



Australian Government

Department of Social Services

Designing the new integrated carer support service

A draft Service Concept for the delivery of interventions to improve outcomes for carers

Version 2 | May 2016

© 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 links provided).

This document must be attributed as:

Department of Social Services. 2016. Designing the new integrated carer support service: A draft Service Concept for the delivery of interventions to improve carer outcomes, Australian Government, Canberra.

CONTENTS

INTRODUCTION	4
Approach to the design of the new integrated carer support service system.....	4
A. STATEMENT OF NEED.....	7
Who are our carers?	7
Current Carer Support Policy Framework	12
Drivers for Change	14
A shift towards prevention	18
B. THE DRAFT SERVICE CONCEPT	21
Service Concept Overview	22
Awareness	23
Information provision	25
Intake.....	27
Education	28
Peer Support	30
Needs Identification and Planning.....	31
A multicomponent intervention	33
Counselling.....	42
Supporting All Carers.....	44
Providing Integrated Support	47
ANNEX A – Carer Support Service Design Project: Design Progression	49
ANNEX B - Carer Support Programmes funded by the Department of Social Services.....	51
ANNEX C - Carer payments funded by the Australian Government	55
ANNEX D - A review of the evidence base	58
ANNEX E- Design Principles (accessible version)	61
ANNEX F- Service Concept Overview (accessible version)	62
ANNEX G- Examples of effective interventions	64
TERMS & ACRONYMS	68
WORKS CITED	69

INTRODUCTION

In recognition of the need to support and sustain the vital work of unpaid carers, the Australian Government committed \$33.7 million over four years to design an Integrated Plan for Carer Support Services (the Plan). The Plan includes two key stages.

The first stage of the Plan was the design and implementation of Carer Gateway. Carer Gateway was established to provide a recognisable source of clear, consistent and reliable information to help carers navigate the system of support and services. Carer Gateway was established in December 2015 and includes a national website providing carer-specific information and a national contact centre.

The second stage of the Plan involves the design of a new integrated carer support service system. The purpose of new service is to deliver supports that reduce caregiver strain (based on a model of social, psychological, physical and financial outcomes) with the twofold objective of increasing a carer's well-being and reducing the risk of the caring role ending.

The ultimate design of the new service will form the basis of a proposal to Government, for consideration on how to proceed with operationalising the service.

This document, the draft Service Concept, represents the first component of the design of the new integrated carer support service system. This paper is not final and presents a *draft Service Concept* for discussion.

Approach to the design of the new integrated carer support service system

To inform the design of the new service system, the Department of Social Services (the Department) is working with carers, service providers, peak bodies and individuals with carer-specific expertise in a process of co-design. This is being undertaken in two phases; the definition of the current arrangements by which carers access support; and the design of the future state.

The design progression is provided under [Annex A](#).

In order to design an effective, sustainable Integrated Carer Support Service, it is necessary to gather information about and analyse the current ways, in which carers receive support. The Department has undertaken three research activities to support this work.

1. An environmental analysis (Current State Report) to identify the organisations currently supporting carers and understand their processes, types of staff and technology.
2. Market research (Carer Service Development Research) to understand the needs of carers in relation to a carer information and support service.

-
3. An analysis of meta-reviews of international evidence on the effectiveness of supports in achieving good outcomes for carers.

The second phase of design is to define the new service. This will be undertaken in three parts.

1. Definition of a Service Concept, which will identify the high level services aimed at providing improved outcomes for carers.
2. Definition of a Service Delivery Model, which will define the services in more detail, the mechanisms by which they will be delivered (e.g. face to face, mobile device, telephone, etc.), participants who will deliver these services and the technology which will support this.
3. Definition of a national carer needs identification tool, which will articulate a design of a nationally consistent needs identification tool.

The role of the Service Concept in the design process

In the context of the wider design, the Service Concept articulates **what** services are going to be delivered and **why** this will assist carers.

The Service Concept identifies a set of carer-specific supports (that could be delivered by the service) that improve carer outcomes. The Service Concept will ultimately form the foundation for the design of the Integrated Carer Support Service, by articulating how the needs of carers will be met by the services described. It is intended to provide a high level framework for more detailed design.

Co-design activities and the development of the draft Service Concept

This draft Service Concept has been developed through an iterative process involving carers, organisations who support carers today and the Carer Gateway Advisory Group (CGAG). Using the findings from the analysis of the current state of the carer service system, the Carer Service Development Research, and a review of the clinical evidence, the Department engaged in co-design workshops with the CGAG, a Subject Matter Expert (SME) Working Group and a Carer Working Group.

The CGAG is comprised of a group of external stakeholders, to advise on the development of the Plan. It plays a strategic role in the development, review and validation of designs, and is comprised of key leaders and representatives from the sector.

The SME Working Group is comprised of a mix of participants who currently work with carers on a day to day basis to provide them support and assistance under current programmes. It is comprised of carers and representatives from Commonwealth Respite and Carelink Centres (CRCCs), Carers Australia state and territory based Carer Associations, service providers, My Aged Care Regional Assessment Organisations, National Disability

Insurance Agency and Aged Care Assessment Teams. The Department has also obtained input from a Carer Working Group, comprised of carers providing unpaid care in a range of circumstances. This group was provided a similar opportunity provide input and ideas about the future services. Using their professional knowledge and their sector expertise, these groups have provided input about the new service system for carers.

This document represents an output of this process of preliminary consultation and development based upon feedback from members of the sector and carers themselves. The co-design process remains underway and this document is expected to evolve as the Department continues to seek feedback through further consultation.

[About this paper](#)

The paper has two parts:

Part A presents the statement of need for the new integrated carer support service, outlining drivers for reform and a set of design principles.

Part B proposes the supports that could be delivered by a new integrated carer support service.

A. STATEMENT OF NEED

There are an estimated 2.7 million people in Australia providing informal assistance, in terms of help or supervision, to people with disability or long-term health conditions, or who are elderly (Australian Bureau of Statistics, 2012). Without the support of their carers, many Australians would not be able to live in their own homes.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability and community care system. The success of reforms to help people remain living in their home as long as possible, in part depends on the willingness, and the ability of carers, to perform a caring role.

Acknowledging the contribution carers make to our society, the Australian Government provides a range of supports specifically for them. However, these services are accessed through pathways across disability, community mental health, and aged care sectors. This fragmentation often leads to confusion among carers about where to go to get the support they need to sustain their caring role. Further discussion on the challenges carers face regarding service pathways can be found on [page 16](#).

Who are our carers?

Carers are defined as people who provide unpaid personal care, support and assistance to people with disability, a medical condition (including terminal or chronic illness), mental illness, dementia or frailty due to age. There are also many carers who provide care to more than one person who may have multiple conditions. The Carer Service Development Research found that approximately one fifth (21%) of carers were caring for two or more people (AMR Australia, 2015).

Carers include family members, friends, relatives, siblings or neighbours. Those carers who are grandparents or foster carers of a child with disability, medical condition (including terminal or chronic illness) or mental illness are also included as carers. All of these people are defined as carers regardless of the amount of care, support and assistance they provide. Many people who are carers may not identify themselves as such and therefore remain 'hidden'.



Why do they care?

Of the 2.7 million carers, 769,800 are primary carers. In 2012 (Australian Bureau of Statistics, 2012) the most common reasons reported by primary carers for taking on the caring role were family responsibility/obligation (26%), the carer feeling that they could provide a better quality of care than others (19%) and emotional obligation (16%).

This is likely driven by the relationship between the carer and person being cared for. Approximately 91% of primary carers were related to the people they are caring for, with approximately 43% of carers caring for partners, 25% of carers caring for a parent and 23% of carers caring for a child.

Carers and economic value

Deloitte Access Economics estimated that in 2015 2.86 million informal carers were providing informal care equalling to an estimated 1.9 billion hours of care¹. On average, that is 673 hours per carer (or 13 hours per week). However, care hours are not evenly distributed; the 540,000 primary carers (19% of all carers) account for 714 million care hours (54% of the total hours provided by all carers) (Access Economics, 2015).

Access Economics estimated if informal carers were no longer available, the replacement value of these unpaid care hours would be \$60.3 billion. This is equivalent to 3.8% of the gross domestic product, and 60% of the health and social work expenditure (Access Economics, 2015).

Caring is stressful

Many carers report positive experiences such as a sense of satisfaction and relief knowing that their loved ones (the majority of care recipients are parents, partners, or children) are being cared for appropriately. They find caregiving rewarding and a way to give back. In studies with large population-based samples, about one third of carers report neither strain nor negative health effects (Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson, 2007). Particularly in the early stages of caregiving, negative effects may not occur. Even when caregiving demands become more intense and result in high levels of distress and depression, carers often cite positive aspects of the experience.

However, caregiving has its challenges. These include:

- difficulty watching the care recipient deteriorate and in pain;
- stress placed on the carer and care recipient's relationship;
- carers' confidence in their own skills and ability to meet the needs of the person or persons they are caring for;

¹ Deloitte Access Economics utilised data drawn from the Australian Bureau of Statistics Series B population projections to estimate the number of informal carers. This was mid-level population projections corrected for factors such as births, deaths and net migration into Australia.

- the time spent caring leaves some carers with little personal time;
- their caring responsibilities can lead to social isolation, even from family and friends;
- difficulty navigating and accessing government services;
- impacts to their own health and wellbeing;
- for those carers living outside of capital cities, access to services can be difficult;
- inability to participate in religious and cultural events, and being involved more generally in their community;
- stress from juggling multiple responsibilities such as employment and education; and
- grief where activities or hobbies are no longer possible due to caring responsibilities (AMR Australia, 2015); and
- a greater propensity for financial hardship.

These challenges can have a negative impact on the health and well-being of informal carers. This creates a tenuous situation given that over one third of carers also have a health condition which in some cases was the same condition as the care recipient (AMR Australia, 2015):

- 23% of those caring for someone with a disability also have a disability;
- 26% of those caring for someone with a mental illness also have a mental illness; and
- 22% of those caring for someone with a chronic illness also have a chronic illness.

A key theme emerging consistently from the research literature over the past 25 years is that caregiving can have negative effects on carers' physical and emotional health, financial situation, social networks and ability to take part in the labour market (Parker, Arksey, & Harden, 2010).

Clinical observation and early empirical research shows that assuming a caregiving role can be stressful and burdensome; caregiving has all the features of a chronic stress experience. Schulz & Sherwood (2009) found a demanding caregiving role, providing assistance with basic activities of daily living for 20 hours or more per week, resulted in increased depression and psychological distress, impaired self-care, and poorer self-reported health.

Some of the most common mental health problems reported by carers include depression, anxiety, and stress. In addition, many report high rates of guilt, sadness, dread, worry, and other negative experiences, as well as distress from witnessing the suffering of their relatives. Health-related concerns include fatigue, sleep disturbances, and risk of illness and injury. Secondary strains are work-related productivity loss, financial strains, relationship stress, loss of time for self-care, and overall reduced quality of life.

Carers need support

"The Committee acknowledges that changing paradigms of care, particularly the shift from institutional care to care in the community has led to increased reliance on informal care provided by unpaid carers, most often relatives of the care receiver. Therefore, the Committee is concerned by evidence which indicates that the current levels of support are

insufficient to give carers the assistance they need to care, or enable them to make genuine choices in relation to their involvement. This is even more concerning in view of the expected increase in demand for care and predicted shortfall in the supply of people to provide that care."

From the 2009 'Who Cares...?' (House of Representatives, 2009)

"By preventing breakdown of the valuable support that carers provide, not only is the financial cost of repairing carers' own health avoided, but the additional cost of providing alternative care for the people they are supporting is avoided too."



The United Kingdom's 2008 National Carers' Strategy

The Carer Service Development Research (AMR Australia, 2015) found strong support for the introduction of a nationally consistent carer service to provide access to relevant information, support and services. The main findings validating the need for a service were:

- access to services is currently difficult for carers to navigate and access;
- carers know there are services available and have heard support can be provided, but are not sure how to gain access; and
- some carers are struggling to cope with the significant pressure placed on them and their caring role.

Without support, these difficulties have the potential to reduce the amount (or diluting the quality) of care provided, as well as increasing the probability of institutionalisation (Long & Spillman, 2009).

Carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases and family breakdown (including loss of the carer) the reason in a further 8% (Association Of Directors Of Adult Social Services, 2010).

When put in the context of the economic value contributed by carers it is essential to identify and deliver supports that:

- Help carers to sustain a caring role and avoid a crisis that might adversely affect or end it (e.g. information, training); and
- Improve carers' well-being as individuals in their own right (e.g. breaks, support to access employment).

An analysis of the United States National Family Carer Support Programme (NFCSP) provided evidence (albeit indirect) that support services can reduce carer depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care (Barber, 2013).

These support services are highly valued by carers. According to national (United States) survey data recently collected by the Administration on Ageing (2011), 77% of carers report that NFCSP services definitely enabled them to provide care longer than otherwise would have been possible, and 89% report that these services helped them to be a better family carer. Nearly half the carers of nursing home eligible care recipients indicated that the care recipient would be unable to remain at home without the carer receiving support services.

Current Carer Support Policy Framework

The Australian Government currently funds support services for carers through a range of programmes, of which, three are transitioning to the National Disability Insurance Scheme (NDIS).

In 2014-15, the Australian Government spent \$170.219 million on the following programmes, supporting approximately 177,100 carers nationally with access to information, education, respite and counselling including:

- The former National Respite for Carers Programme (NRCP) encompassing the following sub-programmes:
 - The National Carer Counselling Programme
 - Carer Information and Support Service
 - Short term and emergency respite
 - Consumer Directed Respite Care
- Mental Health Respite: Carer Support
- Young Carers Programme
- The Young Carer Bursary Programme
- Respite Support for Carers of Young People with Severe and Profound Disability
- Dementia and Aged Care Services grants- carer projects
- Dementia Education and Training for Carers Counselling, Support Information and Advocacy- carer support
- MyTime: Peer Support Groups

A breakdown of these programmes in terms of their target groups, eligibility criteria and funding allocation/carers serviced for the financial year 2014/15 is provided at [Annex B](#).

