences in accessing them.

A list of the questions included in the survey is available at [Appendix B](#).

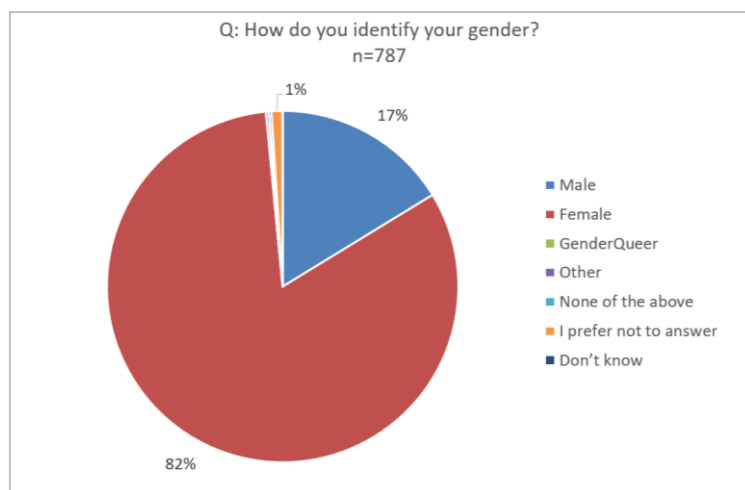
The link to the survey was published on the DSS Engage website, and remained open for the duration of the consultation. The survey was also available in paper form upon request.

About the sample

A total of 905 carers responded to the carer specific survey. Forty responses were received from individuals who identified that they do not provide informal care and as a result their responses have not been included¹ in the results. A further 114 responses were further excluded as they were substantially incomplete².

Demographics

Responses were received from carers spanning a range of age groups. The average age of carers responding to the survey was 56, with the majority identifying as female (82 per cent). This over-representation of females in the survey is not surprising as previous research has demonstrated that carers are most commonly women.



¹ Respondents were considered carers if they answered 'Yes, I care, or have cared for person(s) with:

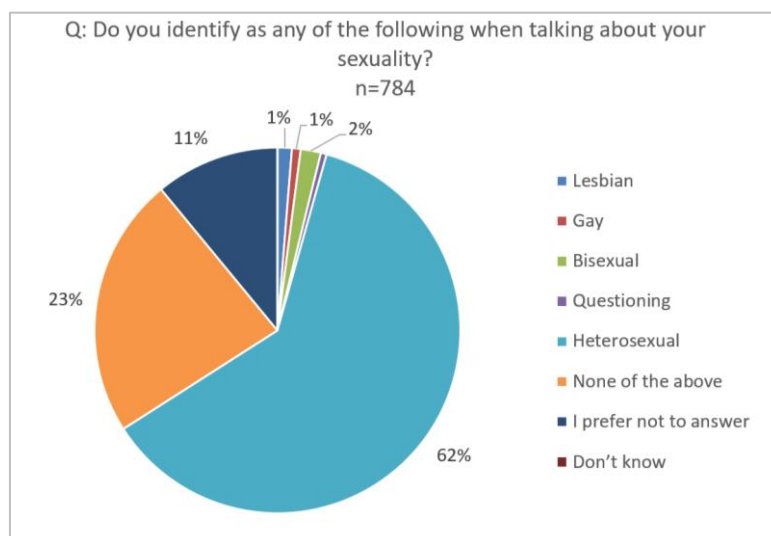
- disability,
- chronic illness,
- terminal illness,
- mental health condition,
- alcohol or other drug dependence,
- frailty due to age,
- Dementia.

² Surveys were excluded where they included five or more unanswered questions.

Seventeen per cent of respondents indicated they were male.

Options including 'GenderQueer' and 'Other' accounted for less than 0.5 per cent of responses, with 1 per cent of carers indicating they would prefer not to answer.

In regards to their sexuality, 5 per cent of respondents identified themselves being LGBTI.



There was a high proportion of respondents (23 per cent) who recorded 'None of the above' as a response to the question. Some comments made in relation to this question suggests that some respondents did not see the option 'I prefer not to answer' and may have recorded this in error. Eleven per cent of carers preferred not to answer the question.

Five per cent of respondents identified as being Aboriginal and/or Torres Strait Islander.

The survey asked respondents several questions aimed at identifying whether the carer or the person(s) they care for, had a CALD background.

Most respondents reported that they, and/or the person(s) they care for, do not speak a language other than English at home (86 per cent). Of the 14 per cent of respondents that do speak a language other than English, the most common languages are Italian (14 per cent), German (9 per cent), Dutch (7 per cent), Cantonese (7 per cent) and Greek (5 per cent).

There was a significant number of the respondents who reported speaking a language (41 per cent) that was not included within the predefined list. Additional languages included:

- Bengali
- Filipino
- Lithuanian
- Tamil
- Urdu
- Sri Lankan
- Ngarrindjeri
- Tiwi
- Armenian
- French
- Auslan
- Indonesian
- Latvian
- Thai
- Japanese
- Slovenian
- Czech
- Ukrainian
- Creole
- Swedish
- Welsh
- Malayalam
- Danish
- TSI Kriol

Most carers (87 per cent) reported being of an Australian background. Seventeen per cent also identified as being of English decent. Thirteen per cent of respondents reported they were from a background not listed in the pre-defined list. Responses recorded included:

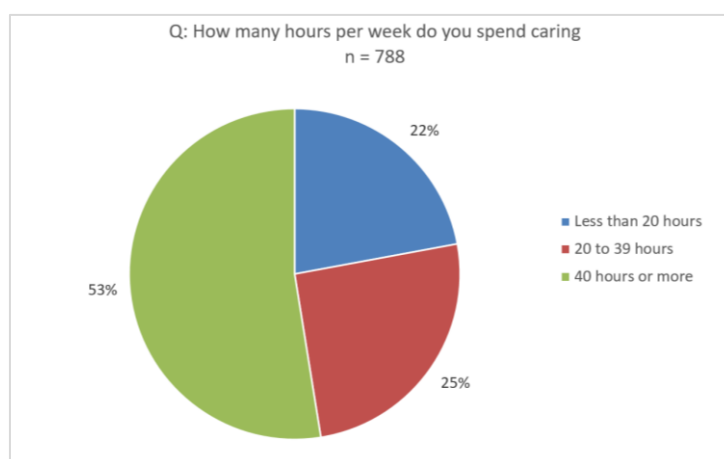
- Filipino
- Lithuanian
- Sri Lankan
- South Asian
- Scottish
- German
- African
- Armenian
- French
- Indonesian
- Malaysian
- Maori
- Aboriginal
- Japanese
- Slovenian
- Czech
- Ukrainian
- Mauritian
- Swedish

DSS notes that the proportion of survey responses from Aboriginal and/or Torres Strait Islander and CALD carers are low and therefore the responses may not represent the broader views of these cohorts. DSS will seek advice to develop more effective strategies to reach and engage with this audience during detailed design work on the integrated carer support service system.

