

**ALZHEIMER'S  
AUSTRALIA**  
**RESPITE  
REVIEW**  
**POLICY PAPER**

**PAPER 33**  
**REPORT PREPARED FOR THE  
DEPARTMENT OF HEALTH AND AGEING**

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## Acknowledgements

This report was completed by Alzheimer's Australia through funding received from the Department of Health and Ageing.

The report aims to contribute to a discussion about respite through the National Aged Care Alliance, and does not purport to represent all their views or the views of Government.

In the time available consultations were only possible in a limited number of States and Territories and as a consequence the views outlined in the report will not be representative of all consumers and services providers.

# CONTENTS

<b>Forward</b>	<b>6</b>
<b>Abbreviations</b>	<b>7</b>
<b>Executive Summary</b>	<b>8</b>
<b>Recommendations</b>	<b>10</b>
<b>1. Introduction</b>	<b>12</b>
1.1 Reasons for the Respite Review	12
1.2 Outcomes of the 2009 report on respite for people living with dementia	13
1.3 Processes of the Review	13
<b>2. Current provision, funding and use of respite</b>	<b>16</b>
2.1 Defining respite	16
2.2 Current program structure and funding of respite	17
2.3 Consumer reports of respite use	21
2.4 Unmet need	22
<b>3. Consumer experience with respite</b>	<b>24</b>
3.1 Satisfaction with current respite services	24
3.2 Consumer preferences and priorities: more day centre and in-home respite	25
3.3 Overnight respite preferences	29
3.4 High care respite	29
3.5 Carer support concerns	29
<b>4. Provider experiences in delivering respite</b>	<b>32</b>
4.1 Provider involvement in multiple programs	32
4.2 The need for a new program structure	33
<b>5. Proposals for a new program structure for respite</b>	<b>36</b>
5.1 Aims of developing a new program structure	36
5.2 Answering the key questions	36
5.3 A new program structure	40
<b>6. Furthering flexible respite provision and choice</b>	<b>42</b>
6.1 Options involving cash payments	42
6.2 Good practice in respite	45
6.3 Furthering good practice in respite	47
<b>References</b>	<b>48</b>
<b>Appendix 1: Alzheimer's Australia Respite Review Consumer Survey</b>	<b>50</b>
<b>Appendix 2: Alzheimer's Australia Respite Review Provider Survey</b>	<b>56</b>



# FORWARD

I am delighted the Department of Health and Ageing has been able to fund Alzheimer's Australia to undertake this project on respite care.

As a carer I know how important respite is to give the family carer a break while giving the person with dementia the opportunity for social engagement and activities. For those caring for someone living with dementia, provision of and access to quality respite care has been a longstanding concern and priority area for change.

The commitment made by the Government to the *Living Longer. Living Better.* aged care reform package, provides a wonderful opportunity to ensure that respite meets the needs of the family carer and the person with dementia, and to make sure that service providers have the flexibility they require to respond to those needs.

From a carer's perspective, I feel this report covers many of the issues currently facing carers, and I hope that it will contribute to the creation of a more flexible system for the delivery of respite through the aged care reform process.

There are many people I would like to acknowledge. My sincere thanks to the people who took part in the consultations and responded to the on-line survey, and the consumers who not only gave their time to provide firsthand insights into the importance of respite in their on-going caring roles but also shared the problems they experience in accessing services that meet their needs.

The close correspondence between their views and those of providers, and the suggestions we received for improving respite, gives me confidence successful outcomes can be achieved as the aged care reforms proceed and that over the next three years we will reach consensus on how to better meet the needs of carers and those they care for.

The state branches in the ACT, Queensland and Victoria of Carers Australia and Alzheimer's Australia, and Community Options New South Wales, deserve special thanks for their assistance with the consultations.

I also want to thank the review team. Dr Anna Howe carried out the major policy and program analysis and reviewed the recent research and evaluations. She also led the drafting of this report and was ably assisted by Samantha Blake in writing it. Glenn Rees provided direction and guidance throughout the project.

I am confident that this report will help inform decisions on respite care in the implementation of *Living Longer. Living Better.* I am grateful to the Department of Health and Ageing for giving Alzheimer's Australia the opportunity to undertake this review.



Ita Buttrose AO, OBE  
National President  
Alzheimer's Australia

# ABBREVIATIONS

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ACFI	Aged Care Funding Instrument
ACAR	Aged Care Approvals Round
ACAT	Aged Care Assessment Team
BPSD	Behavioural and Psychological Symptoms of Dementia
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse
CDC	Consumer Directed Care
CDRC	Consumer Directed Respite Care
CRCC	Commonwealth Respite and Carelink Centre
DACS	Survey of Disability, Ageing and Carers
DBMAS	Dementia Behaviour Management Advisory Service
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
HACC	Home and Community Care Program
LLLB	<i>Living Longer. Living Better.</i>
NRCPC	National Respite for Carers Program

# EXECUTIVE SUMMARY

## Aim of the Review

The opportunity for further development of respite policy arises in the context of measures put forward in the *Living Longer. Living Better.* package of reforms announced in April 2012.

Alzheimer's Australia was funded by the Department of Health and Ageing to undertake a review of respite policy from August to October 2012. The aims of the review were:

1. To examine present levels and recent trends in provision of the range of respite services provided under community and residential care programs, and consumer take-up and satisfaction with current services.
2. To review the issues that have been raised in recent consultations, policy material and research, particularly aspects of present program arrangements and provider operations that are seen to pose barriers to access and limit flexibility of services to respond to carer and client needs, and canvass options for addressing these issues in further consultations.
3. To report on options for addressing these problems in ways that would enhance access to and flexibility of services, and identify the preferred and feasible priorities to be addressed within the *Living Longer. Living Better.* timeframe.
4. To identify a number of better practice approaches that offer prospects for increasing flexibility, including approaches that might be trialled and evaluated over the next five years. Particular attention will be given to approaches that (a) advance consumer direction and (b) contribute to enhancing respite care for people with dementia and their carers.

The review drew on two main sources of information. Background material was drawn from a literature that focused on government reports, research and evaluation studies that have covered various aspects of respite in Australia over the last five years. Primary material came through the consultations with consumers, providers and peak organisations in four States and an on-line survey.

## Defining respite

The Departmental Carer and Respite Working Group had considered this question in some depth and in February 2012 agreed on a definition that recognises the benefits of respite for the carer and care recipient. The review adopted this definition and recommended its adoption in all Australian Government aged care programs.

## Current respite provision

Parts one, two and three of the report present an account of current respite provision. Part one reports on the program structure, use and funding of respite delivered through National Respite for Carers Program, Home and Community Care, residential respite and care packages. Part two and three examine consumer and service provider experiences and barriers to accessing and providing respite.

## A new program structure for delivering respite

The review saw the overall aim of any alternative program structure as being to eliminate, or at least substantially reduce, the boundaries between types of respite to give consumers more choice of the types of respite they wish to use and to give providers more flexibility in the types of respite that they can offer in responding to consumer needs.

In determining a new program structure for respite services, the review aimed to answer the following three questions:

1. Should residential respite continue to be funded within the residential care program?
2. Should all respite provided through the National Respite for Carers Program, Home and Community Care, packages and residential respite, be (a) brought together to form a single Respite Program or (b) be part of the Home Support Program?
3. If the respite is delivered through the Home Support Program (option b above), should it be amalgamated with the rest of the services or maintained as a separate service stream?
4. Further to (2), should package care recipients and their carers continue to be able to access respite both within and outside their package, or should the scope of Home Care Packages be narrowed to focus on direct client care services, mostly personal care, nursing and domestic assistance, and respite be accessed outside the package?

## Future directions

Two main directions for advancing the provision of further choice in respite and increasing the standing of respite in the aged care system were explored in the review and are reported in part six.

First, taking up the adoption of Consumer Directed Care in *Living Longer. Living Better.* the review canvassed options involving payments that enable carers to pay family members or friends, receiving cash instead of services, and trialling a Consumer Directed Care approach that included the option of direct payments.

Second, the many examples of good practice presented during the review by consumers and providers were drawn together in proposals for strategies to promote good practice in all forms of respite.