Each of these funding streams are awarded separately having been historically linked to care recipient focussed programmes. Each has its own eligibility requirements that carers are required to meet, and carer support organisations are required to produce reports against measures for each programme.

Funding for the National Carer Counselling Programme and the Carer Information and Support

Service is provided to State and Territory based Carer Associations through Carers Australia. Funding for the remaining programmes has been allocated to regional organisations, such as CRCCs through grant arrangements. In many cases, organisations are also receiving funding from other streams, such as the state and territory governments.



Most of the organisations surveyed by the Department have, where possible, attempted to obtain funding under as many streams as possible so as to provide a holistic service for carers. This creates an additional administrative overhead for providers and Government as management and reporting is required against individual funding streams.

The Australian Government's most significant area of expenditure on carers is direct payments through the social security system. In 2014-15, the Government spent over \$7 billion on social security payments for carers, including:

- Carer Payment;
- Carer Allowance;
- Carer Supplement; and
- Child Disability Assistance Payment.

Further detail on each of these payments is available at [Annex C](#).

Drivers for Change

Service Utilisation & Macro Drivers of Demand

In 2014-15, the programmes outlined previously, assisted approximately 177, 100 carers. As described earlier, in large population-based samples, about one third of carers report neither strain nor negative health effects (Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson, 2007). This suggests that there will be some carers who will not require ongoing or more intensive support in order to sustain their caring role.

If it were assumed that approximately one third of Australia's 2.7 million carers do not need formalised support, there remains at least 1.782 million who will. This highlights that the current programmes are servicing approximately 9% of the total number of carers who may require some assistance to sustain their caring role. When considered in the context of increasing demand, it is clear the current model will not be sufficient to service carers in Australia.

Demand is increasing and supply is decreasing

There are a number of factors which are causing increasing demand for informal care, coupled with a lowering in the supply thereof. In particular, there is:

- an increased level of disability in the community, related to a growing and ageing population; and
- a lower propensity to provide informal care.

The underlying determinant of the need for care is the level of disability in the community (Howe and Schofield 1996 as cited in Borowski, Encle, & Ozanne, 2007).

The prevalence of disability in Australia fell by 1.5 percentage points between 2003 and 2012, while the rate of profound or severe core activity limitation remained constant at 6.3% in 2003 and 6.1% in 2012 (Australian Bureau of Statistics, 2012). Despite this, due to population growth and ageing, the number of people with severe or profound disability is estimated to increase from 1.3 million to over 2.2 million by 2030 (Australia Institute of Health and Welfare, 2010).

At the same time a number of demographic trends such as declining family size, changes in residential patterns of people with disability, and rising female participation in the formal labour market, will all likely contribute to a decline in the availability of family carers (Organisation for Economic Co-operation and Development, 2011).

Reactive Service Responses

The current service model leans towards the provision of reactive support responses. Interviews with organisations supporting carers, as part of the Current State Analysis, identified that carers usually present at a time of immediate need (Department of Social Services, 2015). This means that services and supports which are put in place for carers are

usually reacting to an immediate or urgent need and have less focus on planned or preventative service provision.

This is related to two factors:

- a lack of awareness of carer supports available in the community; and
- the degree to which carers do not identify themselves as carers and remain 'hidden carers'.

As part of co-design workshops, participants from the Carer Working Group reported that once they were connected with a carer support

organisation, they felt well supported and had a sense of comfort in knowing where to go for assistance. However, in the Carer Service Development Research, it was identified that the hidden carer population is quite large, with 82% of carers not identifying themselves as a carer, on either a part time or full time basis (AMR Australia,



2015). This suggests that there is a high number of carers who do not seek 'carer' supports in the current environment.

Other Drivers for Reform

In addition to the pressures outlined earlier, the current programme design and service structures have led to a range of further barriers for carers in seeking services, and for providers in supporting them.

Carers risk being lost in the care recipient focussed programmes

With several broader reforms underway, including the transition to the NDIS, the introduction of My Aged Care and the Commonwealth Home Support Programme (CHSP), there has been significant changes to the service landscape in which carers seek support for themselves and the person(s) they care for. These programmes have a strong focus on the care recipient as the primary client of the service. Carer support services have reported there is increasing uncertainty among carers about where they can access the support they need (Department of Social Services, 2015).

Additionally, there are three carer support programmes funded by the Department that are due to transition or have transitioned, in full or in part, to the NDIS. This includes the Young Carers Programme, Respite Support for Carers of Young People with a Severe or Profound Disability and Mental Health Respite: Carer Support. Carer organisations reported that

there was a perception that these changes have resulted in less dedicated assistance for carers, as supports provided under these programmes need to be accessed through the NDIS.

The system is hard to navigate

Both the Carer Service Development Research (AMR Australia, 2015) and the Current State Analysis (Department of Social Services, 2015) found that the system as it stands is difficult for carers to navigate. The allocation of funding for different programmes means there is fragmented coverage of carer services across many areas of the country, and carers struggle to identify a single point from which they can access the support and assistance they need. Carers may need to seek support across numerous organisations in relation to the needs of the person(s) they care for and their own needs.

It is unsurprising that carers reported having to undertake extensive research in order to understand what was available to support them. Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse carers reported significant barriers to access, with multiple pathways and difficulty with language resulting in even greater isolation. Carers in rural and remote areas also reported isolation and difficulty in accessing support services (AMR Australia, 2015).

Carer support organisations also face complexity associated with the current funding arrangements, with a need to define which of the carer programmes a carer is eligible for. Complexity is inherent where carers need to be classified in relation to the person they are caring for, particularly where they are caring for more than one person. Carer support organisations are required to juggle funding for the carer based on programme eligibility. For example, someone caring for two people, one who is aged and one who has a mental health condition, is eligible for multiple programmes and in providing support, carer organisations are required to draw down on and manage multiple funding streams.

Carers often have to provide simple information to many organisations

Under current arrangements, carers are commonly required to provide information about themselves, and the person they care for, to multiple organisations across the service system. This is related to a lack of automated information sharing in place. This is both in relation to the needs of the person they care for and their own needs (Department of Social Services, 2015).

Carer experiences are not consistent across the country

As there is limited standardisation of practices across the country, carers sometimes have quite different experiences in accessing supports. A number of organisations raised examples where carers who had moved into their region and had different expectations of the supports they could request and the way in which they could be accessed. This leads to an unequal experience in accessing support across the country. In addition, the current brokerage model utilised in some carer support programmes means there is significant

differences in the level of support provided from one carer to the next (Department of Social Services, 2015).

Locating and accessing respite services is challenging

Respite² is a form of support where a carer is relieved by an individual who provides substitute supervision and assistance to their care recipient. There are three primary forms of respite available, defined based on their delivery settings including:

- Residential or overnight respite: overnight care provided in a residential aged care facility or in a cottage;
- In a community based centre: care provided within a day facility; and
- In-home respite: care delivered by a provider within a private residence (Alzheimer's Australia, 2013).

Both the Current State Analysis (Department of Social Services, 2015) and the Carer Service Development Research (AMR Australia, 2015) found accessing respite is challenging.

In relation to residential forms of support, carers reported that the requirements to obtain respite were often impractical. Carer support organisations reported that many residential providers would not accept short term bookings, requiring carers to book for two week minimum blocks of respite care. They advised that, in doing so, service providers were seeking to ensure there was maximum utilisation of respite beds (without breaks between bookings). They were also seeking longer bookings as there is a high level of administrative effort related to such admissions.

In addition, carer support organisations reported a growing reluctance on behalf of service providers to provide residential respite, likely related to utilisation. As there is limited access to real time availability of data, utilisation of respite beds may be less than 100% and providers may not feel there is enough of a market driver to offer these services.

As planned respite is funded under the main service systems targeted for care recipients (e.g. CHSP), carers face increasing difficulty in seeking this type of support, particularly where they are caring for more than one person.

Carers have also reported that complexities in assessment and administration are a barrier to their ability to access all forms of respite, particularly where there were differences between different providers (Alzheimer's Australia, 2013).

In their review of respite, Alzheimer's Australia (2013) reported that while carers valued this cottage respite because of a home-style, intimate setting, there are only a small number of cottage respite providers making access challenging. Further, where care recipients needs are too high, carers have been unable access to this form of respite.

² Indirect respite, which does not involve replacement care provided by the care recipient but relief from other duties was not identified as a challenge. This form of support is commonly provided as part of care recipient focussed programmes (e.g. domestic assistance for the care recipient) or brokered by a CRCC.

In home and community based respite can also be difficult to access for carers, with some providers maintaining waiting lists. This limits the flexibility of the service as carers may not be able to access this form of respite on the days they require (Alzheimer's Australia, 2013).

A shift towards prevention

There are opportunities to address the challenges outlined through reform of policy structures and service delivery, to better support carers to sustain their caring role.



The philosophical underpinning of this concept is to shift from a reactive response to a planned, preventative model. It is intended to do so by increasing utilisation of services proven to be effective at achieving longer term benefits for carers. In particular, there is intended to be a focus on increasing carer capability and wellbeing so as to reduce pressure on episodic services which have been shown to have limited

long term benefits. Designing the service to achieve this has some inherent challenges, outlined below.

Identifying supports known to improve carer outcomes is challenging

Identifying interventions known to improve carer outcomes presents two dilemmas:

1. A review of the research shows there is a lack of consensus as to those supports which are most effective at improving carer outcomes; and
2. Carer preferences can often conflict with current evidence on what supports tend to have stronger effects. For example, evidence suggests more frequent interactions whereas carers often express a preference for less frequent interactions (Joling, et al., 2013).

A review of the evidence base for interventions to support carers is provided at [Annex D](#).

To address these issues, the draft Service Concept presented in this paper relies on:

- Those interventions (such as emergency respite) that carers access today and express high satisfaction with, as evidenced through the Current State Analysis and survey responses from over 1,000 Australian carers; and
- Those interventions for which there is a sound (clinically and statistically) evidence base to show that they will improve carer outcomes.

Development of an Integrated Carer Support Service will increase demand on current resources

While good supports are available for some carers, there are many who are not accessing support which may assist them in undertaking their caring role.

The new integrated carer support service will provide a visible service which will aim to assist all carers. It will aim to do this in two ways:

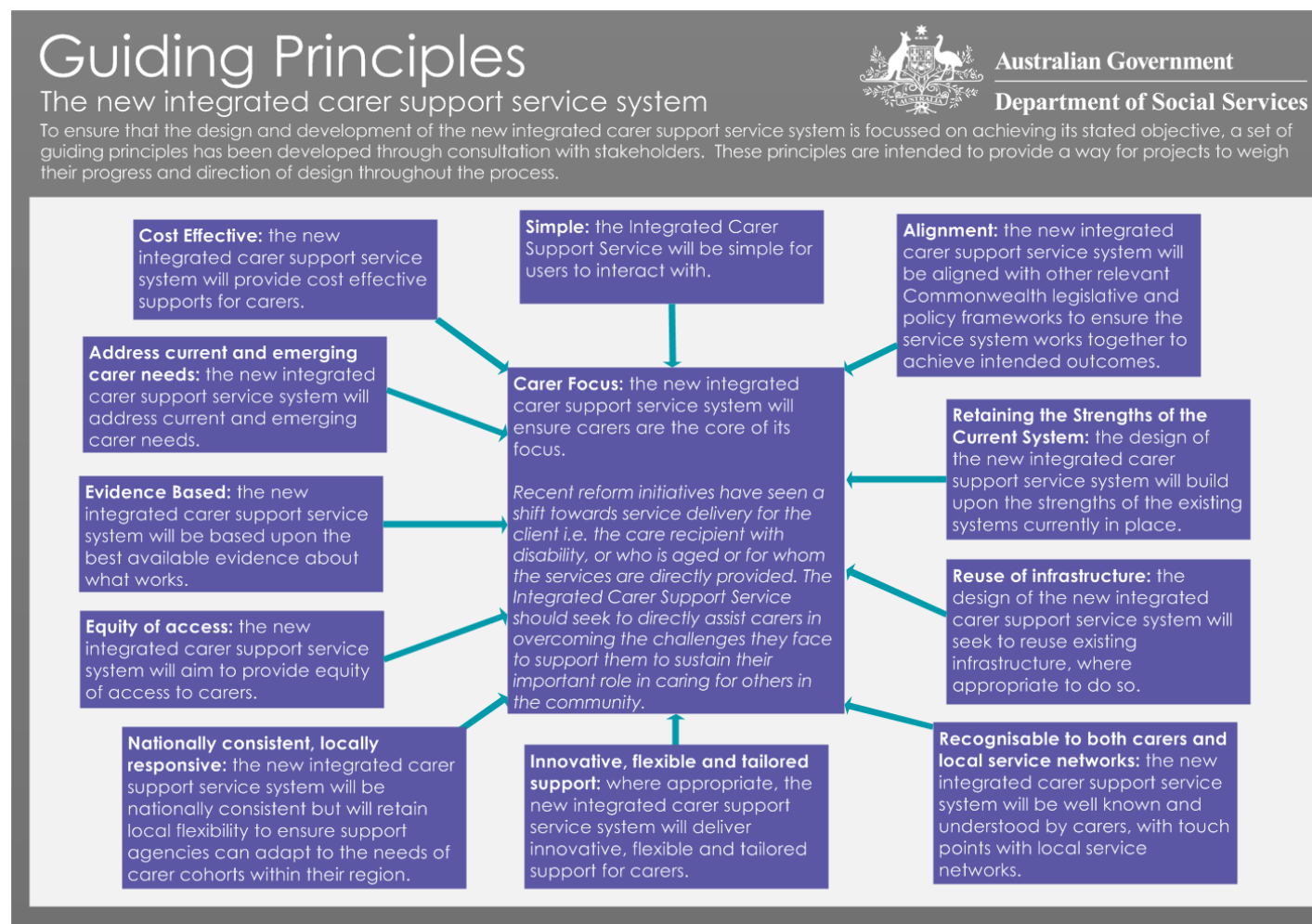
- To proactively support carers to sustain a caring role and avoid a crisis that might adversely affect or end it (e.g. information, training); and
- To provide support where carers are in, or at risk of crisis which might adversely affect or end it (e.g. emergency respite).