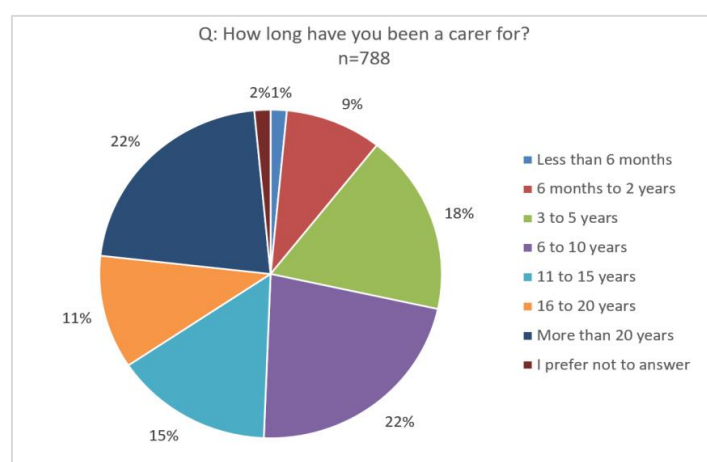
About their caring role

Sixty-eight per cent of carers reported they cared for one person, with 25 per cent caring for two people. Less than 8 per cent of respondents were caring for three or more people.

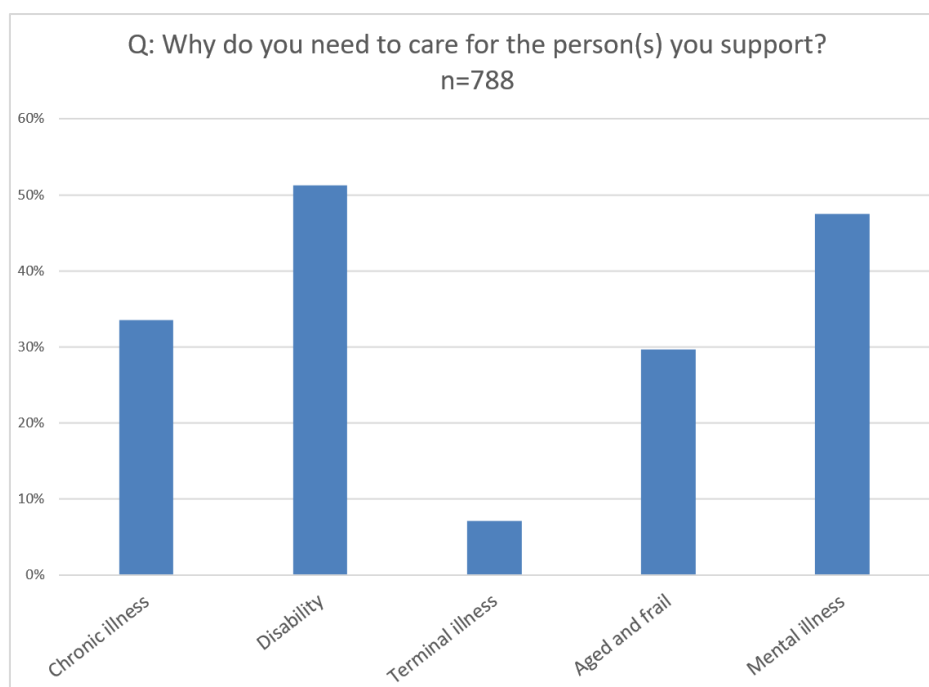
The majority of carers reported that they provided 40 hours or more of care each week (53 per cent), with similar proportions of carers providing 20 to 39 hours of care (25 per cent), and less than 20 hours (22 per cent).



Over 22 per cent had been providing care for more than 20 years, with a similar proportion having done so for 6 to 10 years.



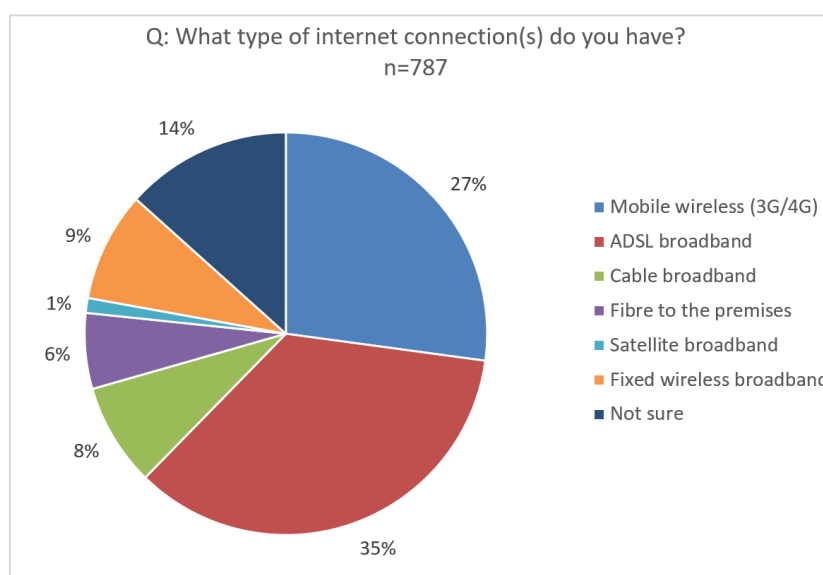
Disability and mental illness were the most likely reasons a person needed to provide care.