# RECOMMENDATIONS

## Recommendation 1

That the definition of respite developed by the Departmental Carer and Respite Working Group be adopted in guidelines for Australian Government aged care programs:

1. The **purpose** of respite is to enable the person receiving care (care recipient) to continue to live at home in the community with a healthy, stress-free carer and to enable the living partnership to continue for as long as is appropriate.
2. In **defining** respite, the needs of both the carer and care recipient should be considered.
3. From the **care recipient's perspective**, respite is the participation in an enjoyable activity (or activities) that is meaningful and appropriate, which provides opportunities for social engagement, companionship and stimulation and which supports them to live in the community for as long as possible and which is delivered in a dignified and respectful way.
4. From the **carer's perspective**, respite is time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care.
5. The **evaluation** of the effectiveness of the respite would be to examine if it met the needs and goals of the carer and the care recipient.

## Recommendation 2

That growth, availability and flexibility of residential respite be supported through:

- The specification of places in aged care planning through a ratio.
- The allocation of new places included in the next Aged Care Approvals Rounds.
- Providers being able to apply for an allocation of places to use for both day and overnight respite to enable diversification of services and enhance continuity of care.

## Recommendation 3

That a dementia supplement be provided for eligible recipients of all forms of respite in line with the dementia supplement for eligible Home Care package recipients. The supplement will increase the funding payable in respect of an eligible respite care recipient by 10 per cent in recognition of the higher costs of caring for people with dementia.

## Recommendation 4

That flexibility in the provision of respite be promoted through:

- Removing boundaries between types of respite and allowing providers to adjust the types of respite they deliver within their allocated funding to meet consumer demand.
- Accountability that is achieved by reporting, not by the application of detailed service types in funding agreements.
- The allocation of additional funding to respite in *Living Longer. Living Better.* to meeting the high demand for centre-based day respite and in-home day respite, with a priority to deliver respite to:
  - People with dementia and other high and complex care needs.
  - Carers and care recipients from culturally and linguistically diverse backgrounds, particularly through recruitment and training of staff with cultural skills that match local community populations.
  - Supporting meaningful social engagement and activities that meet consumers interests and preferences and takes into account their age, gender, location, health, care needs and level of physical ability.

## Recommendation 5

That attention is given to ways of reducing direct and indirect cost barriers to the use of respite by:

- Uniform arrangements for charging fees under the Home Support Program.
- The Age Pension for carers and package care recipients being assessed and paid at the single rate on the same basis as a couple with one partner in residential care.
- A focus on growth funds targeted at supporting caring families to participate in employment.

## Recommendation 6

That the Australian Institute of Health and Welfare be commissioned to conduct an audit of all respite providers to provide baseline data on which respite in the Home Support Program can be monitored.

## Recommendation 7

That funding for the National Respite for Carers Program, a defined ratio of residential respite places, and respite provided through HACC, be consolidated as a component of the Home Support Program at the commencement of the program in 2015.

This program structure is designed to:

- Promote flexibility in the types of respite provided in response to consumer needs and preferences, in line with Recommendation 4.
- Enable Package users to access respite within and outside their package.
- Enable all consumers to choose the mix of respite and other services that best meet their needs across the full spectrum of services in the Home Support Program, in line with Consumer Directed Care.
- Provide opportunities for residential care providers to participate in the Home Support Program and diversify their respite services and adopt good practice approaches to enhance quality of services.

## Recommendation 8

That a scoping study be conducted for a trial of direct payments as an option within Consumer Directed Care approaches in the second half of 2013.

## Recommendation 9

That good practice in all forms of respite care be promoted through a three part strategy that gives attention to:

1. Making flexible use of respite funding allocated through the residential respite program to diversify services with priority given to:
  - Multi-Purpose Services and residential providers in rural and remote communities.
  - Residential care providers delivering respite to particular cultural and linguistic groups.
2. Developing a more coordinated approach that links respite with timely access for carers to counselling and support services.
3. Showcasing high quality services for all types of respite and promoting good practice in respite.



# INTRODUCTION

## 1.1 Reasons for the respite review

The opportunity for further development of respite policy arises in the context of measures put forward in the *Living Longer. Living Better.* (LLLBB) package of reforms announced in April 2012. A number of the recommendations made in the 2009 Alzheimer's Australia discussion paper on Respite Care for People Living with Dementia have been given effect in these measures, and six areas of reform are now identified as being particularly significant for the future of respite. They are:

1. Increased funding for support for carers that will expand the capacity of the National Respite for Carers Program (NRCP), especially the National Carers Counselling Program and Carer Support Centres;
2. Streamlining of respite programs through consolidation of the NRCP into the Commonwealth Home Support Program, together with the Home and Community Care (HACC) program, from July 2014;
3. Expansion of care packages and introduction of new levels of packages from 2012-13;
4. Adjustments to the ratio of residential care places, with implications for the allocation of places to residential respite care;
5. Embedding of principles of Consumer Directed Care (CDC) in all aged care services; and
6. Attention to the special needs of people with dementia and their carers, including the funding of dementia supplements.

The Department of Health and Ageing funded Alzheimer's Australia to undertake an initial review of options for respite care in the context of the reform agenda set out in LLLBB, and accordingly the aims of the respite review were set as:

1. To examine present levels and recent trends in provision of the range of respite services provided under community and residential care programs, and consumer take-up and satisfaction with current services.
2. To review the issues that have been raised in recent consultations, policy material and research, particularly aspects of present program arrangements and provider operations that are seen to pose barriers to access and limit flexibility of services to respond to carer and care recipient needs, and canvass options for addressing these issues in further consultations.
3. To report on options for addressing these problems in ways that would enhance access to and flexibility of services, and identify the preferred and feasible priorities to be addressed within the LLLBB timeframe.
4. To identify a number of better practice approaches that offer prospects for increasing flexibility, including approaches that might be trialled and evaluated over the next five years. Particular attention will be given to approaches that (a) advance consumer direction and (b) contribute to enhancing respite care for people with dementia and their carers.

The National Carer Strategy (the Strategy) was released near the end of the current review and sets out further practical measures to give effect to the Recognition of Carers Act 2010. The review complements Priority 4 of the Strategy, namely to support carers with appropriate, timely and accessible services. The need for respite that is flexible and responsive to need is specifically mentioned under Goal 3: Better information and support for carers.

## 1.2 Outcomes of the 2009 report on respite for people living with dementia

The present review follows on a Discussion Paper, *Respite Care for People with Dementia: It's more than just a short break*, prepared by Alzheimer's Australia in 2009. Since then, action has been taken on two of the 10 recommendations made, and the outcomes as noted in Table 1.1 are now part of the context in which respite services operate.

No action has been taken directly on the other eight recommendations relating to enhancing access to flexible respite care, increasing flexibility of program structures and ensuring quality of respite care. The review provides an opportunity to reconsider these recommendations in the light of other changes that have occurred or are proposed in the LLLB package.

## 1.3 Processes of the review

### 1.3.1 Literature review

The review was not charged with undertaking a comprehensive literature review and instead focused on a number of recent government reports and evaluation studies that provided accounts of programs through which respite services are delivered, including statistics on users and providers. The three main government reports are:

1. The 2010-11 Report on the Operation of the Aged Care Act 1997.
2. The 2008 Community Care Census, which covered all care packages and the NRCP.
3. The 2009-10 Annual Report for the Home and Community Care Program.

The research and evaluation studies examined as a part of the review are summarized in Table 1.2. The design, scale and scope of these studies varied widely, but taken together, they give a view of the diversity of respite and a number of consistent findings emerge.

The major gap that remains is the lack of all but very basic data on the provision and use of respite through the HACC program, which provides by far the major share of all centre-based respite and a substantial share of in-home respite.

### 1.3.2 Consultations and on line surveys

To complement the secondary sources noted above and to obtain consumer and provider views on possible options arising from the measures announced in the LLLB package, the review conducted a number of consultations and an on-line survey. Extensive consultations had already been held though the second half of 2011 in the development of LLLB, including wide-ranging consumer consultations conducted by Alzheimer's Australia in all states and in which over 1000 consumers participated. Reports on those consultations were reviewed for references to respite.

The consultations held for the review were more limited in scope and aimed to investigate a number of more specific questions in depth. The questions distributed to participants to guide the consultations are at Appendix 1A. Separate consultations were held with consumers and providers in the ACT, Victoria, New South Wales and Queensland; the consultations held in Brisbane focused particularly on culturally and linguistically diverse (CALD) communities. Participants were invited through state branches of Alzheimer's Australia and Carers Australia which have close contact with providers delivering respite through the NRCP as well as with consumers, both carers and care recipients. Providers of respite through HACC and residential care were under-represented at the consultations compared to NRCP providers.