The funding allocated to a future model will not be sufficient to service all 2.7 million of Australia's carers. For example, if the provision of formal counselling supports were provided to each of Australia's 2.7 million carers, the cost of this alone would exceed \$1 billion. On the basis that not all carers need formal counselling and some carers will have a higher need for this than others, it is unlikely this would represent the most effective use of funds.

Given that an objective of the future model will be to assist as many carers as possible, it will be necessary to identify those carers who will require a higher level of support so as to target Government assistance for those most in need.

Guiding Principles

To ensure that the design and development of the new integrated carer support service system is focussed on achieving its stated objective, the following design principles have been developed through consultation with stakeholders. These principles are intended to provide a way for the programme to weigh progress and direction of design through the process. *An accessible version of this model is provided at [Annex E](#).*



B. THE DRAFT SERVICE CONCEPT

The draft Service Concept proposes eight services as outlined in the table below.

Support	Description	National Service Delivery	Local Service Delivery
Awareness	Find carers, particularly those most often overlooked, through outreach, partnerships and co-located services, and encourage their use of available interventions	✓	✓
Information	Provide carer-focused information about their situation and availability of carer services. Assist carers to identify appropriate next steps.	✓	✓
Intake	Conduct carer intake, by capturing a set of information to assist in connecting a carer to locally delivered services.	✓	✓
Education	Education and training programmes aimed at increasing a carer's knowledge, educating them about the resources available and teaching skills (e.g. problem solving, lifting techniques)	✓	✓
Peer Support	Connect carers to provide informal support networks through relationship building and shared experiences between carers with similar circumstances.	✓	✓
A multi-component intervention	Deliver a single package of interventions (including carer mentoring, financial support³ and respite support) tailored to the needs of the carer.		✓
Counselling	Individual and/or group counselling sessions.	✓	✓
Needs identification and planning	Gather information about a carer's situation, and assist them with planning their personal and service-based supports.	✓	✓


Channels are the means by which customers receive and access services. Examples include via a website, telephone, social media, face to face, etc. The precise channels by which the proposed supports will be delivered will be designed in the next phase of design.

Therefore, for the purposes of this document, the proposed services are described in terms of their geographical access i.e. local or national. For example, peer support is envisioned to be offered on both a local and national level. On a local level, a carer may obtain peer support through a group in their local community. Alternatively, at a national level, they may participate in an online forum or via social media. An overview of the concept is provided as follows.

³ While access to multi-component support is proposed to occur at a local level, financial support may be delivered through national infrastructure such as standard Australian Government payment systems.

Service Concept Overview

An accessible version of this overview is provided under [Annex F](#).



Supporting carers today...

Each year, the Department of Social Services spends approximately...

\$170 million on carer support services through 9 carer support programmes

With this, we help...








177,069 carers

But carers usually seek support services only at the point they are in a crisis or an emergency has arisen.

Some fast facts...

- There are **2.7 million carers** in Australia. That means that approximately 1 in 8 people are carers.
- Approximately **one third of carers** do not report strain or negative effects associated with caring.
- However, up to **38% of carers*** cease their caring role due to strain.

The service concept seeks to shift towards a preventative model – providing more support (earlier) to more carers.

To do this we need to...	By delivering these services...	Which could be delivered...
help more people to be aware of carers around them or identify themselves as carers by raising...	 Awareness	Nationally- across the general community through mainstream marketing and media. Locally- through outreach to target specific groups who require direct engagement.
help carers find what they need to know through...	 Information	Nationally- through national platforms such as a phone or website. Locally- through phone or face to face as part of needs identification and planning, tailored to carers' individual circumstances.
enable carers to connect with supports (where required) through...	 Intake	Nationally- through phone or self-service via a website. Locally- facilitated through organisations in local areas for those carers are not able to, or where it is not appropriate for them, to use national platforms.
empower carers with more confidence in their skills to care and to look after their own health and wellbeing through...	 Education	Nationally- through a website or e-learning platform, with phone based support. Locally- through face to face education programmes.
help carers to connect with each other to expand their informal support network and learn from the experiences of others through...	 Peer Support	Nationally- through a national platform such as online discussion boards or 'group finder'. Locally- connecting carers at a local/regional level to groups with similar experiences or interests.
guide carers with identifying their needs and plans, and helping to problem solve...	 Needs Identification & Planning Support	Nationally- through carer self-assessment and planning tools online. Locally- telephone or face to face planning and needs identification with a qualified staff member.
provide practical and emotional support and advice for carers...	 Counselling	Nationally- through channels such as webchat or telephone. Locally- through individual or group sessions in face to face settings.


combine supports to maximise their effectiveness and increase uptake for supports with long term benefits...

provide access to someone to help with advice and support to help carers achieve their goals


assist carers to take breaks and to respond to emergencies...

empower carers to select supports and services of benefit to them in their caring role...


Delivered together

 Carer Mentoring

Locally- through phone or face to face support from a qualified staff member.

 Respite Support

Locally- through phone based support to assist in accessing respite services, on both a planned and emergency basis.

 Financial Support

National- delivered via national system but accompanied and coordinated through locally based support services (mentoring and respite support).

* Please note version 1 of this service concept incorrectly stated 58% instead of 38%.

Version: 2

Awareness

The objective of awareness is to find carers; particularly hidden carers, through outreach, partnerships and co-located services, and encourage their use of available interventions.



This task is made more challenging by the fact that the majority (79%) of carers do not necessarily see caring as their primary responsibility (AMR Australia, 2015). This was echoed by both the SME Working Group and the Carer Working Groups who identified that improved awareness of who carers are, must be a focus in awareness raising efforts. The success of the new integrated carer support service will

be dependent on reaching these carers (and following that, encouraging their uptake of the available interventions).

In their comparative review of the long term care systems in the United States of America (USA) and Germany, Gibson and Redfoot (2007) found only relatively small proportions of carers use the supportive services that are available in both countries. The review highlighted the difficulties encouraging family carers to participate in training opportunities, which are free of charge in Germany. Gibson and Redfoot (2007) concluded outreach, “user-friendly” information and referral services are imperative (Gibson & Redfoot, 2007).

Awareness has broader benefits. By increasing the total population’s general awareness of carers (as opposed to a more limited focus on the care recipient), the National Family Carer Support Programme (US) has helped identify carers as legitimate consumers of community services (Feinberg & Newman, 2004).

In terms of awareness raising tactics, the Carer Service Development Research (AMR Australia, 2015) found carers prefer multiple sources: a Google search is seen as the main channel (56%), followed by health professionals (55%). Given the critical role the General Practitioner (GP) plays in the life of the carer, their recommendation would be highly valued (89.5% of carers visit their GP at least once every 12 months: 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2012). However, feedback from the SME Working Group and the Carer Working Groups indicated that health professionals can be difficult to reach. They attributed this to the large amounts of information health professionals receive and the difficulty in achieving awareness when competing with other priorities.

Improved awareness within the broader health sector was echoed in co-design workshops. Participants of the Carer Working Group indicated they would have liked more direction on what they could expect, at the time at which their caring role commenced. This was

commonly within the context of medical setting necessitated by either an unexpected event or a medical diagnosis.

Hospitals also create an environment where carers would be most receptive to the service. Mass media (radio and TV) would also be beneficial; ensuring a broad group of carers could be reached as carers spend a significant amount of time in the home.

In addition to the primary channels outlined above, there was also a need identified to ensure awareness raising efforts also occur in local communities through engagement and education. This is particularly relevant for the need to raise awareness to find hidden carers and reach Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities. For the latter two cohorts, awareness will need to be raised through education and by establishing relationships with community leaders or other cultural organisations in the area. Similar methods may also be required for carers in rural remote areas. Winterton and Warbuton (2011) highlight that issues of isolation are intensified for carers in rural and remote settings, where carers may not feel they can trust services (where available). This is commonly related to the reluctance of people in rural settings to seek assistance from those outside of their own communities.

Design Considerations

- If the proposed model is to achieve a preventative focus, it will be important to identify carers early in their caring journey and connect them to potential supports. For many carers, this occurs within a healthcare setting, where the person they are looking after may be diagnosed with a condition. The challenge in doing so is that carers are commonly focussed on the needs of the care recipient, rather than how they will manage their new role. For example, a study involving the delivery of carer focussed information in a written format within a healthcare setting led to carers overlooking important information which may be of benefit to them (Grande, Austin, Ewing, O'Leary, & Roberts, 2015). This sentiment was reiterated by the Carer Working Group where carers in the group expressed that brochures were simply put in a drawer and not reviewed unless it was of benefit to them at the time. Given this, what would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?
- A key group of carers for whom awareness will need to be targeted is young carers. Young carers include unpaid carers who range from young children to teenagers (4-17 years) and young adults aged 18 to 24. Purcal and Co (2012) argue that the most desirable service goal for young carers is prevention. A primary facet of this involves identification of young carers as early as possible by health/disability services, particularly if formal services may not be adequate to negate the need for a caring responsibility to arise or become entrenched. In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner? Purcal and Co (2012) suggest that a more holistic approach to whole of family support should be taken from the outset within the health care setting. While schools are a potential point of identification, they

may only identify young carers once they have become entrenched, such as where absences are observed or academic performance lowers. If this is the case, should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools?

Information provision

The objective of an information provision service is to provide carer-focused information about their situation, availability of carer support, and assistance for carers to identify appropriate next steps.

The research is fairly clear that the provision of information alone, whether written or verbal, is not particularly effective (Eager et al 2007; Smith et al 2009 - as cited in Urbis Australia, 2013). While information can contribute to carers' knowledge there is little evidence to suggest that better knowledge led to any other types of improved carer outcomes.

"One cannot make meaningful decisions about one's caregiving situation unless adequate and complete information is available."

(Whittier, Coon, & Aaker, 2001)



Knowing that help is available is fundamental to the new integrated carer support service. Especially when considered in light of the Australian Bureau of Statistics services (2012) findings that estimated 8.5% of the 769,800 primary carers were unaware of their entitlements - that's over 65,000 carers potentially missing out on the benefits of support.

However, it is important to note that the need for information goes beyond how and where to get help. Information regarding health conditions and their implications, care needs, costs of care, and how to plan for future care needs is also important for carers (Feinberg, 1997 as cited in Whittier, Coon, & Aaker, 2001). Co-design workshop participants supported the need for this type of information and also identified that information on topics such as managing stress and fatigue, wellbeing, positives of caring, how to access services/supports, coping with grief and change was critical. The latter was highlighted as being particularly important for carers who are looking after someone with a terminal illness.

Parker, Mills, & Abbey (2008) also found that information can be more effective if delivered within the context of an education or psycho-educational programme and is best provided on an ongoing basis, with specific information about services and advice regarding carers'

developing or changing role. This was supported by the feedback from co-design workshop participants that carers often faced information ‘overload’ and that, in order to be effective, information had to be targeted to the carer’s circumstances and the point at which the person is in their carer journey. For example, the needs of a person who has just started their caring role is quite different to a person where their caring role is coming to an end.

In the context of the future integrated carer support service, the objective of information provision is threefold:

- Contribute to the carer population’s understanding of available entitlements/services;
- Contribute to a carer’s individual knowledge of their unique situation; and
- Complement other interventions, such as carer mentoring and education.

Design Considerations

- Feedback from co-design participants to date has indicated that information provision must be tailored to a carer’s individual situation or it is of limited value. While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?

Intake

The objective of intake is to connect carers to services and supports, particularly from national infrastructure, by collecting basic information. This includes:

- Capturing the carer's contact and basic demographic information;
- Recording a snapshot of the carer's circumstances; and
- Determining whether the carer requires an urgent service response.

Intake is a process used in the current service landscape. It provides a mechanism for carer support organisations to prioritise their workloads and responses for carers to those who have the highest need. In this way, initial contact with carers is not protracted but is aimed at capturing the information required to determine who is best placed to assist the carer in relation to needs identification and planning.

In co-design workshops, preferences among carer participants were split, with some carers indicating they would prefer to self-manage this task, for example through an online channel. Other carers highlighted they would seek to do this via telephone or other human interaction.

Design Considerations

- Intake is intended solely to be a service which facilitates access to certain supports. As it involves the collection of information, it does not generally offer carers an immediate benefit in exchange for the provision of this information. Given this, are there ways to make intake a more beneficial process for carers? For example, carers and organisations assisting carers today have indicated how important having plans in place is to carers, that it provides a sense of certainty and relief. In undertaking intake (either through phone or self-service online) carers could opt to register their emergency plans with the service so that in the event of an emergency, information can be readily accessed to deliver respite support.
- Another way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is necessary. For example, to what extent would intake be required to facilitate access to peer support or education? While it will be important as part of the future service to measure outcomes of the interventions developed so as to build upon and improve their delivery, this additional administrative burden may represent a barrier to people otherwise accessing these services. Given this, when should intake be a mandatory process?

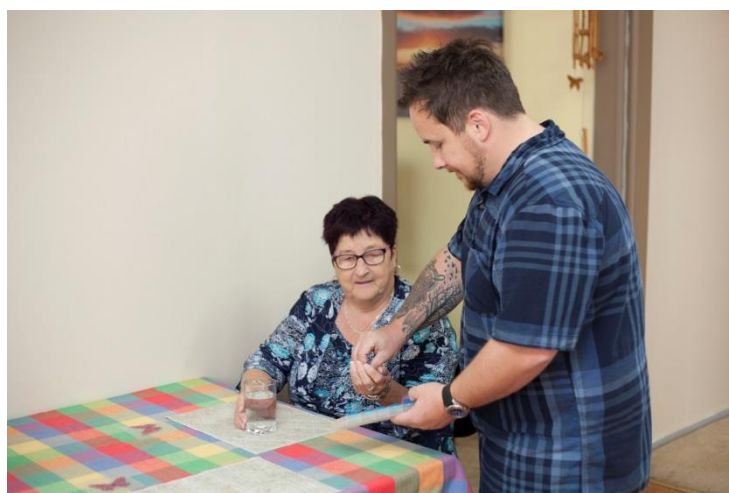
Education

The objective of the education intervention

The objective of education is to improve a carer's social and psychological outcomes through delivery of an education and training programme aimed at increasing their knowledge related to their specific caring role. This may include learning about a specific condition or care need, educating them about the resources available and teaching them specific coping skills for managing common emotional and/or behavioural problems associated with providing care.