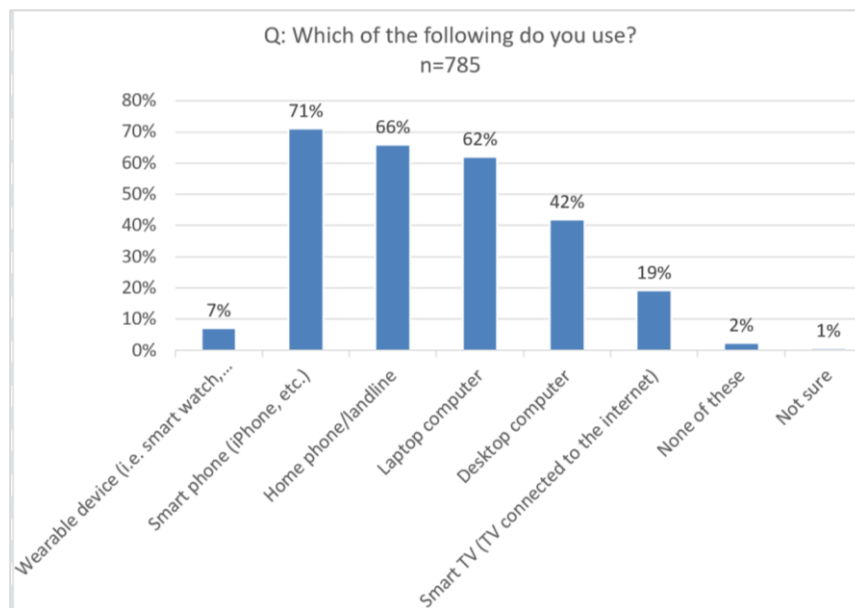
Using technology and the internet

As the draft Service Delivery Model includes digital service delivery, the survey sought to identify the proportion of carers who use the internet and the types of technology they interact with.

Ninety-four per cent of carers reported they have access to the internet in their home, with 35 per cent identifying they use ADSL broadband, and 27 per cent using mobile wireless (3G/4G). A further 9 per cent use fixed wireless broadband. Fourteen per cent of respondents indicated they were not sure about the type of internet they were using.



The most common form of device carers reporting using was a smart phone (71 per cent). Sixty-two per cent of carers were using a laptop computer, and a further 42 per cent were using a desktop computer.



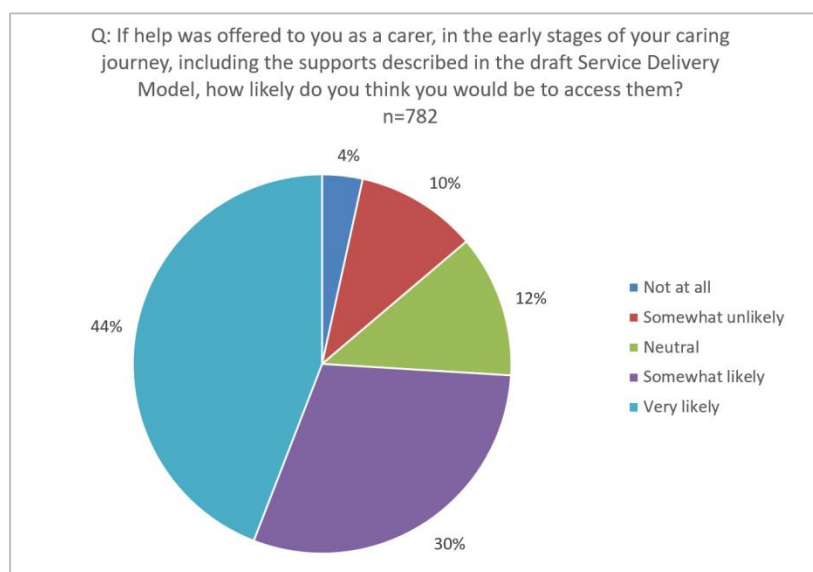
Please note that carers could choose more than one option.

Carer views on the model

Support earlier in the caring journey

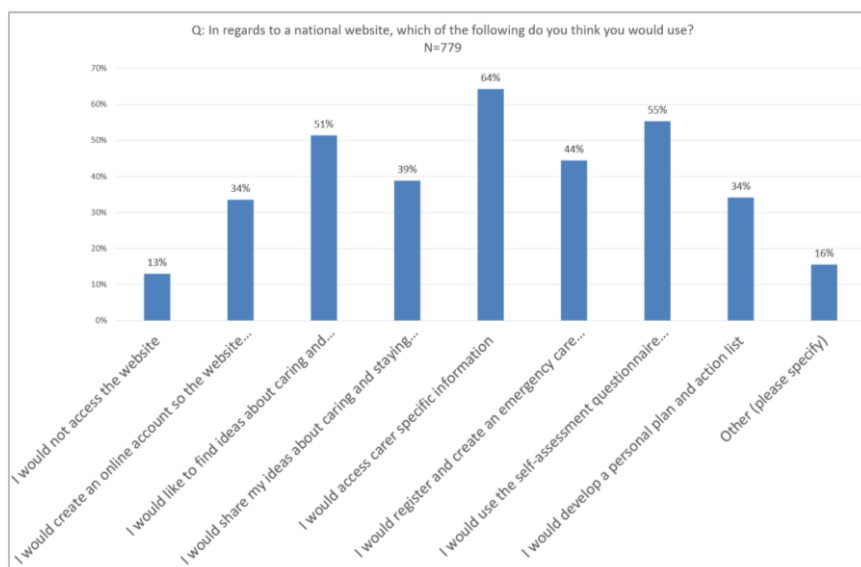
A key finding of research undertaken and co-design activities conducted to date is that carers commonly do not access support until a time of crisis. Many of the carers engaged in consultations highlighted that, in retrospect, they should have accessed support earlier in their caring journey. The draft Service Delivery Model identifies the importance of raising awareness of carers across the community and the sector to drive uptake of supports.

Given this, the survey asked whether carers would be likely to access supports, if offered, earlier in their caring journey. Forty-four per cent of carers indicated they would be very likely to access support earlier, with 30 per cent reporting they would be 'somewhat likely'.



Website

The Carer Gateway website was established in December 2015 as an information service for carers. The draft Service Delivery Model identifies that this service would be expanded, as part of the proposed integrated carer support service system. The survey asked carers to nominate what they would be interested in interacting with on an expanded website.



The majority of carers (64 per cent) said they would access carer-specific information and content. Carers were also interested in using a self-assessment questionnaire to learn more about what might help them to address their needs, and the support they could be eligible for (55 per cent). Further, 44 per cent of carers said they would register and create an emergency care plan so that it is immediately available to a regional hub to coordinate emergency respite for the person they care for.

The draft Service Delivery Model also identifies the possibility of an 'ideas wall' for carers to find and share ideas about caring and staying well. These features were received positively by respondents, with 51 per cent saying they would find ideas about caring and staying well, with 39 per cent saying they would share their own ideas as part of this feature.

Thirty-four per cent of carers said they would create an online account so the website could remember their preferences, and create a personal plan and action list. Thirteen per cent of carers said they would not access the website.