Notwithstanding the short timeframe of the review, there was a high level of interest in the consultations from both providers and consumers. The level of consumer interest was especially evident in an on-line survey conducted by Alzheimer's Australia which attracted 234 responses in a two week period. 133 providers and 30 consumers attended the consultations, with another 58 providers completing a feedback survey. The consumer online survey is at appendix 1 and the provider consultation guide and survey at Appendix 2. Findings from the survey are summarised through the report and selected comments are included to illustrate the responses received.

**Table 1.1: Outcomes of recommendations made in *Respite Care for People with Dementia: It's more than just a short break*, Alzheimer's Australia (2009)**

Recommendation	Outcome
<b>Enhancing access to flexible respite care</b>	
Rec. 3: As consumer directed care offers a means of maximising consumer choice and flexibility of care for people with dementia and their carers, it is recommended that a trial of consumer directed respite care be implemented and that an allocation of NRCP brokerage funds be committed to the trial. Given that carers of people with dementia in special needs groups often have particular needs that require more flexible responses, the trial should specifically include carers of people with dementia in these groups.	Trial of CDC packages and respite implemented in July 2010, ran for 1 one year. Evaluation by KPMG released in January 2012. Positive evaluation of CDC and CDRC resulted in continuing funding of the services that participated in the trial. Proposals in LLLB package for CDC to be offered in all new care packages from early 2013 and a trial conducted in residential care.
<b>Monitoring implementation and evaluation</b>	
Rec 10: In order to monitor and evaluate the effectiveness of changes in delivery of respite care and related programs to people living with dementia, it is recommended that: A concise report on dementia care be included in the Australian Institute of Health and Welfare (AIHW) bi-annual report Australia's Welfare and a full account be presented by updating the 2007 report on Dementia in Australia every five years; The strategies proposed by the AIHW in 2007 for improving the reporting of all aspects of dementia in national data collections be adopted; Funding for research and development be included as a component of the NRCP	Expanded and comprehensive report on Dementia in Australia, including new data sources, released at the Dementia Collaborative Research Centres Dementia Forum in Canberra on 27 September 2012.



**Table 1.2: Recent major research and evaluation studies of respite in Australia**

Title	Authors/date	Scope
Evaluation of the consumer directed care initiative	KPMG. January, 2012	397 respondents to baseline and 6 month follow up surveys. 124 participants and 126 controls in CDC Package trial and 92 participants and 55 controls in CDC respite trial.
Dementia in Australia	Australian Institute of Health and Welfare. September, 2012	Comprehensive analysis of use of services by people with dementia in all Australian government health and aged care programs, including comparisons with all users and including carers.
Respite care in dementia: Carer perspectives	Fielding, Beattie, Readford & Neville. QUT Dementia Collaborative Research Centre, 2012	Survey of 336 carers covering use of and experiences with respite, conducted on-line and by telephone.
Evaluation of the demonstration day respite pilot in residential aged care initiative	Guiver & Barnett. Australian Institute for Social Research, 2011	Survey of 232 carers using 14 of 32 pilot sites, covering prior service use, pathways of entry and exit, and satisfaction.
Dementia and take-up of residential respite care	Powierski, Karmel, Anderson & Peut. Australian Institute of Health and Welfare and Dementia Collaborative Research Centre, 2011	Part of Pathways in Aged Care (PIAC) study. Uses linked data to compares use of residential respite care by people with dementia and others in a cohort of 30,400 people assessed by an ACAT in 2003-04.
Evaluation of the overnight respite and employed carer respite initiatives: Final Report	Urbis, 2009	Three initiatives through the NRCP with 62 of the 80 funded Overnight Community Respite services, mostly cottages; survey of 50 carers; 18 Employed Carer Innovative Projects; 97 Employed Carer Extended Services; Survey of 367 employed carers. Site visits and interviews with providers Analysis of service activity data.
The nature and impact of caring for family members with a disability in Australia	Edwards, Higgins, Gray, Zmijewski & Kingston. Australian Institute of Family Studies, 2008	Survey of random sample of recipients of Carer Payment and/or Carer Allowance, 1002 primary carers completed phone interviews.
Evaluation of Carer Support Measures: Stakeholder Report	Campbell Research and Consulting. 2008	Report of responses of 1481 carers recruited through Commonwealth Respite and Carelink Centres, and quantitative research with carers, providers and peak bodies







# 2. CURRENT PROVISION, FUNDING AND USE OF RESPITE

## 2.1 Defining respite

### 2.1.1 Policy and program perspectives

Respite is defined in a number of program guidelines published by the Department of Health and Ageing as:

Respite received by a carer from a substitute carer who provides supervision and assistance to their care recipient (even though the carer may still be present). This definition applies to respite provided in different settings:

- In the home of the carer or the care recipient;
- In a community based centre, including mobile respite services; and
- In various forms of residential care facilities.

This definition focuses on the carer as the primary beneficiary of respite, but it raises two issues for the delivery of respite as well as for reporting use of respite services. On one hand, many respite services also benefit the care recipient, and the recipient rather than the carer may be recorded as the user. Second, many of those using the same services do not have a carer, and having a carer is not required for access to these services.

These issues were taken into account by the Departmental Carer and Respite Working Group in developing a wider definition of respite at its meetings in late 2011 and agreed on at its meeting in February 2012. The five elements of the wider definition are:

1. The purpose of respite is to enable the person receiving care (care recipient) to continue to live at home in the community with a healthy, stress-free carer and to enable the living partnership to continue for as long as is appropriate.
2. In defining respite, the needs of both the carer and care recipient should be considered.
3. From the care recipient's perspective, respite is the participation in an enjoyable activity (or activities) that is meaningful and appropriate, which provides opportunities for social engagement, companionship and stimulation and which supports them to live in the community for as long as possible and which is delivered in a dignified and respectful way.
4. From the carer's perspective, respite is time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care.
5. The evaluation of the effectiveness of the respite would be to examine if it met the needs and goals of the carer and the care recipient.

This review adopted this wider definition and the data presented through the report include all those using services that have a respite function delivered through HACC, the residential care program and the NRCP, regardless of whether the recipient had a carer.

*“Respite is very important for all involved. Sometimes both the carer and the person being cared for just need a break every now and then!”*

### 2.1.2 Consumer perspectives

Consumer views on the benefits of respite for carers and care recipients support the adoption of a wide definition of respite. Carer comments made at many points through the consultations and in the on-line survey made it clear that these mutual benefits meant that while respite was an essential support for carers, it could not be seen as a service only for carers.

*“Someone PLEASE LISTEN and help make the needed changes to make a better situation of caring”*

Provision of respite is the most important way in which the role of carers is formally recognised in the aged care system, and by the community as a whole. But the findings of this review make it clear that more has to be done to make respite more responsive to consumer needs.

The special case of the role of respite in supporting working carers was also made very evident.

*“We need more respite outside the hours of 9-5 to support working carers.”*

## Recommendation 1

That the definition of respite developed by the Departmental Carer and Respite Working Group be adopted in guidelines for Australian Government aged care programs:

1. The **purpose** of respite is to enable the person receiving care (care recipient) to continue to live at home in the community with a healthy, stress-free carer and to enable the living partnership to continue for as long as is appropriate.
2. In **defining** respite, the needs of both the carer and care recipient should be considered.
3. From the **care recipient's perspective**, respite is the participation in an enjoyable activity (or activities) that is meaningful and appropriate, which provides opportunities for social engagement, companionship and stimulation and which supports them to live in the community for as long as possible and which is delivered in a dignified and respectful way.
4. From the **carer's perspective**, respite is time away from the caring role to engage in other activities of choice, knowing the care recipient is happy and receiving quality care.
5. The **evaluation** of the effectiveness of the respite would be to examine if it met the needs and goals of the carer and the care recipient.

## 2.2 Current program structure and funding of respite

### 2.2.1 Program structure and provision

The four part program structure through which respite is currently delivered, and the number of users in each program, is shown in Figure 2.1.

An account of the use of different types of respite compiled from the 2011-12 Report on the Operation of the Aged Care Act and the latest HACC Annual Report, for 2008-09, detailed in Table 2.1 shows that use of respite was divided very unevenly between the four programs:

1. HACC respite: Over 100,000 consumers used respite delivered through HACC, making it the program through which respite is most commonly accessed. Some 15% of all HACC consumers used respite, either in community based day centres, in the carer's or care recipient's home, or some other form of community respite.
2. Residential respite: About half as many, close to 50,000 consumers, used residential respite.
3. National Respite for Carers Program: Close to 32,000 carers used various forms of respite provided through the NRCP over the year. Figures in the 2010-11 Report on the Operation of the Aged Care Act 1997 show that respite accounted for just on 25% of the 130,477 carers who received assistance from NRCP; the majority received information, carer support and emergency respite, and far fewer received counselling.