The evidence for education as an intervention

In their meta-review of 34 research papers (the papers remaining after applying their inclusion/exclusion criteria to an initial set of 11,009 papers), Parker et al (2010) found the



strongest evidence of effectiveness of any sort was in relation to education, training and information for carers. They found interventions of this type, particularly when active and targeted rather than passive and generic, increase carers' knowledge and abilities as carers. There was some suggestion that this might also improve carers' mental health or their coping.

There was consensus among co-design workshop participants that nationally consistent education resources and programmes would be beneficial and improve the likely uptake of this support. Suggested topics included education on being a carer such as resilience and mindfulness, as well as education about delivery of care. Topics about caring included accessing available supports, caring for people with specific conditions and practical techniques for caring (e.g. lifting techniques).

Carers view their individual situations as complex, unique and very different to other carers. Carers are concerned (as reported in the Carer Service Development Research (2015) that the service would not offer anything specific to their situation. The challenge will be delivering education and counselling interventions specific to the needs of the carer cohorts - without the interventions becoming over specialized and too varied to support economies of scale.

Co-design workshop participants highlighted that education did, in some cases, require access to respite so that carers are able to participate in education sessions. This was particularly relevant for face to face education delivery.

An example of an education intervention is provided at [Annex G](#).

Design Considerations

- As stated earlier, research suggests that carers may be more inclined to accessing services they report high satisfaction with such as respite. However, education programmes commonly provide longer term benefits to carers. Carers report they are commonly time poor and dedicating time to undertaking an education programme may not be perceived as helpful by carers. Given this, how can we encourage carers to access education support?
- While online education is a cost effective and efficient way to deliver education programmes, research suggests that achieving high completion rates can be challenging. If education were to be offered online, how can we encourage carers to participate and complete an education programme?
- There are many organisations who run education programmes for carers funded through programmes outside of the Department's carer support funding and will continue to do so in a future model. Given this, how can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?

Peer Support

The objective of peer support

The objective of peer support is to assist carers to connect with other carers with a similar experience, broadening their informal support network and providing a way to reduce the isolation reported for many carers.

The evidence for peer support as an intervention

Parker, Mills, & Abbey (2008) on the factors that should shape the design of an effective intervention model:

“Factors which do not appear to have benefit in interventions are those which:

- Simply refer carers to support groups;
- Only provide self-help materials; or
- Only offer peer support.”

Strong feedback has been received through the co-design workshops and through the Current State Analysis that peer support should be included in a future support model. Co design workshop participants reported that peer support assisted carers by broadening their informal support network, providing an opportunity for social interaction and in some cases, a period of respite.

The consumer research conducted by AMR Australia (2015) also indicated that carers were looking for this service. Carers surveyed said their responsibilities led to isolation, this was particularly relevant for carers of Culturally and Linguistically Diverse (CALD) backgrounds.

Design Considerations

- What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner? Currently, some models of peer support involve use of professional facilitators or guest speakers. Implementing these models nationally may be too high in cost to sustain in the longer term. Given this, how can a peer support model be designed which encourage carers to participate and remain engaged?
- The evidence above suggests that peer support groups, when used as a standalone intervention, may not be particularly effective. However, peer support may provide a way for carers to connect with the Integrated Carer Support Service in a less formal way. For example, a carer may first join an online forum before deciding whether to proceed to seek more help. Peer support, when used in this way, may help encourage people to engage more using channels such as social media. Consultations to date have highlighted this may be beneficial in reaching those carers who may not have otherwise have sought formal support such as young carers and Aboriginal and/or Torres Strait Islander carers. Should peer support be a service able to be accessed without pre-conditions or structure processes?

Needs Identification and Planning

The objective of this service is to assist carers by identifying unmet needs and providing aid in planning informal and formal supports. This process should seek to:

- Apply preventative thinking to carer supports by identifying actions which will assist in avoiding a crisis that might adversely affect or end the caring role; and
- Improve the carer's wider well-being as individuals in their own right (e.g. breaks, support to access employment).

Needs identification also ensures interventions are targeted at those carers in need of more intensive support. Planning was reported by co-design workshop participants as being highly important for carers and something they were seeking assistance with, particularly early in their caring journey. This highlighted too, that planning was not limited to planning of formal services but areas



of practical need such as accessing government supports, developing an emergency care plan, planning for legal documentation such as Power of Attorney and health service visits.

Beyond this assistance, and in recognition of the limited funding pool, there is a need to target the delivery of multicomponent interventions to those carers most in need of support (and also ensuring equality of access for all carers).

The objective of needs identification is to gather information about a carer's situation, and identify the factors that indicate a need for more intensive support services. This is an activity which is undertaken commonly by carer support services today, albeit not in a consistent manner.

The challenge will be balancing the need to target those most in need of support (or most likely to need more intensive support in the future) with a growing body of evidence that suggests early intervention may reduce the use of more costly and crisis services such as respite and residential care.

If the interventions described above would be made available to every one of Australia's 2.7 million carers the cost alone of the proposed counselling intervention would exceed \$1 billion⁴. This would not represent an effective use of funds on the basis that not all

⁴ From Principal Investigator, Mary Mittelman on the cost of delivering the NYU Caregiver Counselling and Support Intervention "We know that the programme for 406 recipient was implemented by 4 counsellors, each working 0.6 time (or 2.4 full time equivalent counsellors) each with Masters degrees in a health area such as social work. If each counsellor earned \$65,000 a year, the programme would cost $(\$65,000 \times 2.4) / 406 = \385 per recipient per year.

carers need support and it is unclear whether interventions designed to prevent the development of negative outcomes (such as depressive symptoms or unhealthy lifestyle behaviours) are useful and/or cost-effective (Coon & Evans, 2009).

However, there is evidence that self-assessment approaches are also beneficial. A trial of the Carer Support Needs Assessment Tool (CSNAT) involved caregiver led identification of needs through either self-completion or completed jointly with the support worker. Common outcomes of the tool involved provision of information, counselling, education and options for respite. The latter included discussing options for time out such as through family rosters, volunteers and using a personal alarm. The study concluded the use of this intervention resulted in a significant reduction in caregiver strain (Aoun, et al., 2015).

This approach of empowering carers to identify their own needs is consistent with consumer directed care models. From a conceptual perspective, consumer direction is defined as a way of enhancing individuals' autonomy over the care or support they receive (Howe, 2003). Embedding this philosophy within the needs identification and planning process seeks to empower carers in planning both formal and informal supports. Further discussion on consumer direction is included under Financial Support.

Design Considerations

- To what extent do you think goal based planning should be used at the assessment stage of the process? Goal based assessment and planning approaches are common to Consumer Directed Care principles, usually in conjunction with a funded package or financial allocation of some form. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?
- To what extent should self-assessment form part of the future model?

A multicomponent intervention

"The multicomponent studies category was defined to include two or more conceptually different approaches that have been woven into one intervention package. For example, an intervention that combines skill building with ongoing support group involvement, respite, family counselling, or technological equipment would be included in this category."

(Gallagher-Thompson & Evans, 2009).

The objective of a multicomponent intervention

The objective of the multicomponent intervention is to improve a carer's financial, social and psychological outcomes by delivering a combination (personalised to the carer) of interventions at multiple points during the caregiving journey.

The proposed multicomponent intervention has three components:

- Financial support
- Carer mentoring
- Respite support

The evidence for multicomponent interventions

In their review of studies from 1980 through 2005, Gallagher-Thompson & Evans (2009) found that programmes targeting specific components of carers' quality of life (such as perceived burden) and that include some combination of skill building, education, and support are currently the most effective interventions.

This is corroborated by a number of studies that show services that appear to hold the most promise in helping carers are those that use a variety of interventions and address multiple



points in the caregiving process that produce family stress (Pinquart & Sörensen, 2006; Gallagher-Thompson & Coon, 2007).

Co-design workshop participants raised concerns relating to multicomponent interventions only being made available to some carers. Workshop participants felt all carers could benefit from the services contained within (e.g. mentoring or flexible financial support package).

They also highlighted that if the aim was to assist carers to prevent a crisis through early intervention, carers could benefit from such supports at any time, rather than at the point they had a higher level of need.

Two examples of multicomponent interventions are provided at [Annex G](#).

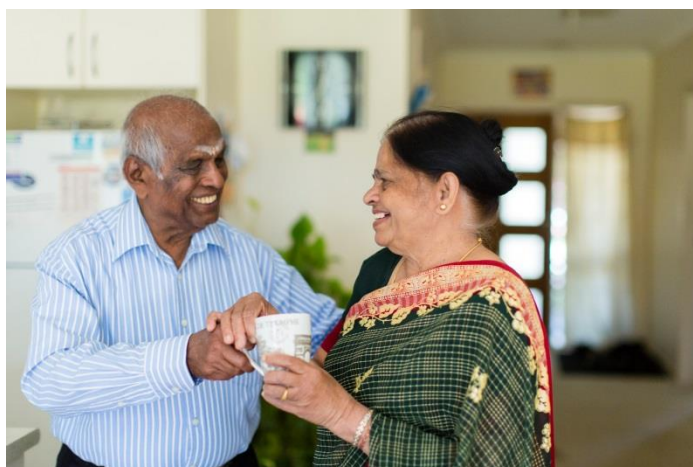
Design Considerations

- Multi-component support seeks to amplify the effects of the supports by combining them. While all carers could benefit from these supports, funding will not extend to providing this type of support to all carers. Given that this model is seeking to apply preventative thinking, how can we ensure these supports are allocated to those carers who will benefit the most from them? What should be the criteria by which this is determined?

The three supports proposed to be available under the multi-component intervention are outlined as follows.

1. Multi-component Support: Financial Support

Parker, Mills, & Abbey (2008) highlight the different priorities of outcomes of interventions from caregivers and health professionals. Top priorities for caregivers were improvements on outcomes and interventions that improved quality of life and provided practical assistance (e.g. relief from household and other duties that prevent carers from fulfilling their caring responsibilities). In contrast, health professionals identified psychological



outcome such as depression and subjective burden.

This gap can be bridged through the provision of financial support which can be directed towards practical supports a carer values. In doing so, this creates a link between a carer's top priority and raising awareness of other interventions (e.g. education and mentoring) that have demonstrated ability to

improve carer outcomes. The expectation is that with advice and support received through mentoring, carers will be able to direct this financial support to paying for practical support to assist them in their caring role (e.g. cleaning, respite, cooking, assistance with transport). It is not the intention that financial support under this model would replace income support payments accessed through the Department of Human Services. The purpose of income

support payments is to provide Australian citizens with a minimum acceptable standard of living.

Financial support in the form of direct cash payments can be seen as contributing to the wider health and social care movement of consumer direction - that is, empowering people to have more say and control in the management of their own care. This was considered a high priority for co-design workshop participants who viewed the flexibility to direct funds to whatever provided relief for that carer (i.e. indirect respite) as valid.

Consumer directed support takes a number of forms and its scope varies from programme to programme. In its most limited scope, consumer direction is about having increased choice and say in care and support arrangements. Most commonly consumer direction involves the provision of a benefit, either in the form of direct cash payments or as a funding package which a provider then administers at the direction of the consumer (Howe, 2003). The evidence is not clear on whether either approach produces better outcomes however, a number of models are in use globally. The models differ widely based upon:

- eligibility criteria (both financial and functional);
- the number of eligible individuals;
- the range of services available to be accessed (the majority involving personal assistance);
- whether relatives can be hired and paid using the funds;
- options for combining varying levels of cash and services (as opposed to a fully cashed out model);
- the amounts received; and
- quality assurance controls and provisions (Howe, 2003).

However, consumer directed care has been demonstrated to have a positive effect on carers in both the literature and anecdotally. The positive effect on carers was evident in the Consumer Directed Respite Care (CDRC) pilot. In their review of the pilot KMPG (Evaluation of the consumer - directed care initiative, 2012) found:

- Even after a short period of operation, CDRC had a considerable positive impact on carers. Many participants felt their capacity to continue in their caring had increased since commencing on the package, and for many having a package gave them a chance to put energy back into their caring role.
- Almost without exception, participants felt the package enabled them to do many of the things they wanted to do or achieve.
- There was a considerable positive impact on carers' participation in social and community activities, their home life and close relationships, level of independence, and health and wellbeing. Participants also experienced an increased 'sense of self', and a sense of greater wellbeing. However, using a validated measure of wellbeing,

there was no statistically significant difference between the CDRC participant group and carers accessing supports through NRCP.

It needs to be noted, however, that during the period of the evaluation participants had access to a full annual package amount (\$4,200) – to be spent in six months or less - and this is likely to have had an impact on the scale of benefits experienced by CDRC participants.

In Alzheimer's Australia's (2013) respite review policy paper, it was highlighted that there were two main mechanisms for furthering consumer direction in relation to respite. One included promoting good practice in the delivery of respite and the second recommended direct cash payments to allow carers to pay family and friends to provide substitute care. This is one way which financial support could be directed towards supports which are meaningful for a carer. Further, it was recommended that direct cash payments be trialled based on consultations with both providers and consumers.

[The need to support recipients of direct payments](#)

Financial support could be delivered in the form of direct cash payments accompanied by information and training on related issues (e.g. financial planning, understanding of needs, and awareness of available services) to maximise its effectiveness in supporting carers.

Evidence shows that direct payments better improve carer outcomes when associated with a support service such as mentoring (in the absence of a support service, carers have reported increased stress levels associated with direct payments).