Carers made further suggestions for website features including:

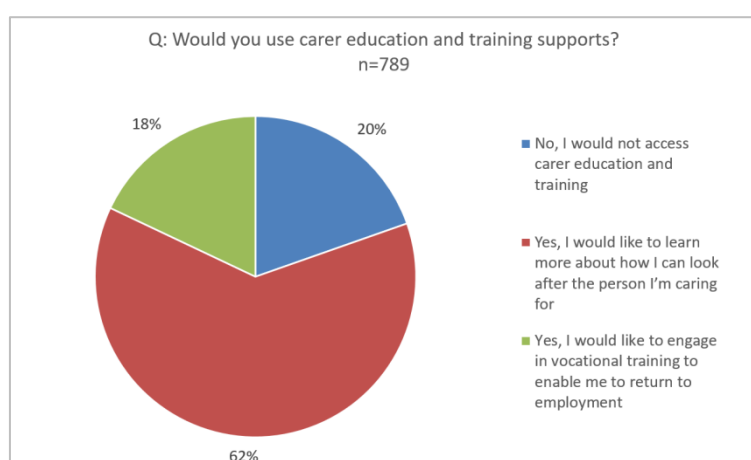
- the ability to store wills and enduring power of attorney;
- a single portal by which carers can access their own support, and that of the person they care for;
- the ability to submit questions and receive answers;
- the ability to sign up to a mailing list;
- the ability to search for respite;
- the need for condition-specific information, particularly around mental health conditions;
- a 'how to' guide on how to navigate services;
- how to work with service providers; and
- a record of treating clinicians to enable better care coordination.

Other comments in relation to the website included:

- that it must be user friendly and offer more value than other government websites, with carers citing difficulties with My Aged Care, Centrelink and Carer Gateway;
- that the website and logins must be secure;
- that some are unable to afford the internet;
- that online workshops would be useful; and
- that information must be specific and relevant to different groups of carers.

Education and training

Many carers indicated they would be interested in participating in education and training activities, with the majority (62 per cent) identifying they would like to learn more about how to care for the person they are looking after. In contrast, 18 per cent of carers said they would like to engage in vocational training to enable them to return to work.



Twenty per cent of carers identified they would not access carer education and training. For carers who were interested in education, they were provided an opportunity to select how they would best like to participate in education and training. Fifty-four per cent said they would like to attend sessions face-to-face. Some associated comments identified that this allowed for a more relatable experience and provided them with an opportunity to meet other carers.

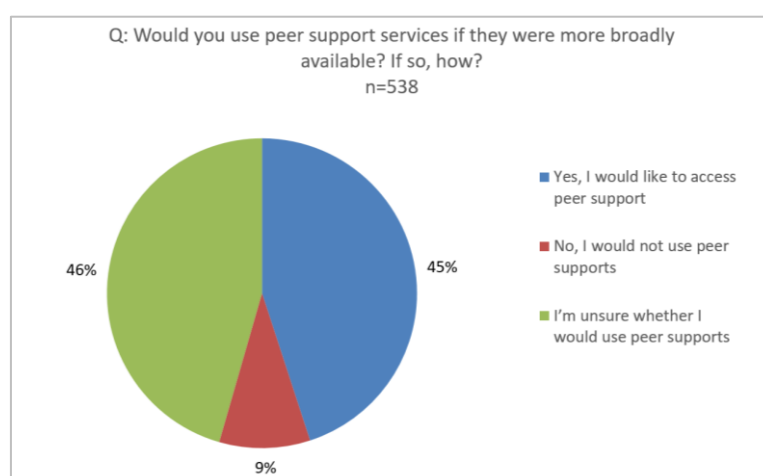
Forty-six per cent of respondents said they would use online education supports. A number of carers felt online support would be more convenient for them to participate in, with the ability to participate from their own home, and at a time of their choosing.

Peer support

Previous research and engagement with carers identified that peer support provides a valuable way for carers to give and receive support from others with similar experiences. The draft Service Delivery Model proposes that peer support be delivered in two primary forms:

- online, through moderated discussion boards and an ideas sharing service (similar to Pinterest); and
- face-to-face, with assistance and support from the regional hubs.

Forty-five per cent of respondents indicated they would use peer support, with a further 46 per cent indicating they were unsure whether they would do so.

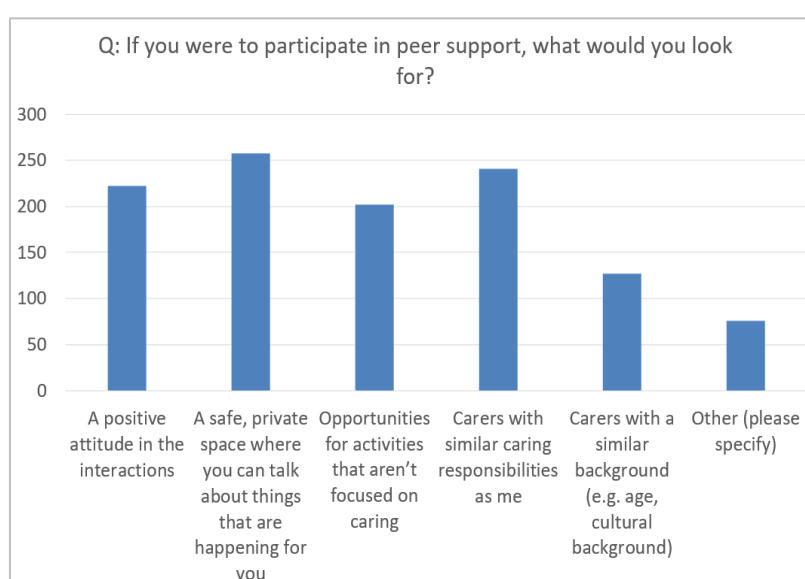


When asked how they would like to access this (online or in-person), 81 per cent said they would like to meet in-person with other carers in their area. There was a significant amount of comment on the importance of peer support and a preference for in-person interactions to help carers build relationships with other carers. The preference for face-to-face peer support was most pronounced in respondents aged 55 years and over.

Thirty-seven per cent also said they would use the online discussion boards. A number of these respondents said they were very time poor and not always able to leave the home. Online discussion boards were viewed by these respondents as a convenient way for them to connect with other carers.