Respite in care packages: Approximately 10% of all recipients of a care package are estimated to have used either community-based respite services or in-home respite services as part of their care package. This estimate represents 7,500 recipients of a care package, out of a total of 75,000 recipients. Based on the 2008 Community Care Census respite was used by 5% of Community Aged Care Packages (CACAP) clients, 28% of Extended Aged Care at Home (EACH) clients and 35% of Extended Aged Care at Home Dementia (EACHD) clients. These proportions were applied to the number of clients receiving each level of package in 2011 to give an estimate of 10% for all package clients. Note that the 2008 Community Care Census data are collected from a self-reported survey from the approved provider of the community care service.

### 2.2.2 Types of respite delivered through different programs

Use of respite is shaped to a considerable extent by current provision, with provision in turn shaped by the different arrangements under which the four programs operate.

#### HACC: Respite provided

Centre-based is the main form of respite delivered to older care recipients and their carers through HACC, functioning as respite for carers as well as meeting direct care recipient needs. The proportion of HACC care recipients who are using respite but who do not have a carer is not known.

A relatively small number of older people receive the HACC service type that is labelled specifically as 'respite' that includes in-home and community respite; most of this respite is provided to younger care recipients. Reporting of HACC service types as respite and day centres does not identify the respite function of day centres.

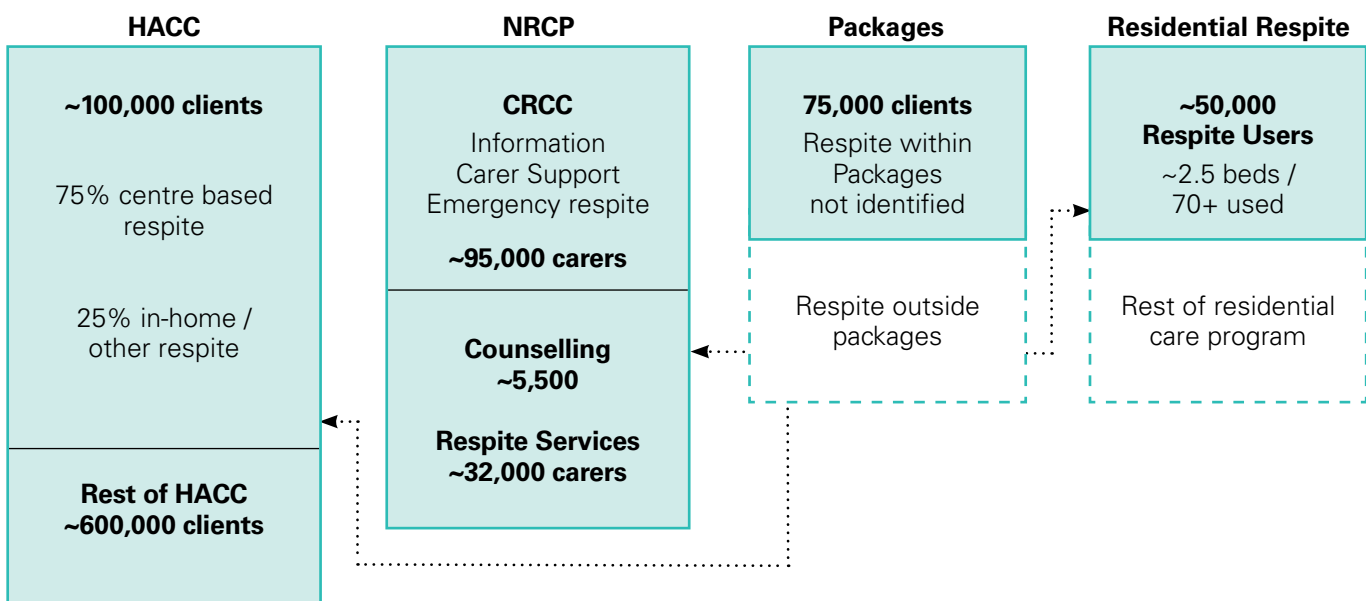
#### HACC: Providers

Centre-based respite is delivered by a great diversity of HACC providers, ranging from large organisations that also deliver a number of other services, to providers operating a single day centre, for example, to serve a particular ethnic community in a single locality. HACC providers may also deliver in-home respite. A Provider's decision to deliver respite is the result of HACC planning in each state and subject to service agreements about the types and amounts of respite to be provided.

#### National Respite for Carers Program: Respite provided

The wider range of respite provided through the NRCP includes not only centre-based and in-home day respite but also individual and group community access respite and overnight in-home and cottage respite, and use of other facilities such as motels for short overnight stays. 11 different categories are used to report these types, but centre-based day respite and in-home day respite account for most use. The 2008 Community Care Census shows that NRCP care recipients used higher levels of respite than Package care recipients, especially as some NRCP care recipients used more than one type of respite. The shares of all NRCP respite episodes accounted for by different types of respite and the average hours per carer per week reported in the Census confirm other reports already cited that show that the major part of NRCP respite is delivered through day centres and in-home respite.

Figure 2.1: Current program structure for provision of respite



**Table 2.1: Respite use under current programs, 2008-09 and 2010-11**

Consumers and rates of use per 1000/70+	No. Consumers 70+	Consumers per 1000/70+
Total HACC recipients aged 70+, 2008-09	594,670	280
HACC respite users (estimated on basis of 11.5% of clients using centre-based respite and 3.8% using in-home and other respite, as per 2008-09 HACC Annual Report.)	90,985	46
Residential respite 2010-11	46,146	22
NRCP carers receiving respite 2010-11	31,862	15
Care Packages 2010-11	74,726	35
Package respite users (estimated on basis of 10% of Care Package recipients using centre-based or in-home respite as part of their package).	7,473	4

Source: 2010-11 *Report on the Operation of the Aged Care Act 1997* and *Home and Community Care Program 1 July 2008 to 30 June 2009 Annual Report*.

The 2008 Community Care Census reports NRCP funding being provided to 490 respite services outlets that are funded for direct provision of a variety of respite services, as well as funding to Commonwealth Respite and Carelink Centres (CRCCs) that is used largely for brokerage. Brokerage funds flow to NRCP funded services, HACC providers and a number of other contracted providers. NRCP services include some 80 overnight respite services, mostly cottage models, some of which are operated by residential care providers.

**National Respite for Carers Program: Providers**

Most of the 54 CRCCs funded as of mid 2012 are not stand-alone centres but operate under the auspices of larger organisations. Of the 40 organisations supporting these CRCCs in mid 2012, 26 were major service providers which also deliver HACC, care packages and/or residential care, including a number that are associated with Multi-Purpose Services in regional areas. Another five were carer organisations and nine were other community based organisations. The CRCCs operate on a regional basis, with more local access through 86 shop-front services. The 490 service outlets that are funded through NRCP are widely spread to serve more localised areas.

**Community Care packages: Respite provided**

Package care recipients can access respite as part of their package, and may access respite outside their package from HACC or NRCP. The 2008 Community Care Census found that only 2% of package users received NRCP support, but they accounted for a much higher proportion of the smaller total NRCP respite users (11%). No data is available on the use of HACC respite by package care recipients, but reports in consultations suggest that accessing respite from HACC services is more common than use of NRCP by package care recipients. All residential respite used by package care recipients is accessed and funded through the residential care program; Aged Care Assessment Team (ACAT) assessment can approve both a package and residential respite concurrently, but it is not known how many package care recipients also use residential respite.

**Community Care packages: Providers**

Package providers must be Approved Providers under the Aged Care Act 1997 and many also provide residential care and/or HACC services. Large, not-for-profit providers dominate the delivery of packages, with many delivering packages through multiple outlets. The smaller scale of NRCP means that few package providers are also NRCP providers.

**Residential respite: Respite provided**

Care recipients are able to access respite in an aged care home for 63 days a year (with extension possible subject to approval). Arrangements for provision of respite through the Residential Care Program include allocation of beds through the Aged Care Approvals Round (ACAR) and a supplement above the Aged Care Funding Instrument (ACFI) respite funding for care recipients receiving high care respite. The allocation of beds for respite is not specified in the residential care planning ratios. It is up to providers to apply for respite places and the ACARs do not routinely include a call for respite places. The lack of clarity about the place of respite provision in the approvals process may itself be a factor limiting provision, and allocations of respite beds are not reported in the ACAR outcomes.