On top of already heavy caring responsibilities, carers may not always be comfortable with, or able to take on, additional tasks such as carer coordination and budget management. This was echoed by some of the carers who participated in the co-design workshops. In contrast, other co-design participants felt positively about a direct payment concept as it acknowledges the carer in their own right while providing them with a level of control over the supports available to them.

Findings from United Kingdom (UK) research into direct payment schemes suggest they can have positive effects on carers and families if they are sufficiently involved in assessment processes (including assessments of their own needs), have access to the right information and advice, and have access to support and specialist services (Carr, 2009).

The Carers UK review of the UK direct payment scheme (introduced in 1997) concluded that without this support the additional responsibilities can overwhelm carers and their families.

"Our survey shows direct payments have enormous potential to improve carers' lives, offering more freedom, control and choice.

However, for the scheme to truly work, carers need adequate support to ensure direct payments do not simply become an additional administrative burden, on top of the existing 'workload' of their caring responsibilities. Our survey demonstrates that for some families, becoming a 'small business can be overwhelming. Without support, problems arise and instead of transforming lives, direct payments can cause added stress, work and make the situation worse."

Choice or chore for carers? 13 November 2008

In their review of the UK direct payment scheme, Carers UK found more than half of those carers questioned reported their overall experience of the scheme was positive, with almost three quarters stating that the care they are able to purchase is better at meeting their family's needs than the previous service.

However, nearly one in ten reported a negative experience of the scheme. Key for many was the lack of support available to help them manage the money, causing added stress, worry and feelings of being overwhelmed. And many (21%) carers say they have less free time since taking on a direct payment because of the time needed every week to deal with insurance, tax, training and all the other aspects of employing someone.

The findings of the Carers UK survey highlight the success of social care reforms such as direct payments is heavily reliant on the ability to support carers. In the case of direct payment schemes these support services include: payroll services, training in employment law, recruitment and employment support.

Design Considerations

- In her early paper on Consumer Directed Care approaches, Howe (2003) notes that where funding allocated to individuals as part of a financial support package is not high (as opposed to some disability packages being in the tens of thousands), the overhead and administrative cost may not be worthwhile to put in place accountability measures for individuals to demonstrate how funds were spent. While some carers as part of the research undertaken have indicated they would be happy to manage a package, others in older demographics have indicated this would be yet another burden. Some carers have openly indicated that if there were no controls applied to these funds, they would have spent the funding on the person they cared for, rather than on supports to help them as a carer. How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?

2. Multi-component Support: Carer Mentoring

Mentoring is a programme comprising individual (in-home) sessions accompanied by ongoing support (telephone based).

The purpose is to help carers learn skills and techniques that will better assist them in their caring role. The relationship formed between a mentor and carer would be one of a close working partnership, the intention being that the mentor helps the carer discover their own answers.

While the term 'mentor' suggests a peer led programme, the intention for this service is to provide a coaching-style service delivered by qualified support staff. In this context, mentoring is intended to be a goal-based coaching programme, focussed on identifying the goals, desires and objectives of the carer.



The concept builds on the positive findings in the review of CDRC pilot (KPMG, 2012). The review identified considerable benefits for carers from being able to plan supports in advance, and from simply being involved in the planning process. For many carers, they felt they were being recognised and valued as carers – often for the first time.

As was seen in CDRC pilot, the relationship with the mentor will be particularly important to the success of the intervention. The strength of this relationship (and the effectiveness of the mentor's skills) will help carers in building their capacity to self-identify needs and goals, building their capacity to self-manage, and receiving emotional support and advice on a wide range of issues related to their caring.

The concept was supported by co-design workshop participants who recognised this occurs in an informal sense through some support organisations today. This service was originally envisioned as a 'coaching' support programme however, feedback obtained related most strongly to the term 'coaching' as carers did not see this term as reflective of the partnership-style relationship they were seeking. Other feedback related to the delivery of the service such as the need to ensure those delivering this service are appropriately trained, that it is available via multiple channels and that it is appropriate to the type of carer being supported (i.e. young carers).

Design Considerations

- It is evident from our research and from consultation with carers and organisations that carers' needs vary over time. This service is intended to provide carers with goal based planning and coaching support. Coaching programmes are normally funded for a time-limited period such as the Stronger Carers Programme 10 week programme or beyondblue's New Access Coaching Service. When would a coaching programme be most effective for a carer?
- Some carers may not want a coaching programme which extends over time, despite the potential benefits, preferring only intermittent contact when they feel they need it. Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors should be able to determine whether the carer has the capacity to forgo coaching until another time?

3. Multi-component Support: Respite support service

Respite support is focused on assisting carers to plan for the use of, and facilitate access to, respite services in a planned or emergency situation.

High levels of carer satisfaction with respite services

Carer satisfaction is generally high for respite services and carers report significant increases in peace of mind knowing that it is available (Association of Directors of Adult Social Services, 2010).

In a survey of National Respite and Counselling Programme users, Campbell Research and Consulted (as reported in Howe, 2013) asked respondents whether they agreed strongly or agreed with a number of statements about respite. Of the 1,500 survey responses, 81% of carers reported that respite helped them continue caring, and 92% would recommend respite to others. Almost as many reported that respite was also good for the person they were caring for (79%) and over two thirds reported the care recipient was happy with use of respite.

Low levels of uptake for respite services

Despite the high levels of satisfaction, uptake (by carers) is low with only 10.7% of primary carers reported as using respite services (Australian Bureau of Statistics, 2012).

Howe (2013) identified two contributing factors:

1. Difficulty in navigating the system. Many carers found coordinating and arranging services complicated due to the multi-programme structure and the lack of standardised access requirements.
2. Lack of timely access also kept carers from using respite when they needed it. Two out of three respondents to the on-line survey (234 responses) had this experience. Waiting times for booked respite varied considerably, from two weeks to six weeks.

A third factor identified through our current state analysis (Department of Social Services, 2015) is the difficulties in finding available respite services. One organisation described five officers being assigned to assist in finding an available respite bed in an emergency, an activity which can take some hours. There was also sometimes reticence on behalf of the person they care for to receive respite care.

Lack of evidence to demonstrate the effectiveness of respite

There is a lack of quality evidence that respite services effectively reduce carer burden and mental and physical health problems (Lawton et al 1989; Eager et al 2007; Shaw et al 2009; Mason et al 2007; Stolz et al 2004; Lee & Cameron 2008 as cited in Urbis Australia, 2013).

In a review (Mason, 2007) to determine the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, no reliable evidence was found that respite care either delays entry to residential care or adversely affects frail older people. For all types of respite, the effects upon carers were generally small with better-controlled studies finding modest benefits only for certain subgroups. However, many studies reported high levels of carer satisfaction.

Barber (2013) points to research that provides evidence indicating the use of respite services can alleviate carer burden, and enable families to continue providing care in the home and avoiding or delaying institutionalisation. Yet the effectiveness is highly dependent on the timing and the type of respite care services being provided, and Barber suggests the respite interventions are most effective if provided early on before the strains of caregiving deplete the carers' reserves and resources.

Respite in a future service system

Given the Government's significant investment in respite, the objective of this service in this context, is to provide carers with the advice and support needed to ensure its effectiveness. The specific functions of the support would likely include:

1. Respite planning - assisting the carer to identify suitable respite services and plan for their future use.
2. Respite booking - assisting the carer to identify and book available respite services.
3. Respite support - supporting carers to overcome reluctance or resistance on the part of the care recipient to receive care and teaching techniques to cope with separation issues such as stress and guilt.

The inclusion of respite support in a multicomponent intervention is consistent with good practice in respite (Howe 2013).

Co-design workshop participants raised some concerns around the limitation of this service to carers with a particular level of need, as respite can be viewed as an early intervention support. Further, they highlighted that this service reflected a traditional view of direct respite services.

In relation to the utilisation of this service in an emergency, co-design workshop participants felt this needed to be a standalone service for these instances. While the service remains the same, it is acknowledged there will need to be a direct pathway for emergency respite support which is not immediately paired with a multicomponent intervention.

Design Considerations

- The inclusion of respite support within a multi-component support package is consistent with recommendations arising from the literature. A number of carer organisations have reported anecdotally that more flexible responses such as brokered respite, have resulted in longer term outcomes. It is for this reason that this service is proposed to be coupled with financial support, as a form of consumer directed respite and coaching. This could mean a shift towards using respite as a complementary, not primary support. Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects? What might these be and how can they be mitigated?

Counselling

The objective of the counselling intervention

Improve a carer's psychological outcomes through delivery of traditional psychotherapy individual and/or group sessions, such as the Cognitive Behavioural Therapy (CBT).

An example of a CBT intervention described at [Annex G](#).

The evidence for counselling as an intervention

The Carer Service Development Research (AMR Australia, 2015) and Current State Analysis (Department of Social Services, 2015) both found counselling to be essential in providing carers with much needed emotional support. Counselling can be delivered via a multitude of means including telephone, face to face counselling and via video/web conferencing (e.g. Skype). Some organisations interviewed were contracted to provide counselling across States with large areas classed as rural or remote (e.g. Western Australia). These organisations reported carers were receptive to counselling via telephone or video/web conferencing and considered this to be a cost effective mechanism of providing counselling at a time that was convenient to the carer.

These observations are supported by the evidence base. Gallagher-Thompson & Evans (2009) found counselling delivered the most effective interventions for carers, with outcomes focused on symptoms of psychological distress—notably, depression and anxiety.

It is important to note the effectiveness of counselling interventions in Randomized Control Treatments may be tempered when implemented in community settings. This is borne out in the experiences implementing the New York University School of Medicine's Alzheimer's Disease Centre counselling intervention (refer to [Annex G](#)).

Many communities have faced resistance from carers to accept help from others in the form of counselling (both individual and family counselling sessions) (Mittleman, 2009). This is particularly relevant where there are cultural or religious sensitivities to accessing this.



This sentiment was echoed in our interactions with carers as part of co-design workshops. Some carers expressed that they had thought accessing services such as counselling was tantamount to 'admitting defeat' and a failure to provide adequate care. A number of

participants who had held this view had gone on to utilise counselling services. They reported that they had not immediately accessed the service but wished they had done so earlier as it had proven to be a valuable support in the time to come. There was strong consensus among both workshop groups that improved education about the benefits of counselling was required to encourage more carers to access the service.

In relation to online delivery methods for counselling, feedback raised during co-design and the Current State analysis has elicited advantages (anonymity, increased ability to specialise and deliver outside normal access hours, potential to reach more carers) and disadvantages (a lesser degree of trust built through face to face contact, less opportunity for an ongoing clinical relationship outside of the service).

Design Considerations

- While counselling has been shown to be highly effective at reducing carer strain, delivery of counselling to large numbers of carers is challenging due to the resources involved. Similar challenges are being faced in the mental health sector where many people who would benefit from counselling are unable to access the service due to long waiting lists and high costs. Comparative research of delivery modalities (i.e. telephone counselling versus online programmes) has demonstrated that digital and telephone counselling are as effective as face to face counselling. Utilisation of lower cost channels such as telephone or online to deliver counselling will mean more carers will be able to receive counselling.
- Much of the evidence relating to effective counselling programmes for carers is focussed on CBT. What other counselling programmes and techniques would be beneficial in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?

Supporting All Carers

There are a number of carers who belong to cohorts who may require additional assistance to access the supports they require. These include young carers and carers who are Aboriginal and/or Torres Strait Islander, Culturally and Linguistically Diverse or who identify as Lesbian, Gay, Bisexual, Transgender and/or Intersex. While many considerations in supporting these cohorts relate to components of the Service Delivery Model, their individual needs and challenges are described below. These are specified to provide a further lens by which to view the services outlined within this concept.

Young Carers

There is a recognised need to support young carers to sustain their caring role and continue to develop and progress in their own right. Data from the UK, USA and Australia suggests that between two and four per cent of children and young people up to the age of 18 undertake caring tasks (Purcal, Hamilton, Thomson, & Cass, 2012). As outlined in the report by Social Policy Research Centre (2012), young carers are at risk of negative impacts from their caring role. These include difficulties in school attendance and attainment which has longer term impacts in terms of young carers' opportunities for further education, training and employment. The report highlighted that time constraints due to caring responsibilities and commonly low income household circumstances affected young carers' social lives, including their friendships and social and recreational activities. This lead to impacts on young carers' social integration, physical health and personal wellbeing (Social Policy Research Centre, 2012).



Culturally and Linguistically Diverse Carers

As highlighted by the research by AMR Australia (2015), carers from culturally and linguistically diverse communities face significant challenges in accessing support for their caring role. The complexity of the system in its current state, coupled with language and cultural barriers add to a sense of increasing isolation for these carers.

Carers from culturally and linguistically diverse backgrounds may require additional support in order to access carer supports. Some services such as Awareness and Needs Identification will need to be delivered at both a national and a local level to help address access issues for these carers. Feedback obtained through the Current State Analysis and through co-design indicates that raising awareness through community leaders is essential in order to reach carers in these communities (Department of Social Services, 2015). There is a need to ensure services are accessible in order to raise awareness, provide information and conduct needs identification at a local level where carers from these communities are not able to, or are uncomfortable accessing national infrastructure to seek support.



These are considerations for detailed service design which need to be considered further as part of the next step in the design of the Integrated Carer Support Service: the design of the service delivery model and associated policy blueprint.

Aboriginal and Torres Strait Islander Carers

As outlined earlier, Aboriginal and Torres Strait Islander carers report significant barriers in accessing support services, attributed to the numerous pathways and cultural difficulties (AMR Australia, 2015). Co-design participants highlighted that carers in this cohort are reluctant to access funded services due to their mistrust of government.

Carer support organisations who work with Aboriginal and Torres Strait Islander carers all report that trust built through relationships with elders and community leaders are the most effective mechanisms by which to identify and support carers in these communities. For this reason, there is a need to provide some services at a local level which can be more efficiently facilitated at a national level (e.g. awareness, intake, needs identification) to ensure equity in access.

Such considerations extend to other services to be provided under a future model.

Lesbian, Gay, Bisexual, Transgender and/or Intersex Carers

Lesbian, gay, bisexual, trans/gender diverse and intersex (LGBTI) people in care relationships include carers who identify as LGBTI and carers of LGBTI people. LGBTI carers look after a

range of people with a variety of care needs. They often take on a caring role for friends and 'family of choice' as well as biological family.