The survey asked what carers valued in peer support. The most important factors were:

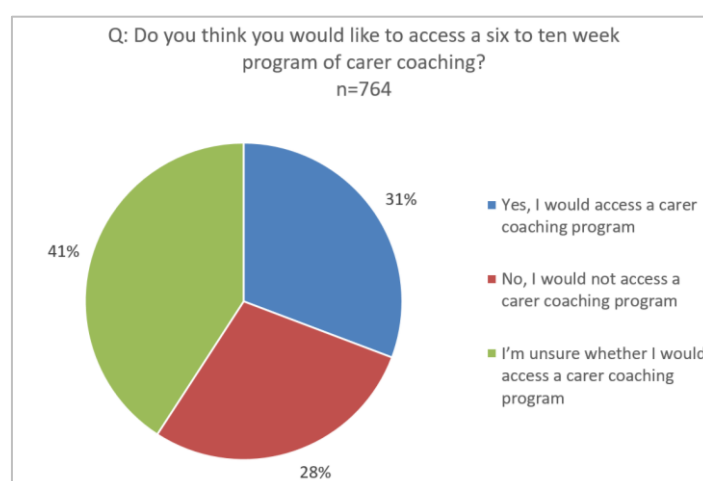
- a safe, private space where they can talk about the things that are happening for you (71 per cent);
- being able to talk with carers with similar caring responsibilities (66 per cent);
- a positive attitude in the interactions (61 per cent); and
- opportunities for activities that aren't focussed on caring (56 per cent).



Carers offered other suggestions in addition to the pre-defined options. Many were seeking an accepting and non-judgemental environment, where they feel it is safe to share their experiences and learn from other carers. Other suggestions included a preference for small groups, or the opportunity to meet with other carers with the same educational background.

Carer coaching

The draft Service Delivery Model includes a six to 10 week coaching program, with support delivered either in-person and/or via phone. These programs are currently available in a limited number of areas in Australia and have been demonstrated as an effective support for carers. The survey asked whether or not carers would participate in a coaching program. Almost equal numbers of carers said they would (31 per cent) or would not (28 per cent) access a coaching program. A significant proportion of respondents indicated they were unsure (41 per cent), with a number of comments suggesting they would need to understand more about what the program entailed before deciding. There were comments by some carers that access to an online program such as this would be useful, with some carers identifying that they had participated in, or were volunteering in, existing programs.

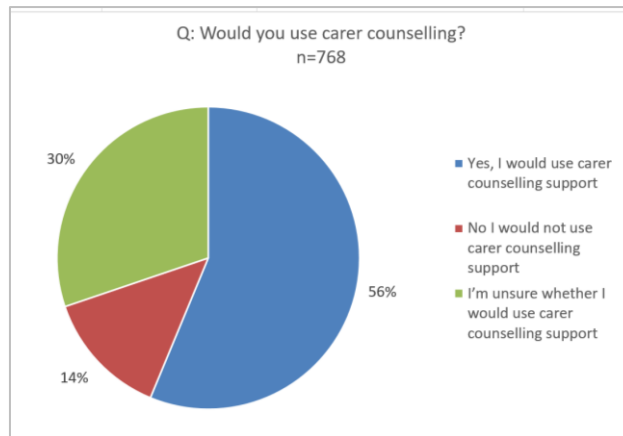


There is limited access to carer coaching programs currently across Australia. Given this, it is likely that the high proportion of carers responding that they were unsure whether they would access coaching, may be likely related to a lack of knowledge about what the service could offer. Evidence from existing programs reflects a high degree of carer satisfaction with the service and improvements in a range of outcomes, including improvements in carer self-efficacy and reductions in depression and anxiety.

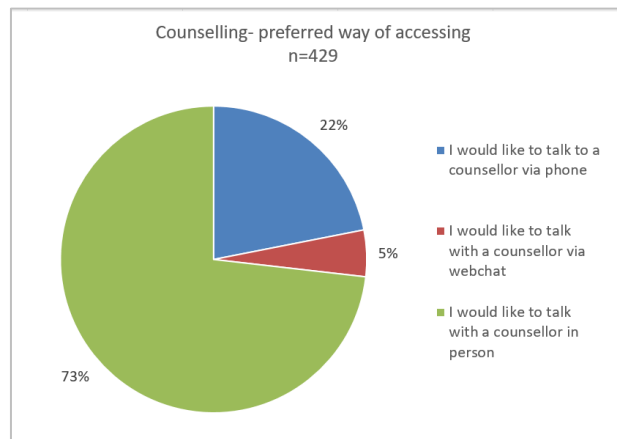
Carer counselling

The draft Service Delivery Model proposes that counselling be delivered via phone, webchat (online) and face-to-face. This is in-line with the mental health sector's delivery of counselling and assists people to access support on an anonymous, on-demand basis.

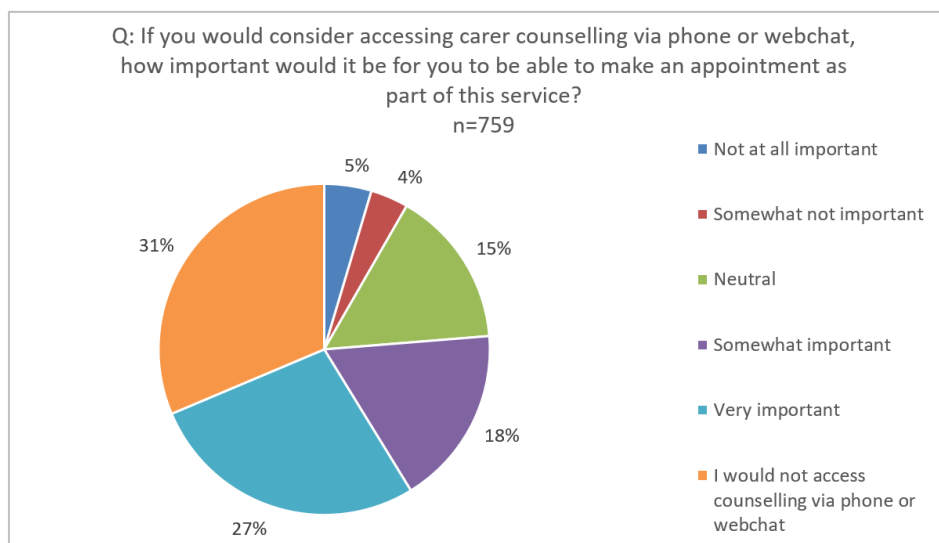
Fifty-six per cent of carers said they would use carer counselling, with a further 30 per cent identifying they were unsure.



Seventy-three per cent of carers who indicated they would use counselling, said they would prefer to do so in a face-to-face setting, with 22 per cent nominating that they would use phone counselling. Five per cent of respondents nominated webchat as a preferred channel.