**Residential respite: Providers**

There is considerable variation in the level of respite offered by providers, and the way in which it is offered, ranging from scattered beds to dedicated respite units that operate along the lines of cottage models. A substantial proportion of all residential respite is offered by a smaller proportion of all homes and some provide no respite at all. Some providers receive HACC funding for centre-based respite and/or NRCP funding, and the delivery of day respite through aged care homes was promoted by the Demonstration Day Respite Pilot in Residential Aged Care Facilities Initiative, which funded day respite in 31 aged care homes for four years from 2007-08. This funding was continued to mid 2012 and has since been extended.

**Table 2.2 Use of respite delivered through the NRCP**

Respite Type	Percentage of Users	Average Hours
Day centre	40%	9.5
In-home respite	36%	5
Individual and group community access	13%	~5
Overnight community respite (cottage)	3%	51.4 hrs (~ 2 nights/days per episode)
Other including mobile respite	7%	Variable hours

Source: 2010-11 *Report on the Operation of the Aged Care Act 1997*

### 2.2.3 Funding of respite

No comprehensive account of respite funding is available. The only program in which funding for respite is specifically identified is the residential care program. In the NRCP, respite services are likely to account for a substantial part of funding compared to information and counselling. Information is used by more care recipients, but on a one-off or occasional basis, and is a lower cost service. As both information and counselling support use of respite, total NRCP funding is taken as funding for respite.

NRCP funding of \$203 million in 2010-11 provides a useful benchmark for estimating the relative importance of respite funded through the other programs. In 2010-11:

- NRCP funding was 14% more than residential respite funding.
- NRCP funding was equivalent to some 10% of total HACC funding. Around 3 times as many HACC care recipients used respite as used NRCP respite, but far more HACC respite was relatively low cost centre-based day respite rather than more costly in-home, one-to-one respite or overnight respite. Allowing for these factors and likely lower hours of use per HACC user, HACC funding spent on respite estimated at 1.5 times NRCP funding would amount to \$305 million (\$203 million x 1.5), equivalent to 14% of total HACC funding.
- It is not possible to directly measure the amount of total package funding received that is used to pay for respite. However, an estimate can be made based on the recorded hours of respite used as a share of total package hours, and taking account of the relative cost of different services. On average, CACP clients used 2.8 hours of respite per week in 2008, which represents over half the total average of 5.4 hours of direct assistance, whereas EACH clients averaged 5.5 hours of respite per week out of a total average of 14.1 hours of direct assistance (2008 Community Care Census, p.39-41). Based on these hours, it can be estimated that respite might account for around 20% of Package funding. This estimate assumes that the hourly cost of respite is lower than the cost of personal care and domestic assistance on the basis that it involves use of day-centre-based respite services rather than one to one, in-home support. Note that the 2008 Community Care Census data are collected from a self-reported survey from the approved provider of the community care service.

The summary of these estimates in Table 2.3 shows that the largest share of all respite funding, just over one third, comes from HACC, with the other three programs each accounting for around 20%.

The fragmentation of respite delivery and funding across four programs, delivering different types of respite under different conditions, means that respite is currently less effective than it should be as a key element of aged care. The current arrangements give rise to many barriers to access for carers and care recipients and limit providers' capacity to respond to consumer needs.

**Table 2.3: Funding of respite care in Commonwealth programs, 2010-11**

Program		Program Funding \$m	% of total estimated respite funding
NRCP	Total	202.9	23.4
Residential respite	Total	178.2	20.6
HACC	Total funding \$2,106.8 Respite est. @ 14%	305.0	35.3
Care Packages	Total funding \$896.5 Respite est. @ 20%	179.3	20.7
<b>Total</b>		<b>865.4</b>	<b>100.0</b>

Source: Total funding for each program taken from *Report on Government Services, Productivity Commission, 2012*.

### 2.2.4 Recent trends in use of respite

#### Overview

Trends in use of respite provided under the NRCP and residential respite from 2007-08 to 2010-11 are detailed in Table 2.4.

#### Community based respite provided under the NRCP (Table 2.4, Part A)

Use of NRCP respite services increased closely in line with the increase of 13% in NRCP funding.

The proportion of all NRCP care recipients using respite services remained steady at just under 25%, and there was only a very marginal increase in the intensity of use by carers, as indicated the average hours of respite per carer.

The number of NRCP care recipients using counselling services declined quite markedly.

#### Residential respite (Table 2.4, Part B)

Use of residential respite increased well ahead of the growth of the population aged 70+.

Compared to the population increase of the 8.1%, all indicators of respite use increased much more; the number of individuals admitted for respite increased by twice as much and the number of respite beds days used increased by almost three times as much.

Residential respite use increased across the older population rather than intensity of use; the number of respite admissions per person, average stay per episode, and total respite days used per person were stable.

#### Balance of use of community and residential respite

Increases in the use of both community and residential respite are constrained by the funding and supply of services, but the figures above show that the balance has shifted somewhat towards residential care. For every 100 users of residential respite in 2007-08, 72 used NRCP, but by 2010-11, this had fallen to 69. It may be however that where NRCP services could not meet need, care recipients were referred to HACC respite services. No detailed data are available on the use of different kinds of NRCP services used or changes over the three years.

#### 2.2.5 Movement from respite to permanent care

The use of residential respite ahead of admission to permanent care has been increasing steadily over time (AIHW, 2011a:63, Table 6.4). Just over one third of those having a respite admission in 2010-11 were subsequently admitted to permanent care in that year; this proportion, 35.4%, compares to 30.0% making this move a decade earlier.

These figures are an undercount on two grounds:

- Individuals who are admitted to respite care and become permanent residents at the same admission are not counted in these figures.
- As these figures are limited to residents who used respite and permanent care in the same year and so under-estimate use of respite over a longer time span ahead of permanent care.



A fuller account of the use of residential respite is given in the Pathways in Aged Care Project (AIHW, 2011b) which analysed patterns of service use by care recipients over the two years following assessment by an ACAT in 2003-04. Focusing on the 34,400 who had not used any services prior to the assessment, 20% used residential respite over the next two years, almost all of them also using some community care services (HACC, Veterans Aged Care and/or care packages). Use of respite was highest among those whose recommended long term living arrangement was low level residential care, at 26%, and lowest for those with a recommendation for high level residential care. These findings indicate that use of residential respite may be especially effective in delaying entry to low care residential care until high care is needed, and that it may facilitate permanent admission should it become necessary.

## 2.2.6 Trends in provision and funding of residential respite

### Recent trends

Under the residential aged care planning process, there is no separate allocation of residential respite places. Rather, a portion of each permanent allocation is used for the provision of respite, and funding is provided according to the level of care required by individual respite residents. A continuing question is the extent to which use of residential respite matches the bed allocation, as numerous comments made in the consultations suggested that respite beds are also being used for care recipients receiving post acute care or waiting for a permanent care bed.

Provision and funding of residential respite in 2007-08 and 2010-11 is detailed in Table 2.5.

Three aspects of the trends in respite provision and funding warrant note.

1. Provision of residential respite bed days has grown more than twice as fast as total bed provision, at 22% compared to 8%. While the share of all bed days used for respite is small, this proportion has also increased by 14%.
2. Funding of residential respite has increased very substantially, with the increase of 40% well ahead of the increase in respite use. This increase is however not substantially ahead of the increase in funding for residential care overall, and the share of all residential care funding going to respite has increased only very marginally and in 2010-11 accounted for only 2.24% of total funding.
3. The residential respite supplement for high care respite introduced in 2007-08, has had a modest effect on funding and accounts for less than 10% of respite funding. The supplement is paid to providers offering high care respite and who reach at least 70% of the places they are expected to provide for respite. The supplement is a small addition to the residential care program budget, and reducing the threshold for qualifying for the Supplement from 70% to say 65% or 60% of places allocated to individual providers could stimulate further provision for relatively little marginal cost.