It is recognised by Government that LGBTI people may have experienced:

- inequitable treatment;
- stigma, family rejection and social isolation; or
- a life event or experience of fear of rejection coupled with actual or fear of discrimination.

In addition, the lack of recognition of a person's experience, identity, relationships and caring role can add additional stress within an already complex dynamic.

In designing a future service which caters to LGBTI carers, it is recognised there will need to be an understanding of these issues and a commitment to enabling the needs of LGBTI people to be understood, respected and visible through the associated services and service delivery.

Carers in Regional, Rural and Remote Settings

Carers in regional, rural and remote settings face significant challenges in their caring role. While the difficulties faced by carers in these areas are similar to those in metropolitan areas, the problems are intensified in these settings. Challenges include:

- perceived stigma for accessing respite services and admitting they need help, as resilience is commonly valued in these areas;
- fear of community members finding out the condition of the person they are caring for (particularly where this is a mental health condition) resulting in reluctance to access respite;
- a lack of access to information, particularly through limited internet connectivity;
- a lack of access to general or specialised respite services due to distance or limited availability of services in the area;
- a lack of access to services available through the broader service systems which may provide an indirect respite effect for the carer;
- limited flexibility of those services which are available; and
- increased social isolation (Winterton & Warburton, 2011).

In designing a future model, the delivery of these services will need to be flexible to ensure that rigid access channels do not prohibit these carers from accessing support they require. Options for tackling these challenges will be explored further through the design process.

Providing Integrated Support

Assistance for the person they care for

Feedback from co-design participants has highlighted that carers often seek support for the person they care for ahead of enquiring about support for their own needs.

Therefore, to ensure the service offers value for carers and can assist in connecting them to supports, the service must have connections with organisations who provide support for the person they care for. This includes:

- My Aged Care
- National Disability and Insurance Agency
- State based disability services
- Department of Veterans Affairs



The design of the service will need to include relationships with these organisations to support carers in navigating the system.

Support to Access Employment

Balancing employment whilst caring for someone, or returning to the workforce after a caring role has ended has been identified as a key challenge for carers. To assist those carers who are balancing employment and their caring responsibilities, the Integrated Carer Support Service will help with:

- advice on information on managing their responsibilities; and
- access to the supports under this model such as planning and financial support to help them achieve their goals.

For carers who are returning to the workforce after the end of their caring role, the Integrated Carer Support Service will help connect carers with mainstream employment services to access support with:

- undertaking training to return to work;
- assistance in applying for roles; and
- obtaining gainful employment.

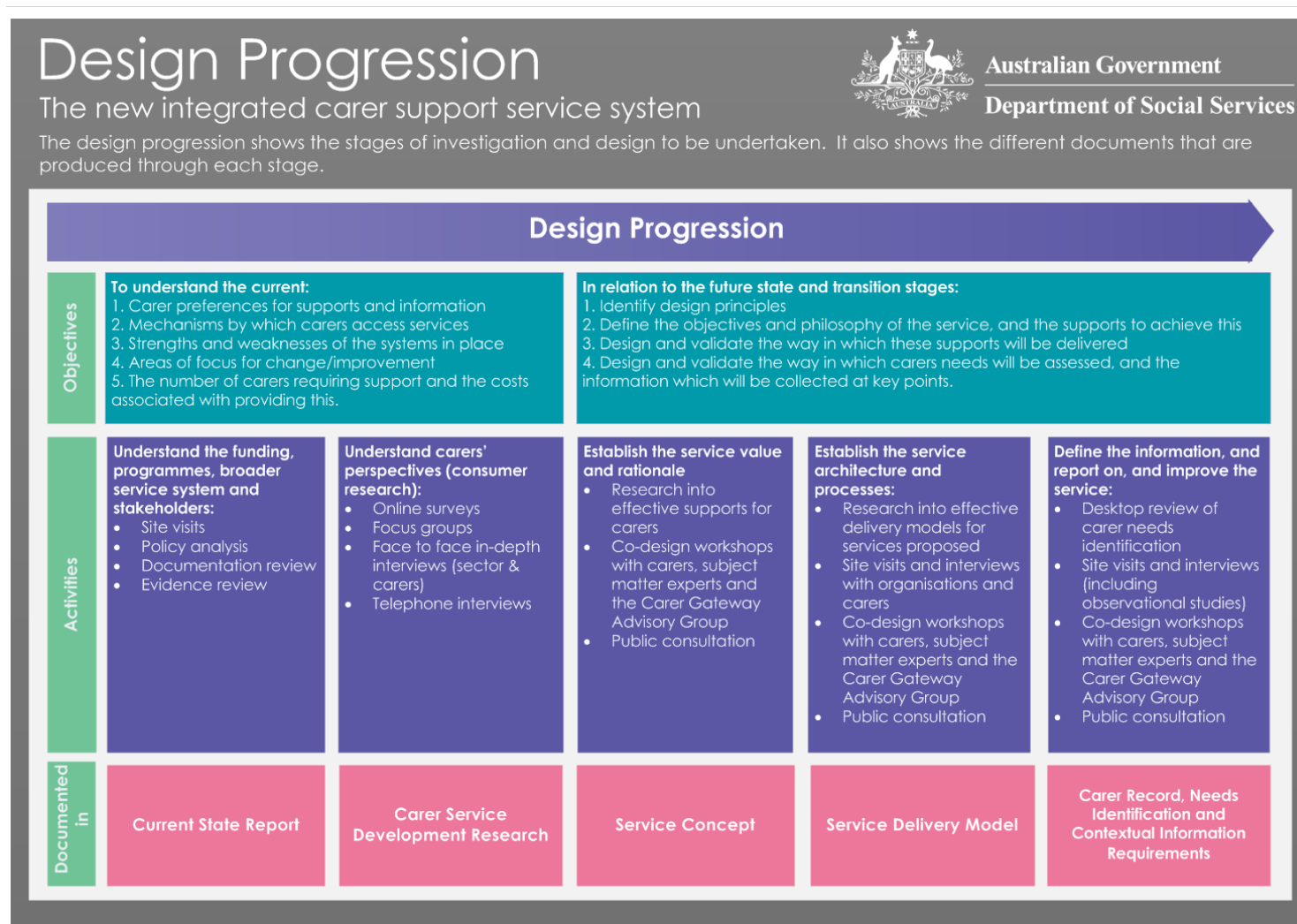
Support when caring changes or ends

It is recognised caring can, for many carers, become a primary focus of their day to day lives. With the responsibility that comes with caring, many carers are concerned largely with the needs of the person they care for, rather than planning for their own future.

There are two primary ways caring can transform; the person being cared for may move into residential care; or they may pass away. Where the person they are caring for transitions into residential care, carers may experience a range of emotions through this time, and this may add to their feelings of strain.

Where the person being cared for passes away, understandably, carers experience grief and stress. During both of these times, carers may need support, particularly emotional forms of support. However, there will need to be a balance in supporting past carers to transition from their caring role, and the need to assist current carers.

ANNEX A – Carer Support Service Design Project: Design Progression



Design Progression Overview

The design of the new integrated carer support service system has two primary phases:

1. formulate an understanding of the current state; and
2. the design of the new integrated carer support service system.

The purpose of the first phase is to understand the current:

- a. carer preferences for supports and information;
- b. mechanisms by which carers access services;
- c. strengths and weaknesses of the systems in place;
- d. areas of focus for change/improvement;
- e. the number of carers requiring support and the costs associated with providing this.

This will allow the second phase, designing what the new service should look like, to be informed through an understanding of the key people who the service will need to support, including their needs, preferences and challenges in the current environment.

Two primary activities were undertaken as part of this first stage of work:

1. A current state analysis: an examination of the current funding programmes, the context of carer supports within the broader service system and the capabilities which exist in the environment. This report was developed through site visits, policy analysis, reviews of documentation and peer reviewed evidence.
2. Carer Service Development Research aimed at understanding carer's perspectives on their needs, current supports they access and their preferences in relation to a future service.

There are a number of core objectives of the second phase, to design the new integrated carer support service system:

- a. identify the design principles;
- b. define the objectives and philosophy of the service, and the supports to achieve this;
- c. design and validate the way in which these supports will be delivered; and
- d. design and validate the way in which carers needs will be assessed, and the information which will be collected at key points.

The design principles, objectives and philosophy of the service, and the supports to meet this are outlined in this document, the **Service Concept**. The concept has been developed through research into effective supports for carers, co-design workshops with carers, subject matter experts and the Carer Gateway Advisory Group.

The way in which the supports will be delivered will be outlined in the **Service Delivery Model**. The Service Delivery Model will be developed through research into effective delivery models for the services. In addition, site visits and interviews with organisations and carers will be undertaken to seek their perspectives. Co-design workshops with carers, subject matter experts and the Carer Gateway Advisory Group will be used to develop and refine the delivery model.

Finally, the **needs identification and information requirements** of a future service will be developed through a review of carer needs identification tools and research, site visits and interviews and further co-design workshops. The Service Concept, Service Delivery Model and Information Requirements will be validated and refined through public consultation.

ANNEX B - Carer Support Programmes funded by the Department of Social Services

Programme	Target Groups	Eligibility	Service Categories	Number of Carers Supported (2014/15)	Funding Allocated (2015/16)
National Respite for Carers Programme (NRCP)	<p>The NRCP supports and assists Primary Carers of people who are unable to care for themselves because of frailty or a disability. NRCP services are targeted to assist carers of:</p> <ul style="list-style-type: none"> • Frail Aged Australians (aged 65 years and over, or aged 50 years and over if Aboriginal or Torres Strait Islander); • People with Dementia; • People with Dementia and Challenging Behaviours; • Younger People with disability (people under the age of 65 years, or under the aged of 50 years if Aboriginal or Torres Strait Islander); • People with a terminal illness requiring Palliative Care; • People with High Care Needs; and • Employed Carers. <p>Within those target populations, respite service providers must ensure their services are accessible, particularly with regards to carers of:</p> <ul style="list-style-type: none"> • People from CALD backgrounds; • People from an Indigenous background; • Care Leavers, including Forgotten Australians, former child migrants and people from the Stolen Generation; • People who live in rural or remote areas; and • People who are financially and socially disadvantaged. <p>It should be noted that not all NRCP funded services are required to cater for all NRCP target populations.</p>	<p>To be eligible for services, the carer's role must be ongoing, or likely to be ongoing, for at least six months.</p> <p>The carer must be providing care or support to a dependent family member or friend from one or more of the NRCP target groups for 'everyday types of activities'.</p> <p>The expectation of six months or more of care does not apply to a carer of someone who needs palliative care.</p>	Short term or emergency respite	59,699	\$60.298m
			National Carers Counselling Programme (NCCP)	6,461	\$4.886m
			Carer Information and Support Service (CISS)	34,152	\$3.958m
			Consumer Directed Respite Care	482	\$2.553m
Mental Health Respite: Carer Support (MHR:CS)	<p>MHR:CS identifies a number of groups of carers as facing additional disadvantage, including:</p> <ul style="list-style-type: none"> • Indigenous carers, including members of the Stolen 	To be eligible to receive services, a carer must be providing care to a person because of his/her mental illness (unless seeking support from a MHR:CS initially funded prior to 2011–12, whose client base may include up to 25 per	Mental Health Respite: Carer Support	40,644	\$63.974

Programme	Target Groups	Eligibility	Service Categories	Number of Carers Supported (2014/15)	Funding Allocated (2015/16)
	<p>Generations and Indigenous kinship carers</p> <ul style="list-style-type: none"> carers with CALD backgrounds, including humanitarian entrants and recently arrived migrants and refugees older parent carers young carers carers needing urgent assistance or support, including those at risk of homelessness carers in rural and remote communities Forgotten Australians, and lesbian, gay, bisexual, transgender and intersex carers. <p>Services are required to prioritise and actively target these special needs groups, or others identified locally, for which there are significant populations in their coverage area, or who are inadequately supported.</p>	<p>cent carers of people with intellectual disability).</p> <p>Carers must have poor physical or mental health, or other impediments, impacting their caring capacity. Highest priority will be given to carers assessed as most in need of support and without access to similar respite or carer support through other government-funded services (e.g. state disability services or the National Respite Carer Programme).</p>	Carers and work	5,243	\$1.473
Young Carers Respite and Information Services	<p>The target group for the information component of the Young Carers Programme are carers aged 25 and under.</p> <p>The target group for the respite and education support component of the Young Carers Programme are students with a significant caring role who need support to complete their secondary education. As such, under this component, a student with a significant caring role is under 18 years of age, and who is a major provider of care and support for a parent, partner, child, relative or friend with a chronic illness, disability, mental illness, alcohol or other substance dependence or who is frail aged. Assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities of communication, mobility and self-care.</p>	<p>The information component of the Young Carer Programme is open to all young carers.</p> <p>To be eligible to access Respite and Education Services, these students must be:</p> <ul style="list-style-type: none"> Completing secondary education; Completing secondary education at a vocational institution; or Primary school students and secondary carers, who also have extensive responsibilities within the family and have been assessed as struggling to complete their education because of their caring role. <p>Indications that a student with a significant caring role is struggling with the demands of school and caring include:</p> <ul style="list-style-type: none"> Frequently missing school; Having no time to complete homework; Feeling very distracted when they are at school and experiencing limited connectedness with their school community; and/or <p>Considering leaving secondary school or the equivalent education prematurely.</p>	Direct Respite	4,633	\$1.7m
			Educational Support		\$5.893
			Information and Referral	2,782	\$0.596m
Young Carer Bursary Programme (YCBP)	The target group for the YCBP are carers aged 25 and under.	<p>The key eligibility requirements of the YCBP are as follows:</p> <ul style="list-style-type: none"> Young carers, aged 25 years and under; Studying* full-time or part-time; <ul style="list-style-type: none"> in secondary school toward higher Vocational and Educational training (VET) qualifications such as apprenticeships or TAFE, or at university (first undergraduate degree only); Not in receipt of another bursary or scholarship; and Permanent residency status or Australian citizenship. 	Bursaries	300 (2015 calendar year)	\$1.235m