Carers who indicated they would be interested in accessing counselling via phone or webchat were also asked if it would be important for them to be able to make a defined appointment with the service. Forty-five per cent of carers felt this would be of value, while 24 per cent indicated it was somewhat important, not at all important, or neutral.



Comments against this service were commonly reflective of the counselling experiences carers have previously had. There was a mix of feedback on counselling as a support including:

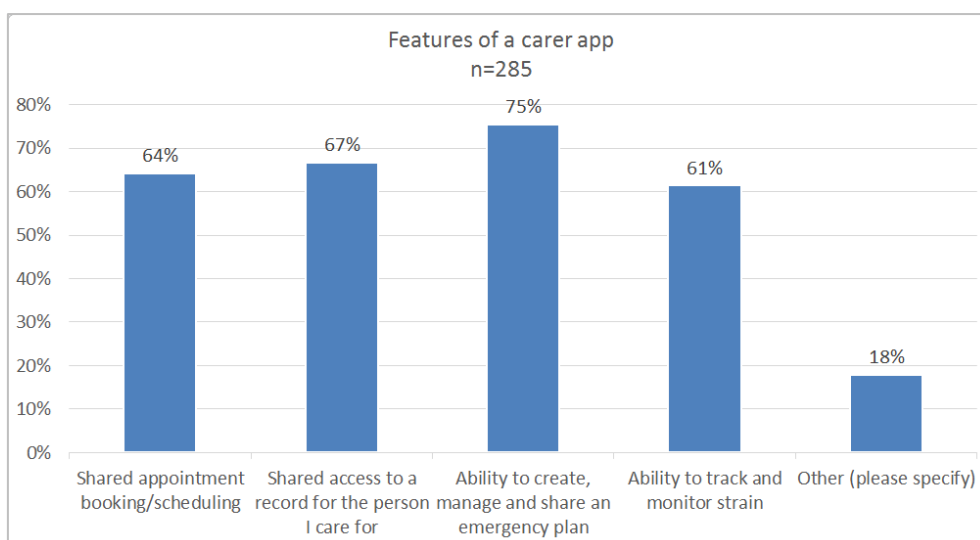
- that previous counselling experiences had been poor, with some comments reflecting that there had been no benefit, that the counsellors had been exhausted themselves, or that they did not understand their situation;
- that they did not need counselling;
- that counselling would need to be delivered by a qualified professional;
- that counselling is another way by which carers would be dictated to by 'professionals';
- that, in some cases, there were significant wait times to access current carer counselling;
- concerns that counselling is unaffordable and that carers would need subsidised for free access;
- that some carers are accessing counselling through their GP and a mental health plan, and this is their preferred way of doing so;
- that counselling would not be helpful, and there is a need for more practical support; and
- questions regarding whether or not it would be possible to attend with another person.

Carer App

It was identified during co-design activities that a carer app (or similar) may provide a convenient and valuable way for carers to access some supports. Carers were invited to provide their thoughts about whether they would find an app useful, and if so, what the core features they would be interested in using were. Thirty-seven per cent of carers indicated they would use a carer app if available, with 30 per cent indicating they were unsure. An analysis of respondents who answered this question shows a correlation with their age, with carers aged up to 54 being more inclined to use an app.

For those carers who would use an app, when asked about the most valuable features, 75 per cent of carers felt that the ability to create, manage and share an emergency action plan would be useful. Carers also thought it would be helpful to access a shared record for the person(s) they care for (67 per cent), be able to view and manage a shared appointment calendar (64 per cent), and track and monitor their strain (61 per cent). Eighteen per cent of carers nominated other features they felt would be useful including:

- the ability to share documents and link with other services/records (e.g. My Aged Care, NDIS);
- reminders to look after themselves;
- behaviour tracking for the care recipient (e.g. for carers of persons with mental health conditions, etc.);
- the ability to manage medication;
- the ability to engage with a trained person when advice is required;
- the ability to engage with discussion forums; and
- the ability to track hours worked/cared for Centrelink.



Other comments offered on this by carers included:

- that they would use all of the features listed and thought it would be useful;
- that an app would not be accessible for many carers;
- that the ability to track and monitor strain was offensive;
- the need to ensure the functionality was relevant for different groups of carers;
- that the app should not provide routine scheduling functionality (i.e. shared appointment reminders, etc.);
- concerns about security; and
- that the app should not just duplicate information available on the internet.

Additional comments

Carers were invited to provide further comments on the draft Service Delivery Model as part of the survey. Many of the comments reflected concerns and themes that have been raised throughout previous research and carer engagement activities, including the Carer Service Development Research.

A copy of the Carer Service Development Research can be viewed at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/for-carers/carers-gateway-research>.

Much of the commentary made throughout the survey included the need for practical supports to lower the burden on carers. Carers were also concerned that services were being offered online, with many responding that in-person support was preferred. Other themes included:

- **overarching views:**
 - support for the draft Service Delivery Model and implementation; and
 - the need for more support for carers to maintain their wellbeing.
- in relation to being **aware** of the proposed integrated carer support service system:
 - need to ensure that the integrated carer support service system would be offered under a consistent brand in future.
- in regards to the integrated carer support service system's **relationship** with other Government agencies:

- as there is a current lack of coordination amongst current programs, it would be important for the integrated carer support service system to link and integrate with other services, locally and across Government.
- in regards to the **consultation** itself:
 - need to engage more fully with carers;
 - carers encountered issues with completing the survey; and
 - carers had not read the draft Service Delivery Model prior to completing the survey.
- in regards to **education and employment**:
 - some carers found it challenging trying to juggle work, education and/or job seeking with their caring role;
 - the need for more organisations to be carer aware, although there was comments about the good support some carers received from their workplace; and
 - young carers, in particular, require support to continue to participate in education and the broader community.
- in relation to the **staffing** of the integrated carer support service system:
 - concerns that peer workers may not have knowledge or professional skills required to assist carers appropriately; and
 - need to ensure the service included people with lived experience.
- in regards to **respite**:
 - need for the availability of more respite, and not to be judged solely on the person they were caring for;
 - should be easier to access and book respite; and
 - a desire to attend carer retreats.
- in regards to **support for the person they care for**:
 - concerns about the broader reforms and what this means across other systems; and
 - carers were seeking more assistance for the person(s) they care for.
- in regards to **income support**:
 - seeking improved financial support, particularly where they had left work to provide full-time care.
- in regards to the **funding and implementation** of the integrated carer support service system:
 - concerns that regional hubs will represent a cost cutting exercise, which will not result in improved supports; and
 - block funded models will not drive improvements.
- in regards to **accessing** services:
 - concerns that services will be delivered through a call centre;
 - concerned there may be limited local support; and
 - support should be free.