Table 2.4: Trends in use of respite, 2007-08 – 2010-11

	2007-08	2010-11	% Increase 2006-07 to 2010-11
Population 70+	2,000,755	2,163,500	8.1
<b>Part A: National Respite for Carers Program</b>			
Funding \$m*	179.5	202.9	13.0
Carers receiving information*	82,881	93,341	12.6
Carers receiving respite services*	28,425	31,862	12.1
Carers receiving counselling*	6,694	5,274	-22.2
Total carers receiving NRCP assistance*	118,000	130,477	10.6
Hours of respite*	4,300,000	5,000,000	16.3
Hours per carer using respite services	152	157	3.2
<b>Part B: Residential Respite</b>			
Respite admissions#	51,293	59,276	11.7
Persons admitted for respite*	39,530	46,146	17.0
Persons admitted for respite per 1000 70+	1.97	2.13	10.1
Respite bed days#	1,182,640	1,447,914	22.4
Average no of respite episodes per person	1.35	1.28	-
Average stay per respite episode	23.8	24.5	-
Ave total days per respite care recipient (average episode x episodes)	32	31	-
Total admissions#	105,030	118,178	12.5
Respite as % all admissions	48.8	50.2	-

Sources: \* Data on NRCP and residential respite from the *Report on the Operation of the Aged Care Act 1997*, 2007-08 and 2010-11

# Data on residential respite from *AIHW Residential Aged Care in Australia: A Statistical Overview*, 2007-08 and 2010-11.

## 2.2.7 Planning for respite

Use of residential respite has increased steadily over the last four years. Figures in Table 2.4 Part B show that the number of individuals admitted for respite increased by 17% between 2007-08 and 2010-11, and the rate of use of respite increased from 1.97 to 2.13 per 1000 population aged 70 and over. Provision of day respite by residential care providers has also grown and continued expansion of centre-based respite in residential aged care homes is supported by the findings of the evaluation of the demonstration day respite pilot initiated in 2007-08. Positive outcomes reported for care recipients and providers lead to continued funding for the initiative and clearer recognition of respite in the aged care planning process would now mainstream this initiative.

These trends call for clarification of the place of respite provision in the aged care planning process and specification of a ratio for funding to support continued growth. The current method of allocation of respite beds does not give providers flexibility to seek approval for a mix of bed-based and centre-based respite in the same way that they can apply for residential places and/or packages. By way of illustration, specification of a ratio of 3 places per 1000 aged 70 and over for respite would see 6491 places designated as at mid 2011. Funding these places at the average cost of respite beds used, \$45,459 would result in \$289.3m being made available for respite compared to actual expenditure of \$178.2m.

Inclusion of respite provision in the aged care planning process and calling for applications in the annual Aged Care Approvals Rounds could stimulate interest on the part of Approved Providers. Flexibility in delivery of respite could be further promoted by specifying targets in terms of funding equivalent to the current implicit target and allowing Approved Providers to apply for a mix of beds and day places, with unit prices set for each type.

## Recommendation 2

That growth, availability and flexibility of residential respite be supported through:

- The specification of places in aged care planning through a ratio.
- The allocation of new places included in the next Aged Care Approvals Rounds.
- Providers being able to apply for an allocation of places to use for both day and overnight respite to enable diversification of services and enhance continuity of care.

## 2.3 Consumer reports of respite use

A final view of the use of different forms of respite comes from the responses to the on-line survey and the evaluation of the Employed Carer Initiatives that delivered a variety of types of respite.

### 2.3.1 On-line survey respondents

Of the on-line survey respondents, 90% had used respite, and one in two had used more than one type. Centre-based community respite and in-home respite were used most widely:

- Just over half had used in-home day respite.
- One in three had used day respite in a local community centre.
- One in three had used overnight respite in a residential aged care home.

A wide variety of other services were also used but by far fewer consumers:

- Around 15% had used each of day respite in a centre at a residential aged care home
- Around 15% had used overnight respite in a respite cottage
- Very small numbers had used any other form of respite, including in-home overnight respite and respite in other settings such as holiday respite. While used by smaller numbers of carers, these diverse forms of respite play important roles in supporting those who use them.
- Carer support services of counselling and support groups or social events for carers were well received, each being used by 30-40% of respondents.

At the same time as reporting these high levels of use, one in four consumers had tried to use respite at some time but been refused. The two most common reasons for refusal were:

- The care recipient's care needs were too high. While this reason was given in all settings, inability to manage behaviour and dementia was a particularly frequent limitation for overnight respite in cottage settings. As was the refusal of a person post their admission to respite despite the carer being assured that high care needs could be provided for, in such situations carers or family members were required to take the person home again ahead of the agreed date.
- Short stays of a few days could not be booked in residential care homes where respite stays had to be for two weeks or longer. Having to make bookings months in advance and even then finding no respite beds were available was another reason for not being able to access residential respite.

**Table 2.5: Provision and funding of residential respite, 2007-08 and 2010-11**

	2007-08	2010-11	% Increase 2007-08 to 2010-11
Population 70+	2,000,755	2,163,500	8.1
<b>Total and respite bed provision</b>			
Total bed provision	171,832	185,482	7.9
Total bed days (beds x 365)	62,718,680	67,700,930	7.9
Respite bed days	1,182,640	1,447,914	22.4
Respite as % all bed days	1.88	2.14	13.8
<b>Residential respite funding</b>			
Funding for respite used \$m (2009-10)	\$127.3	\$178.2	39.8
Respite Supplement \$m (including in total respite funding above)	8.4	12.9	53.6
Respite supplement as % of all respite funding	6.6	7.2	9.1
Total residential care funding \$m	\$6002.9	\$7954.4	32.5
Respite as % of all residential care funding	2.12	2.24	5.6
Ave funding per respite bed used (respite funding/respite beds used)	\$39,290	\$ 45,459	15.7

Source: Report on the Operation of the Aged Care Act, 1997, for 2007-08 and 2010-11 and AIHW Residential Care in Australia: Statistical Overviews, 2007-08 and 2010-11.

### 2.3.2 Employed carers use of respite

The Employed Carers initiatives offered a wide variety of respite services, and the distribution of hours used shows the types of services that proved most useful and practically accessible for employed carers. Of the 97 services in the Extended Respite Services initiative:

- 60% of hours used were in centre-based day respite
- 18% were in in-home day respite
- Other day respite options of host-family, individual and group community access respite together accounted for only 6%.
- Overnight respite options accounted for around 10% of all hours, half in overnight community houses.

Of the 18 Innovative Projects, only six provided on-going respite and the others provided assistance to working carers through case coordination/care packages/brokerage, pre-employment and training for carers, working with employers, including a key worker project, and two research projects. Of the on-going respite services, the three centre-based projects attracted the largest number of users, while the host home projects had very low take up. The project that provided day respite only, to the largest number of care recipients had the lowest cost per carer; the higher costs and very low take up of home host respite suggest that this model is not viable.

### 2.3.3 What do consumers want?

Comments made by both consumers and providers in the consultations and the report of the Overnight Community Respite and Employed Carer Initiatives, together with the evidence of recent growth in use of community and residential respite indicate that demand already exceeds the supply of respite and that the shortfall is set to increase.

In this context, an important question for this review was to establish the priority needs of carers and provider capacity to respond for them. Part 3 takes up this question.

## 2.4 Unmet need

The AIHW report on Dementia in Australia 2012 presents several sets of analyses of data from the 2009 ABS Survey of Disability, Ageing and Carers (DACS) on the use of and further need for respite. These data focus on primary, co-resident carers, and far more people with dementia living in the community had such carers than those without dementia; conversely, they were far less likely not to have a carer at all. Fully 92% of people with dementia living in the community had a carer, about half of whom were co-resident.

Comparison of the use of respite of all kinds on the part of primary carers of people with dementia (dementia carers) and all primary carers (detailed in the AIHW report Table 4.30) shows:

- Far more dementia carers had used respite, some 40%, compared to just over 10% of all primary carers. Most of the use of respite was within the three months prior to the DACS Survey.
- Fewer dementia carers had never used respite, 61%, while some 90% of all primary carers had never used respite.
- The main reason for not using respite was that it was not needed; just over 60% of dementia carers said they did not need respite compared to close to 90% of all primary carers.
- Among carers who had never used respite, dementia carers were much more likely to report that their care recipient did not want the services than was the case for all primary carers, 30% compared to 13%.

A key finding is that the proportions of carers who needed and used respite matched for both dementia carers, at around 40%, and for all primary carers, at around 10%. These figures do not mean that there is no unmet need for respite as comparison of the need for additional support (detailed in the AIHW report Table 5.20) shows that:

- Just over half of all dementia carers reported a need for additional support compared to one third of all primary carers.

- The main unmet need reported by dementia carers was for more respite care, with 48% reporting this need compared to 15% of all primary carers.
- All primary carers were instead much more likely to report their main need as being more financial assistance, close to 40%, compared to less than 20% for dementia carers.

It is not possible to compare these figures with the level of use and unmet need for respite reported in the 2003 DACS, as detailed in the 2009 Alzheimer's' Australia Discussion Paper Respite Care for People Living with Dementia as that report drew on data for both co-resident and non-co-resident primary carers (Bruen & Howe, 2009: 18).