Programme	Target Groups	Eligibility	Service Categories	Number of Carers Supported (2014/15)	Funding Allocated (2015/16)
Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP)	<p>The target group for the RSCYP activity is a primary carer:</p> <ul style="list-style-type: none"> • whose needs are not being met by other state or territory government programmes; and • who is caring for a person with a severe or profound disability under 30 years of age; or • who is caring for a person under 65 years of age where the carer stress is assessed as significant. 	<p>Primary Carer</p> <p>A primary carer is the person who provides the most assistance, in terms of help or supervision, to another person. The assistance has to be ongoing, or likely to be ongoing, for at least six months. The assistance may be to a person in the same or a different household.</p> <p>Carer</p> <p>A carer, as defined in the Carer Recognition Act 2010, is an individual who provides personal care, support and assistance to another individual who needs</p> <ul style="list-style-type: none"> • it because that other individual: • has a disability; • has a medical condition (including a terminal or chronic illness); • has a mental illness; or • is frail and aged. <p>Under this programme, non-Australian Citizens are eligible to access services providing they have permission to be a resident of Australia by the Department of Immigration and Border Protection and they meet the programme's eligibility requirements.</p>	N/A	5,347	\$7.939m
My Time: Peer Support Groups for Parents and Carers of Children with Disabilities or Chronic Medical Conditions	<p>MyTime Peer Support Groups are aimed at parents and carers of children with disability or chronic medical condition up to 16 years of age. A range of parents and carers could participate in the groups, including:</p> <ul style="list-style-type: none"> • carers with CALD backgrounds; • Indigenous families; • mothers and fathers; • teenage and young parents; and • parents and carers who are located in non-metropolitan areas. 	N/A	N/A	2,755 (for six months only in financial year 14/15)	\$3.77m

Programme	Target Groups	Eligibility	Service Categories	Number of Carers Supported (2014/15)	Funding Allocated (2015/16)
Former Commonwealth HACC - Counselling, Support, Information and Advocacy (CSIA)	<p>The programme is directed towards assisting:</p> <ul style="list-style-type: none"> frail older people with functional limitations as a result of moderate, severe and profound disabilities; and the unpaid carers of these frail older people. <p>Carers provide a major part of care for frail older people. Carers of older people play an important role in the community and contribute enormously to the quality of life of the person receiving care. Carers of older people are a specific target group of CSIA as it is recognised that carers need support, recognition and assistance in their role.</p>	Only people in the target population and their carers are eligible to receive CSIA services.	Counselling, Support, Information and Advocacy (CSIA)	13,457	\$10.15m
Dementia and Aged Care Service Grants	<p>The target groups for priority areas for action include but are not limited to:</p> <ul style="list-style-type: none"> older Australians, to support healthy and active ageing; workforce groups that provide services to older Australians, including health, allied health, and staff in aged care services; families and carers of older people and those with early onset dementia; aged care providers, including those providing services to older Aboriginal and Torres Strait Islander people or in remote areas; and older people with diverse needs, and their families and carers. 	N/A	Round 3 (8 carer projects)	Not available	\$0.724m
Dementia Education and Training for Carers	The DETC aims to improve the quality of life of people living with dementia by increasing the competence and confidence of carers, by providing courses that aim to enhance their skills, or processes that connect a carer to information. The DETC is currently delivered through 40 Commonwealth Respite Carelink Centres	N/A	N/A	Not available	\$1.07m

ANNEX C - Carer payments funded by the Australian Government

In 2014-15, the Australian Government spent over \$7 billion on social security payments to assist and support carers.

Payment	Description	Payment Rates – February 2016 –	Recipient numbers as at 30 June 2015	Expenditure – 2014-15
Carer Payment	<p>An income support payment for people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment.</p> <p>Like other income support payments Carer Payment is income and assets tested.</p>	<p>Single – \$867.00 per fortnight*</p> <p>Member of a couple - \$653.50 per fortnight*</p> <p>*Maximum fortnightly rate including Pension Supplement and Energy Supplement</p> <p>Carer Payment is indexed twice per year, in March and September.</p>	255,542	\$4.6 billion
Carer Allowance	<p>An income supplement for people who provide daily care and attention in a private home to a person with disability or a severe medical condition.</p> <p>Carer Allowance is not income and assets tested, and may be paid in addition to Carer Payment.</p>	<p>\$123.50 per fortnight</p> <p>Carer Allowance is indexed once per year, in January.</p>	601,364	\$2.1 billion

Payment	Description	Payment Rates – February 2016 –	Recipient numbers as at 30 June 2015	Expenditure – 2014-15
Carer Supplement	<p>An annual payment that provides eligible carers with additional financial security, and assists in alleviating financial pressures.</p> <p>Carer Supplement is paid to those who receive a qualifying payment on 1 July each year, and is paid in addition to the qualifying payments.</p> <p>Qualifying payments include Carer Payment, Carer Allowance, DVA Carer Service Pension, Wife Pension and DVA Partner Service Pension.</p> <p>A carer can receive multiple Carer Supplements – one in respect of each qualifying income support payment they receive, plus one in respect of each person they care for who attracts Carer Allowance.</p>	<p>\$600 per annum per qualifying payment</p> <p>Carer Supplement is not indexed.</p>	614,763	\$551.7 million

Payment	Description	Payment Rates – February 2016 –	Recipient numbers as at 30 June 2015	Expenditure – 2014-15
Child Disability Assistance Payment	<p>An annual payment that assists eligible carers with the costs of support, aids, therapies or respite in respect of a child with disability.</p> <p>Child Disability Assistance Payment is paid to those who receive Carer Allowance in respect of a child aged under 16 on 1 July each year, and is paid in addition to Carer Allowance and the Carer Supplement.</p> <p>A carer can receive multiple Child Disability Assistance Payments - one in respect of each qualifying child.</p>	<p>\$1,000 per annum per qualifying payment</p> <p>Child Disability Assistance Payment is not indexed.</p>	152,662	\$171.0 million

ANNEX D - A review of the evidence base

The state of research on interventions to support carers

The international body of research literature on interventions to support carers has grown substantially (Parker, Arksey, & Harden, 2010). It now covers the prevalence of care-giving; the impact and outcomes of caring for those who have care-giving responsibilities; issues related to combining paid work and care; and the effectiveness of support and services for carers. Some studies examine issues from the perspective of specific sub-groups of carers, for example: older carers; children and young people who provide care; carers of people with particular medical conditions⁵. Studies have adopted different methodologies ranging from randomised control trials to small-scale qualitative pieces of work.

Unfortunately there is little consensus on what works best. Primarily due to the fact that the intervention literature is characterized by a host of methodological problems (Schulz, et al., 2008) (Eagar, et al., 2007):

- Sample sizes are often too small to detect even large effects;
- Randomized controlled trial methods have been used infrequently and are often implemented inappropriately; and interventions are not well described;
- Treatment implementation data are infrequently collected or reported;
- Interventions are poorly defined, so systematic reviews are often attempting to synthesise results of quite different intervention approaches and service models;
- The target group is not always being defined or identified by needs assessment. 'As such, it is difficult to determine if the intervention being studied is actually required by the carer or whether, in fact, another intervention may have been required.'; and
- The goal of most carer interventions is poorly defined, and the outcome measures are often not related to effectiveness of the intervention. Many simply rely on carer satisfaction measures.

In Victor's (2009) wide ranging review (covered all unpaid carers looking after relatives and friends of all ages and all condition groups), of the 107 eligible intervention studies the appraisal tool used suggested that the quality of 97 of those studies was poor.

Based on screening and reviewing over 11,000 (299 articles were reviewed in full) research articles, Parker et al (2010) formed a similar view:

"Beyond this, there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is **not** the same as saying that these interventions have no positive impact. Rather what we see here is poor quality

⁵ As cited in Urbis (2013), Eagar et al (2007) found that although the majority of studies focused on carers of people with dementia, there were no major differences between the needs of carers of people with dementia and other conditions and care needs.

research, often based on small numbers, testing interventions that have no theoretical 'backbone', with outcome measures that may have little relevance to the recipients of the interventions.

The evidence on respite care is the key example of this. While qualitative evidence shows that respite care is often a lifeline for carers, the research that has evaluated it has often been too small to allow statistically significant effects to be identified, has been poorly designed, and has used outcome measures that are sometimes frankly baffling. To take a single example from a study included in one of the reviews, why would we expect respite care to increase carers' knowledge, or to improve their sleep patterns after it has finished?"

What interventions are supported by evidence?

Noting there was a reasonable amount of evidence identified about interventions offering: access to support; emotional and social support; education and training, and carer breaks. There was very little evidence about: support to access services in personalised forms such as direct payments which give control to the person receiving support; interventions targeted at carers' physical health; interventions aimed at helping carers to maintain or access employment; befriending schemes; and complementary therapies.

Based on a meta-review of intervention studies, primarily Parker, Mills, & Abbey (2008), Parker, Arksey, & Harden (2010), Gallagher-Thompson & Evans (2009), there appears to be a core group of interventions that have been shown to be effective in improving carer outcomes.

In their review of studies from 1980 through 2005, Gallagher-Thompson & Evans (2009) identified three categories of interventions that can be considered evidence-based⁶:

1. The **psychoeducational–skill building** category was defined to include studies focusing on increasing carers' knowledge of the specific disorder (e.g., Alzheimer's disease) and teaching them specific coping skills for managing common emotional and/or behavioural problems associated with that disease. Specifically, there are positive findings within this category for four subcategories of treatment: depression management, behaviour management, anger management, and the approach that teaches carers how to respond to the changing behaviours of care recipients.
2. The **psychotherapy– counselling** category was defined to include studies that involved implementation of specified forms of individual or group therapy or counselling. This category delivered the most effective interventions.
3. The **multicomponent studies** category was defined to include two or more conceptually different approaches that have been woven into one intervention package (e.g. education plus counselling and/or skill building). Programmes that target specific components of carers' quality of life (such as perceived burden) and that include some combination of skill building, education, and support are currently

⁶ Their review spanned more than 350 articles. Of these only 19 studies satisfied the EBP criteria which includes: a minimum number of participants; same age group; the same treatment; the same target problem; prospective design; and random assignment. In addition, the treatment outcomes must have been better than those of the control or comparison condition.

the most effective interventions. This is corroborated by a number of studies that show services that appear to hold the most promise in helping carers are those that use a variety of interventions and address multiple points in the caregiving process that produce family stress (Pinquart & Sörensen, 2006; Gallagher-Thompson & Coon, 2007).

Gallagher-Thompson & Evans (2009) also identified several studies that showed promise in the psychoeducational–skill building category but did not meet all of their evidence-based criteria. For example, teaching carers skills for environmental modification to address functional concerns, such as safety in the home.

The Gallagher-Thompson & Evans findings are supported by the findings from Parker et al (2010). In their meta-review of 34 research papers (the papers remaining after applying their inclusion/exclusion criteria to an initial set of 11,009 papers) they found the strongest evidence of effectiveness of any sort was in relation to education, training and information for carers. They found interventions of this type, particularly when active and targeted rather than passive and generic, increase carers' knowledge and abilities as carers. There was some suggestion that this might also improve carers' mental health or their coping.

Counselling (delivered as part of a multi-component intervention) was also shown to be effective in the New York University School of Medicine's Alzheimer's Disease Centre study of counselling intervention by Mittelman, Haley, Clay, & Roth (2006). The longitudinal study, the longest of its kind, found the long lasting (in brackets) positive effect of this intervention on depression (3 years), carer appraisals of behaviour problems (up to 4 years), and delay in nursing home placement (by 1.5 years) to be both clinically and statistically significant.

ANNEX E- Design Principles (accessible version)

Principle	Statement
Carer Focus	The new integrated carer support service system will ensure carers are at the core of its focus.
Simple	The new integrated carer support service system will be simple for users to interact with
Cost Effective	The new integrated carer support service system will provide cost effective supports for carers
Alignment	The new integrated carer support service system will be aligned with other relevant Commonwealth legislative and policy frameworks to ensure the service system works together to achieve intended outcomes.
Address current and emerging carer needs	The new integrated carer support service system will address current and emerging carer needs.
Evidence based	The new integrated carer support service system will be based upon the best available evidence about what works.
Equity of access	The new integrated carer support service system will aim to provide equity of access to carer support services delivered across the country
Retaining the Strengths of the current system	The design of the new integrated carer support service system will build upon the strengths of the existing systems currently in place.
Reuse of infrastructure	The design of the new integrated carer support service system will seek to reuse existing infrastructure, where appropriate to do so.
Nationally consistent, locally responsive	The new integrated carer support service system will be nationally consistent but will retain local flexibility to ensure that support agencies can adapt to the needs of carer cohorts within their region.
Innovative, flexible and tailored support	Where appropriate, the new integrated carer support service system will deliver innovative, flexible and tailored support for carers.
Recognisable to both carers and the local service networks	The new integrated carer support service system will be well known and understood by carers, with touch points with local service networks.

ANNEX F- Service Concept Overview (accessible version)

The objective of the new integrated carer support service system will be to help carers continue their caring role by delivering supports and services proven to reduce caregiver strain and improve their wellbeing, by refocussing carer support as an early intervention service. This draft Service Concept outlines the types of supports proposed to achieve this.

Supporting carers today...

Each year, the Department of Social Services spends approximately \$170 million on carer support services through 9 carer support programmes. With this, we assist 177,100 carers. However, carers usually seek support services only at the point they are in a crisis or when an emergency has arisen.

The service concept...

The service concept seeks to shift towards a preventative model- providing more support (earlier) to more carers).