Issues relating to the survey

There are a number of limitations in analysing the survey data including that many respondents indicated that they had not read the draft Service Delivery Model discussion paper prior to completing the survey. Reasons for this included that the document was too long and too wordy to read, while others had been unable to locate the document on the website. Therefore, in some responses, comments were directly contrary to what is included within the draft Service Delivery Model.

Some technical issues were identified shortly after the survey opened for responses which prevented respondents from selecting more than one option for some questions. The issue was rectified; however, it did cause some respondents to prioritise a single answer for multi-select questions, and also enabled respondents to skip some questions without answering.

Additionally, organisations within the sector, including service providers, peak bodies and others, opted to distribute the survey directly to their members or mailing lists in hardcopy for completion. It is unknown whether the copies of the survey would have been accompanied by a copy of the draft Service Delivery Model.

APPENDIX A: Public Submissions

The table below lists the responses for which consent was provided to publish their submission. These are able to be viewed at <https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/>.

Respondent Type	Name
Service Provider	Whittlesea City Council
Carer	Gerald White
Service Provider	Intereach
Service Provider	Community Lifestyle Accommodation
Service Provider	Aftercare
Service Provider	The Kirribilli Centre
Service Provider	WA Country Health Service
Service Provider	NSW Commonwealth Respite and Carelink Centre State Managers Network Meeting
Service Provider	Carer Support and Respite Centre Inc.
Carer	Dianne Stewart
Service Provider	Midlas
Service Provider	CareWest Ltd
Service Provider	Sutherland Shire Carer Support Service Inc.
Service Provider	Media Access Australia
Service Provider	The Royal Australian & New Zealand College of Psychiatrists
Service Provider	Carers and Disability Link Inc.
Carer	Fiona Scott
Service Provider	Merri Health
Service Provider	Stroke Foundation
Service Provider	Quality Aged Care Action Group Inc.
Service Provider	National CRCC Working Group
Service Provider	Interchange Illawarra
Peak Body	Aged and Community Services Australia
Service Provider	Country North Community Services Inc.
Service Provider	Neami National
Peak Body	Illawarra Forum
Peak Body	BaptistCare Australia
Peak Body	National Mental Health Consumer and Carer Forum
Peak Body	National Disability Services
Carer	Joyce Bastian
Peak Body	Alzheimer's Australia
Service Provider	BrainLink Services Limited
Service Provider	Siblings Australia

Respondent Type	Name
Service Provider	Anglicare SA
Peak Body	Carers Australia
Other	NSW Community Care Forum
Other	Sutherland Shire Aged Care Interagency
Peak Body	National Rural Health Alliance
Service Provider	Anglicare Diocese of Sydney
Service Provider	Wellways Australia
Carer	Autism Aspergers Advocacy Australia
Service Provider	Loddon Mallee Mental Health Carers Network
Other	Combined Pensioners & Superannuants Association of NSW (CPSA)
Peak Body	Anglicare Australia
Carer	Bobb (Autism Aspergers Advocacy Australia)
Carer	Sjon
Service Provider	Bendigo Community Health Service
Service Provider	Chinese Australian Services Society Ltd
Other	Seniors Collaborative Action Project (Barossa Council)
Other	Mental Health Community Coalition ACT
Other	Australian Association of Gerontology
Other	ADACAS
Other	Victorian Carer Services Network
Service Provider	Uniting Care Australia
Peak Body	COTA Australia
Carer	Sharon Munn
Service Provider	Uniting Care Wesley Bowden
Other	Victorian CHSP Carer Programs Network
Peak Body	Tandem Inc.
Service Provider	Advance Diversity Services
Service Provider	Multicultural Centre for Women's Health (MCWH)
Service Provider	Advance Diversity Services
Service Provider	Queensland Advocacy Inc.
Service Provider	Carer Support Network SA
Service Provider	FECCA
Service Provider	Schizophrenia Fellowship of NSW
Service Provider	Children and Young People with Disability Australia
Service Provider	Mental Health Australia
Other	NSW Carers Advisory Council

APPENDIX B: Carer Survey Questions

About being a carer

- Do you currently provide, or have previously provided, unpaid care and support to a family member or friend who has any of the following? (Yes or No)
 - ☐ Yes, I care, or have cared for person(s) with:
 - Disability
 - Chronic illness
 - Terminal illness
 - Mental health condition
 - Alcohol or other drug dependency
 - Frailty due to age
 - Dementia
 - ☐ No, I do not, or have not cared for a person with any of these conditions.
- How many people do you care for? (number)
- What are their ages? (conditional)
- How many hours per week do you spend caring?
 - ☐ Less than 20 hours
 - ☐ 20 to 39 hours
 - ☐ 40 hours or more
- How long have you been a carer for? (select one)
 - ☐ Less than 6 months
 - ☐ 6 months to 2 years
 - ☐ 3 to 5 years
 - ☐ 6 to 10 years
 - ☐ 11 to 15 years
 - ☐ 16 to 20 years
 - ☐ More than 20 years
 - ☐ I prefer not to answer
- Why do you need to care for the person(s) you support? (you can select more than one)
 - ☐ Chronic illness
 - ☐ Disability
 - ☐ Terminal illness
 - ☐ Aged and frail
 - ☐ Mental illness

Demographic details and carer cohort

The following questions are asked so that we can understand the needs and experiences of different groups in the community.

- How old are you?
- What is your home postcode?
- Do you identify as any of the following (select one)?
 - ☐ Aboriginal
 - ☐ Torres Strait Islander
 - ☐ Aboriginal and Torres Strait Islander
 - ☐ None of the above

- We're asking this so that we can understand the needs and experiences of different groups in the community. You may not prefer to answer. Do you identify as any of the following when talking about your sexuality? (you can select more than one)
 - ☐ Lesbian
 - ☐ Gay
 - ☐ Bisexual
 - ☐ Questioning
 - ☐ Heterosexual
 - ☐ None of the above
 - ☐ I prefer not to answer
 - ☐ Don't know
- How do you identify your gender?
 - ☐ Male
 - ☐ Female
 - ☐ GenderQueer
 - ☐ Other
 - ☐ None of the above
 - ☐ I prefer not to answer
 - ☐ Don't know
- Do you or the person you care for speak a language other than English at home? (select one)
 - ☐ Yes
 - ☐ No, English only
- If yes, what language(s) are spoken? (select all that apply)
 - ☐ Arabic
 - ☐ Cantonese (Traditional Chinese)
 - ☐ Croatian
 - ☐ Dutch
 - ☐ German
 - ☐ Greek
 - ☐ Hindi
 - ☐ Hungarian
 - ☐ Italian
 - ☐ Korean
 - ☐ Macedonian
 - ☐ Maltese
 - ☐ Mandarin (Simplified Chinese)
 - ☐ Polish
 - ☐ Punjabi
 - ☐ Russian
 - ☐ Serbian
 - ☐ Spanish
 - ☐ Vietnamese
 - ☐ Other: (free text)