However, two of the studies summarised above provide some indicators that access to respite has increased:

- The survey of 336 dementia carers conducted by the Dementia Collaborative Research Centre at Queensland University of Technology in 2011 found that 77% had used respite and that the most common reason for not using respite was not needing it. These outcomes suggest that access to respite for dementia carers has increased since 2003 when it was estimated that only 31% of dementia carers needing respite had used it, another 27% needed but had not used respite, and 42% said they did not need respite.
- Campbell Consulting reported a number of aspects of use and satisfaction with respite. The results indicate that NRCP users gained a high level of access to needed respite, especially in-home respite.
  - The highest use was for in-home respite at 28%, another 25% used but needed more, only 6% were unable to get in-home respite and some 40% did not need in-home respite.
  - A similar proportion used centre-based respite, 25%, but only another 9% used but needed more and 5% were unable to access community based respite; some 60% did not need community based respite.
  - smaller proportion had used or needed residential respite, 11%, but another 11% had used and need more and 8% could not access needed residential respite; 70% did not need residential respite.

The higher level of respite use by carers of people with dementia calls attention to the need to strengthen the capacity of all respite services to provide for care recipients with cognitive loss and disturbed. Means to this end by way of increasing use of the Dementia Behaviour Management Advisory Service (DBMAS) by respite services, and extending the Dementia Supplement for Home Care Packages to all forms of respite, and enhancing dementia-specific approaches in all types of respite are taken up in the next parts of this report.

## Recommendation 3

That a dementia supplement be provided for eligible recipients of all forms of respite in line with the dementia supplement for eligible Home Care package recipients. The supplement will increase the subsidy payable in respect of an eligible care recipient by 10 per cent in recognition of the higher costs of caring for people with dementia.





# 3. CONSUMER EXPERIENCE WITH RESPITE

## 3.1 Satisfaction with current respite services

Satisfaction with current respite provides some important insights into how far increasing flexibility in the delivery of respite might require new and different forms of respite compared to greater flexibility in the delivery of the kinds of services that are currently available.

One indication of satisfaction is whether carers who had accessed different types of respite services would use them again. High proportions of respondents to the review on-line survey reported that they would use services again: 90% or more for in-home day respite and for overnight respite in a residential aged care home or respite cottage; around 85% for day respite in a community based centre or in a residential aged care home. The numbers using other forms of respite were too small to give reliable results for comparison. Respondents who used counselling, support groups and social events for carers appear very satisfied, with over 95% saying they would use these services again.

Further reports of satisfaction are given in four of the recent evaluations summarised in Table 1.2. The reports of high levels of satisfaction among respite users point to the aspects of respite that are most important to consumers and that should be pursued in developing further services, and conversely, indicate areas of actual and potential dissatisfaction that need to be addressed.

### 3.1.1 Respite care in dementia care: carer perspectives, 2012, Dementia Collaborative Research Centre at Queensland University of Technology

Three out of four of the 336 carers surveyed in this project had used some kind of respite over the preceding year, with many using more than one type of respite. Approximately half had used each of in-home day respite, centre-based day respite and residential respite, with 6% using emergency respite and 19% some 'other' type. At least 85% were either satisfied or very satisfied with each type of respite, and over 90% wanted to continue using the respite services they received. Carers' proxy reports of satisfaction on the part of the person they cared for showed somewhat lower satisfaction, particularly for residential respite (62% satisfied or very satisfied).

Just on one in four had not used respite, and the main reasons they gave were that they had never needed to use respite, followed by the person with dementia refusing to attend.

### 3.1.2 Evaluation of the Consumer Directed Care Initiative, 2012, KPMG for the Department of Health and Ageing

This evaluation found that over 80% of carers using both 'standard' NRCP respite and CDC respite care agreed or agreed strongly with several statements about satisfaction with different aspects of the respite services they used. While more of those who received CDC respite were likely to agree strongly with these statements, satisfaction with the several wider areas of independence and relationships compared to six months previously was lower, and markedly so for the standard respite

group, and there was no significant difference in overall wellbeing scores, using a standard measure (ICECAP-O).

The report notes that these outcomes may have been at least in part due to CDC carers receiving more services than they had previously, and that the two groups in the study thus had different points of comparison. Whereas all those in the group who received 'standard' respite were already receiving NRCP respite, many of those in the CDC group had not previously been using respite: only 16% had accessed any NRCP support, about 50% had used HACC or some other community services, but just under 30% had not used any services and prior service use for the remaining 5% was unknown. This difference in prior use of respite is especially likely to have affected reported levels of satisfaction compared to six months prior to time of the evaluation. Receipt of respite had a strong positive impact on the lives of those who had previously used no or little services, compared to those who had experienced little if any change in respite use.

These caveats mean that it is as valid to conclude that satisfaction increased with access to more services, so that higher satisfaction cannot be attributed solely to CDC compared to standard respite. There are also implications for the design of future evaluations.

### 3.1.3 Evaluation of the Overnight Community Respite and Employed Carers Respite Initiatives: Final Report 2009 Urbis

This evaluation found high levels of satisfaction two types of respite that have widely differing levels of use.

Overnight respite in community houses rated very highly among the 50 carers surveyed:

- Over 90% reported that they were very satisfied with the friendliness and attitude of staff.
- Around 85% were very satisfied with communication, the extent to which the service took account of the needs and wishes of the person being cared for, and the quality of care.
- Between 65-75% reported they were very satisfied with affordability, flexibility, availability and the amount of service available (e.g. the number of nights on any given stay).



The survey of over 350 employed carers using services provided through the employed carers initiative also found high levels of satisfaction, and among those reporting that they were very satisfied or satisfied, the majority were very satisfied. These proportions were

- Over 90% reported that they were satisfied with the friendliness and attitude of staff, and a similar level of satisfaction was reported for quality of the care provided (78% and 68% very satisfied respectively).
- More than 80% were satisfied with communication, the extent to which the service took account of the needs and wishes of the person being cared for, affordability, flexibility and accessibility of the service.
- Only satisfaction with the amount of service provided was markedly lower, at 74%, and the proportion who were very satisfied, 40%, was the lowest for all aspects of the services.

In generalising from these findings, it has to be noted that cottage respite is not widely available and many of the small group of carers who were surveyed used the service only once. In contrast, among the wide array of 97 respite services offered through the extended services initiative for employed carers, centre-based day respite was by thus far the most used, and it was used on an on-going basis. The findings of the larger scale survey can be more readily taken as applying to other centre-based day respite.

### **3.1.4 Evaluation of the Carer Support Measures Stakeholder Report, 2008, Campbell Research and Consulting**

This project conducted a mail survey of NRCP users, with close to 1500 returning a completed survey. The response rate of 25% (out of 5951 surveys distributed by NRCP providers) is satisfactory for a survey of this kind. The survey asked respondents whether they agreed strongly or agreed with a number of statements about respite. Fully 81% of carers reported that respite helped them continue caring, and the 92% who would recommend respite to others gives a strong endorsement for respite. 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. Carer ratings of in-home and centre-based respite were very similar, with around 65-80% giving a rating of excellent or good to respite giving them a proper break, being beneficial for the care recipient, being available at a suitable time, and being at a suitable place from both the perspective of the carer and care recipient (residential respite was not rated). In contrast to these high levels of satisfaction, only half of all carers reported that they were able to get enough respite and that it was easy to get. The main conclusion that can be drawn from these findings is that priority has to be given to increasing the quantum of all forms of respite that is available.

### **3.1.5 Value of Alzheimer's Australia and Carers Associations as brand names**

The positive profiles of well established services delivered by Alzheimer's Australia and Carers Australia and through their state bodies demonstrate the value of 'brand labels'. Carers were very positive in their acceptance of services that were clearly identified as most relevant to carers and those living with dementia.

The role of respite in supporting the carer and the client in their community and not just in the home was also noted. The need to recognise that 'family' and 'community' could have different meanings for different groups was a central issue raised in the CALD consultations.

## **3.2 Consumer preferences and priorities: more day centre and in-home respite**

### **Why consumers prefer in-home and day centre respite**

Respite in day centres and in-home respite are the most widely used forms of respite, and carers want more of both these forms of respite. Presented with a choice between these types

of respite, two out of three respondents to the review on-line survey opted for more centre-based respite and one third for more in-home respite. This question attracted a large number of further comments and many of these comments showed that many carers wanted more of both so they could choose the type of respite that best met their needs at different times.