To do this we need to...	By delivering these services...	Which could be delivered...
Help more people to be aware of carers around them or identify themselves as carers by raising...	Awareness	Nationally- across the general community through mainstream marketing and media. Locally- through outreach to target specific groups who require direct engagement.
Help carers find what they need to know through...	Information	Nationally- through national platforms such as a phone or website Locally- through phone or face to face as part of needs identification and planning, tailored to carers' individual circumstances.
Enable carers to connect with supports (where required) through...	Intake	Nationally- through phone or self-service via a website. Locally- through organisations in local areas for those carers who are not able to , or where it is not appropriate for them, to use national platforms.
Empower carers with more confidence in their skills to care and to look after their own health and wellbeing through...	Education	Nationally- through a website or e-learning platform, with phone based support. Locally- through face to face education programmes.
Help carers to connect with each other to expand their informal supports network and learn from the experiences of others through...	Peer Support	Nationally- through a national platform such as online discussion boards or 'group finder'. Locally- connecting carers at a local/regional level to groups with similar experiences or interests.

To do this we need to...	By delivering these services...	Which could be delivered...
Guide carers with identifying their needs and plans, and helping to problem solve...	Needs Identification & Planning Support	Nationally- through carer self-assessment and planning tools online. Locally- telephone or face to face planning and needs identification with a qualified staff member.
Provide practical and emotional support and advice for carers...	Counselling	Nationally- through channels such as web chat or telephone. Locally- through individual or group sessions in face to face settings.
Combine supports to maximise their effectiveness and increase uptake for supports with long term benefits...	Multi-component Support Package	The following three services, carer mentoring, respite support and financial support are intended to be delivered together.
Provide access to someone to help with advice and support to help carers achieve their goals	Carer mentoring	Locally- through phone or face to face support from a qualified staff member
Assist carers to take break and to respond to emergencies...	Respite support	Locally- through phone based support to assist in accessing respite services, on both a planned and emergency basis.
Empower carers to select supports and services of benefit to them in their caring role...	Financial Support	Nationally- delivered via national system but accompanied and coordinated through locally based support services (mentoring and respite support)

Some fast facts...

- There are 2.7 million carers in Australia. That means that approximately 1 in 8 people are carers.
- Approximately 30% of carers do not report strain or negative effects associated with caring.
- However, up to 58%⁷ of carers cease their caring role due to strain.

⁷ Please note that version 1 of this service concept incorrectly state 58% instead of 38%.

ANNEX G- Examples of effective interventions

An example of an effective education intervention

The table outlines the basic components of a psychoeducational skill-building approach Coping with Caregiving (CWC), a 10-week group educational intervention grounded in cognitive and behavioural skills.

The CWC workbook and class focuses on improving caregiver well-being by teaching strategies to use when caregiving responsibilities become stressful, and how to manage the difficult behaviours associated with the care recipient's memory problems. The course also reviews skills to improve the carer's sense of well-being, including ways to relax and increase pleasure in daily life.

Coping with Caregiving: Phases, Goals and Related Home Practice

Phase	Goals	Home Practice
Initial Phase		
Class 1	Overview of dementia, understanding frustration, and practicing relaxation	Daily relaxation diary
Class 2-4	Identifying unhelpful thoughts about caregiving, changing unhelpful thoughts into adaptive thoughts or more helpful ways of thinking, and linking to behaviours	Relaxation diary, daily thought record
Second Phase		
Class 5-6	Understanding types of communication and practicing how to be more assertive in caregiving situations and others	Practice assertive communication
Third Phase		
Class 6-9	Identifying pleasant events and activities, understanding and overcoming personal barriers to increasing pleasant events.	Daily mood rating, pleasant events tracking form
Class 10	Review of major skills taught	Apply skills in everyday situations
Fourth Phase		
8 Boosters	Maintain skill base and fine-tune skills	Apply skills in everyday situations

CWC participants reported a reduction in depressive symptoms and an increased use of positive coping strategies when compared with the control group (in this case a peer support group).

Two examples of effective multicomponent interventions

New York University School of Medicine's Alzheimer's Disease Centre

Counselling was also shown to be effective in the New York University School of Medicine's Alzheimer's Disease Centre study of counselling intervention (Mittelman, Haley, Clay, & Roth, 2006).

The intervention treatment consisted of four components:

1. Two individual counselling sessions tailored to each carer's specific situation;
2. Four family counselling sessions with the primary carer and family members selected by that carer;
3. Participation in a weekly support group; and
4. "Ad-hoc counselling," meaning the continuous availability (for an unlimited period of time), by telephone, of counsellors to carers and families to help them deal with crises and the changing nature of the patient's symptoms over the course of the disease.

Counsellors also supplied resource information and referrals for auxiliary help, financial support. An interesting side note relates to an unintended consequence of the research design. Counsellors interviewed carers, completing a set of structured questionnaires when they enrolled in the study and at regular intervals afterwards. Mittelman et al (2006) report that many carers commented that they found these interviews to be helpful because they provided additional contact with the counsellors and an opportunity to talk about their feelings and needs and to receive advice and information about resources.

REACH II

An extract from <http://www.firstreportnow.com/articles/reach-va-dementia-caregiver-support-program>

The National Institute on Aging/National Institute of Nursing Research REACH II (Resources for Enhancing Alzheimer's Caregiver Health) randomized controlled trial provided education, support, and skills building in home and by telephone. The study results demonstrated that when caregivers received such support, there was significant improvement in adverse physical and psychological consequences often associated with caregiving, including depression, anxiety, sleep disturbance, hospitalization, and mortality.

The intervention included nine 1-hour individual home sessions, three 0.5-hour individual telephone sessions, and five 1-hour monthly telephone support group sessions. Topics included education, support, and skills training to address 5 caregiving risk areas: safety, social support, problem behaviours, depression, and caregiver health.

At baseline, 86% of the caregivers said they were overwhelmed, 80% reported feeling like crying, 89% were frustrated as a result of caregiving, 56% reported feeling cut off from family/friends, 53% said they felt lonely, and 39% reported having worse health than in the previous year. When asked about stress, 60% rated their stress as ≥ 6 on a 10-point scale, with 10 representing extremely stressed.

At follow-up, the caregivers showed significant improvements in burden, depression, impact of depression on daily lives, and caregiving frustrations. In addition, the difference of almost 2 hours in the amount of time per day spent on caregiving duty tended toward significance.

In subjective assessments of benefits of the intervention, the caregivers felt the programme benefited them, helped them understand the disease and their role in caregiving, and increased their knowledge and ability to provide care. In summary, 96% of the participants believed the programme should be provided by the VA to caregivers.

An example of an effective counselling intervention

Extract from the Rosalynn Carter Institute for Caregiving - Caregiver Intervention Database

The nine-week Cognitive Behavioural Therapy (CBT) intervention assisted Alzheimer's disease (AD) caregivers in reducing anxiety and the risk for mental health compromise by altering appraisals and coping behaviours to enhance resistance to environmental demands and reduce vulnerability. The CBT intervention featured two-hour weekly meetings.

Each week one new skill designed to assist caregivers in reducing anxiety was examined. Each session started with a brief social period to encourage cathartic expression and instil a supportive atmosphere. AD caregivers were encouraged to discuss environmental demands and anxiety-provoking situations experienced over the past week. Caregivers discussed challenges or benefits experienced by completing homework assignments. Through these discussions, interventionists encouraged the receipt and enactment of new skills.

The middle third of the session focused on skill acquisition. AD caregivers received weekly handouts of the material to be discussed from the treatment manual. Each session concluded with the practice of a relaxation exercise. Brief homework assignments (requiring a daily maximum of 20 minutes) were given to caregivers at the conclusion of the session. These assignments were designed to examine whether the AD caregiver demonstrated receipt and enactment of the weekly skill.

Noting the data were collected from a relatively small sample, the nine-week CBT intervention reduced anxiety as measured by self-report and clinician-administered psychological assessment scales. Moreover, these reductions in anxiety were maintained through a six-week follow-up period suggesting that CBT may offer caregivers assistance in modulating anxiety across time.

TERMS & ACRONYMS

ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CBT	Cognitive Behaviour Therapy
CDC	Consumer Directed Care
CDRC	Consumer Directed Respite Care
CHSP	Commonwealth Home Support Programme
CRCC	Commonwealth Respite and Carelink Centre
CSIA	Carer Support, Information and Advocacy
DETC	Dementia Education and Training for Carers
DSS	Department of Social Services
CGAG	Carer Gateway Advisory Group
LGBTI	Lesbian, Gay, Bisexual, Transgender and/or Intersex
NCCP	National Carer Counselling Programme
NDIA	National Disability and Insurance Agency
NDIS	National Disability and Insurance Scheme
NFCSP	United States National Family Carer Support Programme
NRCP	National Respite for Carers Programme
SME Working Group	Subject Matter Expert Working Group
The Plan	The Integrated Plan for Carer Support Services

WORKS CITED

- Access Economics. (2015). *The economic value of informal care in Australia in 2015*. Canberra: Carers Australia.
- Alzheimer's Australia. (2013). *Respite Review Policy Paper*. Alzheimer's Australia.
- AMR Australia. (2015). *Carer Service Development Research*.
- Aoun, S. M., Grande, G., Howling, D., Deas, K., Toye, C., Troeung, L., et al. (2015). The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. *PLoS ONE*, 1-16.
- Association Of Directors Of Adult Social Services. (2010). *Supporting Carers: Early Interventions And Better Outcomes*.
- Australia Institute of Health and Welfare. (2010). *Australia's welfare 2009: Australia's welfare series no. 9*. Canberra: Australia Institute of Health and Welfare.
- Australian Bureau of Statistics. (2012). *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings*. Canberra: Australian Bureau of Statistics.
- Barber. (2013). Viewing the National Family Caregiver Support Program through The Family Impact Lens. *Family Science Review*.
- Borowski, Enclé, & Ozanne. (2007). *Longevity and Social Change in Australia*. Sydney: UNSW Press.
- Carr, S. (2009). *The implementation of individual budget schemes in adult social care*. Social Care Institute for Excellence.
- Coe, R. (2002). It's the Effect Size, Stupid- What effect size is and why it is important. *Annual Conference of the British Educational Research Association*. University of Exeter, England.
- Coon, D., & Evans, B. (2009). Empirically based treatments for family caregiver distress: what works and where do we go from here? *Journal of Geriatric Nursing*.
- Department of Health and Ageing. (2012). *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*. Canberra: Commonwealth of Australia.
- Department of Social Services. (2015). *Carer Gateway Project: Current State Analysis*.
- Eagar, Owen, William, Westera, Marosszeky, England, et al. (2007). *Effective Caring: a synthesis of the international evidence on carer needs and interventions*. Centre for Health Service Development .
- Gallagher-Thompson, D., & Evans, D. (2009). Empirically based treatments for family caregiver distress: what works and where do we go from here? *Psychology and Aging*.
- Gibson, M., & Redfoot, D. (2007). *Comparing Long-Term Care in Germany and the United States: What Can We Learn From Each Other*. AARP Public Policy Institute.

-
- Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M. P., Schinfeld, S., & Hauck, W. W. (2002). Effects of the Home Environmental Skill-Building Program on the Caregiver–Care Recipient Dyad: 6-Month Outcomes From the Philadelphia REACH Initiative. *The Gerontologist*.
- Goldstein, S. M., Johnston, R., Duffy, J., & Rao, J. (2002). The service concept: the missing link in service design research? *Journal of Operations Management*.
- Grande, G. E., Austin, L., Ewing, G., O'Leary, N., & Roberts, C. (2015). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *British Medical Journal*, 1-9.
- Howe, A. (2003). *Is Consumer Directed Care a direction for Australia?* Sydney: Alzheimer's Australia.
- Howe, A. (May 2013). *Alzheimer's Australia Respite Review Policy Paper*. Department of Health and Ageing.
- Joling, Marwijk, v., Smit, Horst, v. d., Scheltens, Ven, v. d., et al. (2013). Does a Family Meetings Intervention Prevent Depression and Anxiety in Family Caregivers of Dementia Patients? *PLoS one*.
- KPMG. (2012). *Evaluation of the consumer - directed care initiative*. Department of Health and Ageing.
- Long, & Spillman. (2009). Does high caregiver stress predict nursing home entry? *Inquiry*.
- Mason, A. (2007). The effectiveness and cost effectiveness of caregivers of frail older adults. *Journal of the American Geriatrics Society*.
- Mittelman, M., Haley, W., Clay, O., & Roth, D. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*.
- Organisation for Economic Co-operation and Development. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. Organisation for Economic Co-operation and Development.
- Parker, Arksey, & Harden. (2010). *Meta-review of international evidence on interventions to support carers*. Social Policy Research Unit (University of York).
- Parker, D., Mills, S., & Abbey, J. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence Based Healthcare*.
- Parker, G., Arksey, H., & Harden, M. (2010). *Meta-review of international evidence on interventions to support carers*. Social Policy Research Unit (University of York).
- Purcal, C., Hamilton, M., Thomson, C., & Cass, B. (2012). From Assistance to Prevention: Categorizing Young Carer Support Services in Australia and International Implications. *Social Policy and Administration*, 788-806.
- Schulz, & Sherwood. (2009). Physical and Mental Health Effects of Family Caregiving,. *American Journal of Nursing*.
- Schulz, R., Newsom, J., Mittelman, M., Burton, L., Hirsch, C., & Jackson, S. (2007). Health effects of caregiving: the carer health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioural Medicine*.

-
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2008). Dementia Caregiver Intervention Research: In Search of Clinical Significance. *Gerontologist*.
- Social Policy Research Centre. (2012). *Young carers: Social policy impacts of the caring responsibilities of children and young adults*. Sydney: Department of Family & Community Services NSW.
- Urbis Australia. (2013). *Evidence Based Research On Carer Needs And Support Services*.
- Victor, E. (2009). *A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence*. The Princess Royal Trust for Carers, University of Nottingham.
- Whittier, S., Coon, D., & Aaker, J. (2001). Caregiver Support Interventions. In *Family Caregivers In California: Needs, Interventions and Model Programs*. Center for the Advanced Study of Aging Services (University of California, Berkley).
- Winterton, R., & Warburton, J. (2011). Models of care for socially isolated older rural carers: barriers and implications. *The International Electronic Journal of Rural and Remote Health Research, Education, Practice and Policy*, 1-13.