- What cultural background(s) do you or the person(s) you care for identify with? (select all that apply)
 - ☐ Australian
 - ☐ English
 - ☐ Italian
 - ☐ Chinese
 - ☐ Dutch
 - ☐ Indian
 - ☐ Greek
 - ☐ Other: (free text)
-

Use of technology

- Do you have access to the internet at home?
 - What type of internet connection(s) do you have? (you can select more than one)
 - ☐ Mobile wireless (3G/4G)
 - ☐ ADSL broadband
 - ☐ Cable broadband
 - ☐ Fibre to the premises
 - ☐ Satellite broadband
 - ☐ Fixed wireless broadband
 - ☐ Not sure
 - Which of the following do you use? (you can select more than one)
 - ☐ Wearable device (i.e. smart watch, fitness tracker)
 - ☐ Smart phone (iPhone, etc.)
 - ☐ Home phone/landline
 - ☐ Laptop computer
 - ☐ Desktop computer
 - ☐ Smart TV (TV connected to the internet)
 - ☐ None of these
 - ☐ Not sure
-

Likely use of services

The following questions are about your preferences in accessing supports and services proposed in the draft Service Delivery Model. These services have been selected based on (1) the evidence on their effectiveness in supporting carers, (2) feedback and input from carers, and (3) feedback and input from people who help support carers currently.

- If help was offered to you, as a carer, in the early stages of your caring journey, including the supports described in the draft Service Delivery Model, how likely do you think you would be to access them? (select one)
 - ☐ Not at all
 - ☐ Somewhat unlikely
 - ☐ Neutral
 - ☐ Somewhat likely
 - ☐ Very likely

- Why? (free text)
-
- In regards to a national website, which of the following do you think you would use? (you can select more than one)
 - ☐ I would not access the website
 - ☐ I would create an online account so the website remembers my preferences and my details for next time
 - ☐ I would like to find ideas about caring and staying well from other carers
 - ☐ I would share my ideas about caring and staying well
 - ☐ I would access carer specific information
 - ☐ I would register and create an emergency care plan so that if something happens to me, I know my regional hub has all the information they need to look after the person(s) I care for
 - ☐ I would use the self-assessment questionnaire to learn more about what might help me to address my needs and what support I might be eligible for
 - ☐ I would develop a personal plan and action list
 - ☐ Other: (free text)

Would you use carer education and training supports?³

- ☐ Yes, I would like to use carer education and training supports
 - ☐ I would like to learn more about how I can look after the person I'm caring for
 - ☐ I would like to learn more about how I can look after the person I'm caring for
 - ☐ I would like to engage in vocational training to enable me to return to employment
- ☐ No, I would not access carer education and training

If so, how would you like to do so? (you can select more than one)

- ☐ I would like to attend education and/or training programs in person
- ☐ I would like to complete this education and/or training online, at a time convenient to me.

- Comments (free text)

- Would you use peer support services if they were more broadly available?⁴ If so how?
 - ☐ Yes, I would like to access peer support
 - ☐ I would like to meet and talk with other carers in my local area
 - ☐ I would like to talk with other carers on the online discussion board

³ Under the proposed Model, the purpose of education and training would be to help carers to build skills to:

- care for the person they are looking after;
- build resilience to enable them to maintain their caring role;
- increase their capacity to communicate with health professionals, and navigate and access service systems (eg: NDIS); and
- attain care related qualifications (certificate level) should carers wish to enter or return to the workforce in a care related field.

⁴ Peer support seeks to help carers to connect and share their caring experiences.

- ☐ No, I would not use peer supports
- ☐ I'm unsure whether I would use peer supports
- Comments (free text)

- If you were to participate in peer support, what would you look for? (you can select more than one)
 - ☐ A positive attitude in the interactions
 - ☐ A safe, private space where you can talk about things that are happening for you
 - ☐ Opportunities for activities that aren't focused on caring
 - ☐ Carers with similar caring responsibilities as me
 - ☐ Carers with a similar background (e.g. age, cultural background)
 - ☐ Other (free text)

- Do you think you would like to access a six to ten-week program of carer coaching?⁵
Coaching would involve one-on-one support, where a coach assists a carer to achieve specific goals through the provision of advice and education.
 - ☐ Yes, I would access a carer coaching program
 - ☐ No, I would not access a carer coaching program
 - ☐ I'm unsure whether I would access a carer coaching program
- What are the reasons for your answer? (free text)

⁵ Under the proposed model, carer coaching is intended to help carers to acquire skills and resilience to assist them in managing their caring role. This would be delivered one on one, with a trained mentor assisting a carer to identify and focus on their goals, desires and objectives.

GLOSSARY

Term	Description
ACAT	Aged Care Assessment Team
Channel	The way in which a consumer interacts with a service (e.g. via phone, online, in person)
Coaching	A one-on-one support program, where a coach assists a carer to achieve specific goals through the provision of advice and education
Cohort	Refers to a group of people with a shared characteristic or attribute
CRCC	Commonwealth Respite and Carelink Centre
DSS	Department of Social Services
Forecast	A prediction of future events or volumes
Integrated carer support service system	The integrated carer support service system is the collective term for the set of supports proposed to be delivered for carers
My Aged Care	A clear entry point to the aged care system through a website and national 1800 phone number
Multi-channel	Refers to the ability for consumers to access a service more than one way (e.g. phone, on-line, in-person)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
Needs Assessment	A method of identifying and addressing a person's needs
Peer Support	A form of support, involving the giving and receiving of help, by individuals with shared experience or knowledge
PHN	Primary Health Network
RAS	Regional Assessment Service (aged care)
Regional Hub	The regional organisation responsible for delivering services at a regional level for the integrated carer support service system
Sector development	Activities that support and improve service delivery for carers, and build the capacity of funded services and the broader sector
Service mapping	Refers to an analysis of available services within a given region
The Plan	The Integrated Plan for Carer Support Services