*"So I could have time to freely make changes to the house in safety and have time to myself to re-vitalise and maybe go out for a coffee with friends."*

*"Respite in day centre is good when it is suitable to the person's interests, engaging, stimulating and meet their level of physical activity."*

Four sets of reasons were given for opting for centre-based respite: the care recipient enjoyed the opportunities for social engagement and activities in or outside the centre; their needs were met, including needs for dementia care; benefits for carers by way of giving them time to do other tasks and to socialise; and assisting working carers.

In-home respite was preferred for somewhat different reasons: care recipients were more comfortable in familiar surroundings, they had high care needs that could not be catered for in a day centre, and some care recipients resisted using day centre respite, but benefits for carers were mentioned far less often.

*"Home care is what (the person I care for) really wants! If they don't know where they are, or what is really going on around them, then it may not matter as much."*

*"Because mum feels more comfortable in her own home and gets more anxious and confused at out of home day respite."*

*"Mum's never been one to go to clubs or outings etc. and make new friends, it's not part of her makeup and now as she's gotten older it's more challenging."*

Further comments showed that rather than choosing between centre-based and in-home respite, many carers wanted more of both rather than having a strong preference for one or the other. Having both options would give carers the choice to mix and match respite to their needs at different times.

***"I personally would like to have both. More hours of care at a day centre is good, so long this can fulfil the needs of my husband, by providing outings for example, and more respite care in our home is good too, as this is good for his needs. But all these can become very costly, unless more benefits are given to the carer."***

***"I believe one on one care in the home is more beneficial for someone who has dementia. However, isolation away from the community is not beneficial. More hours at a day centre should be available for when needed."***

Giving high priority to increasing the quantum of these types of respite also opens the way for addressing other consumer priorities for longer hours in day centres, more choice of activities in centres and more trained staff in both in-home and centre-based respite services. Expansion of centre-based and in-home respite will also enable demands for increases in respite arising from the growth of packages to be met with packages funding used to purchase respite services.

***"I know the stimulation of the company of others and the activities they do is good for mum and she is in the care of qualified staff."***

***"Person affected with the disease (AD) is able to socialise more with others, and the outings and activities arranged is also stimulating for the person affected."***

***"Being able to access day respite and just drop them off in the morning and pick them up in the afternoon is such a help."***

***"My husband enjoys company, and as I am getting older I am getting more tired, however they can only accommodate him for 6 hours 1 day a week because of the great demand on people to be cared for in our community."***

***"Although Mum is now in a nursing home, a few hours of respite, provided by a carer in my home, would have been helpful."***

***"My mother receives 3 hours per week respite carer services. She has been assessed and approved for EACH, but we are still on the waiting list for a provider. There should be another category between the current two types of assessment CACP and EACH/EACHD. The 3 hours per week that the CACP provides is not adequate for many Carers - if this could be increased to 10 hours per week that would be of enormous help to most Carers."***

The following aspects of both in-home and centre-based respite are identified for attention to make these services more responsive to consumer needs

### **3.2.1 More hours and more flexible hours of operation**

Many carers who had only 2-3 hours respite on one day a week wanted more hours a day, and on more days. More hours in centre-based respite were most commonly called for, with more hours of in-home respite raised less often. More places for residential respite were also wanted to give carers more frequent breaks, and to reduce long waiting times experienced

by some carers. Residential respite beds being used for other purposes (post acute, transition care, or by individuals waiting for long term care beds) along with rigid time limits (minimum of two weeks respite must be used) were often given as reason for lack of availability in residential respite. Provision of transport to and from day centres effectively added to respite hours by reduced demands on carers' time.

***"I work from 9 to 5. It takes 30 minutes to go to the day centre. It is difficult for me to come to the office at nine after dropping my mother. I hope the day centre can have longer opening hours."***

The most common call with regard to flexible hours was for longer hours of operation, beyond the usual 10am to 3 pm hours of many day centres. Longer operating hours were however mentioned far less often than just more hours. Extended hours were especially sought by carers who were striving to continue working, in particular someone caring for a person with younger onset dementia. There were very few mentions of workplace measures, such as changes in work hours, that could facilitate balancing work and caring that included using respite care. Opening at weekends was mentioned less frequently.

### **3.2.2 Timing of access**

Lack of timely access was the main factor that kept carers from using respite when they needed it. Two out of three respondents to the on-line survey had this experience. 93% of respondents said that the most important change in respite would be to have respite available when it is needed and on the days that is needed. Many carers found coordinating and arranging services more complicated than they need to be due to the many agencies they had to contact for assessment, to find out about services and secure referrals.

***"I would like to see the process of admitting someone into the Respite Centre/Nursing Home be simplified. The admission on waiting list should be shortened. Provide more Emergency Respite Services when needed."***

Long waiting times were mentioned mostly in relation to residential respite, although consumers and providers both mentioned instances of community care service providers closing their books as the waiting periods were too long. Waiting times for booked respite varied considerably, from two weeks, which was thought reasonable, to six weeks, and in one case, 17 people on a waiting list for three respite places made access very unlikely. Being able to access planned community respite was often cited as a barrier to accessing respite that impacted on the carer being able to receive an adequate break. Being able to get respite when the need arose at short notice was raised more often than, and distinct from, emergency respite which was raised in very few instances.

### 3.2.3 Making access easier

While growing numbers of carers are using respite, the most common barrier that carers reported was difficulty in navigating the system. Complexities in assessment and other administrative processes were compounded by differences in requirements from one provider to another. Providers also called for standardised processes and this issue is taken up further in Part 4.

***“Got told in my assessment process to tick respite whether we needed it or not as if you did want it later down the line it was vital you tick it now. There was a lot of confusion about what respite was and how to access it.”***

***“I just stumbled across respite. My whole journey was filling in forms and getting services by stumbling across them.”***

Some carers felt they did not know how to access services and were left not knowing what to do next. In some cases, eventually getting respite was a matter of luck rather than good planning.

Several instances were given of consumers being ‘left in the lurch’ when good services came to an abrupt end because short term funding for pilot projects or other experimental services ran out. Such instability in the service system was very disruptive.

Many carers also raised concerns about the person they cared for that posed barriers to accessing services, including resistance to using services on the part of the care recipient. Ways of addressing these concerns are taken up in discussing carer support below.

### 3.2.4 Flexibility in activities in respite programs

The suitability of activities within day centres and residential respite was of concern to many carers, to the point of deciding not to use services. The need for activities to be responsive to the needs of all care recipients was recognised as a vital part of any service provision. Carers of people with all types of dementia and in particularly younger onset dementia, and of carers of people from CALD backgrounds often raised their concerns about the need for variety and flexibility in activities to suit individual care recipient needs and for different programs at different times.

Day centres are widely used by care recipients who do not have a carer as well as being a setting for respite. Enhancing the activities provided would benefit all care recipients, regardless of the reason they are receiving care. There was support for linking carer support groups and counselling to day centres so carers could attend support groups and activities while their care recipient was at the day centre, as well as being involved in the day centre if they chose to, especially at the first use of a day centre.

***“Having a stranger to look after mum in our home is a big issue of trust for us. The carer has to be able to speak the language. A day centre that is accessible readily, comfortable for mum and has someone could speak the language.”***

The other issue raised at several consultations was the value of having therapy services as part of respite care, in both day centres and residential respite. This issue is of particular relevance to the integration of Day Therapy Centres into the Home Support Program, but is beyond the scope of this review.

### 3.2.5 Responding to cultural and linguistic needs

The most common response to meeting the respite needs of CALD care recipients was to have bi-lingual workers in all settings, whether day centres, in-home respite and residential respite. Not all providers are however able to realise this outcome notwithstanding considerable effort to do so.

The availability of respite varied for different CALD groups, with longer established communities having more, but still not sufficient, access to respite services than smaller and more recent communities. Two ways of addressing these needs were proposed. One involved building capacity in CALD community organisations, to move from self help to formal services. The second noted that some seniors centres for CALD groups, as distinct from day centres, at times refused to allow members to attend when their dementia or other care needs progressed, and ways of extending the capacity of these centres need to be considered. In the longer term structural changes in delivery with CDC seem more likely to yield more dividends, subject to the evaluation proposed below.

### 3.2.6 Responding to dementia care and other high care needs

The high need for respite care on the part of people living with dementia is indicated by some three out of four NRCP clients caring for someone with some degree of dementia. People with dementia also account for a larger share of users of EACH and EACHD packages compared to people without dementia who are much more likely to be CACP clients. Half of the respondents to the review on-line survey reported that changes in the availability of dementia specific respite would be important for them.

***“Newly arrived groups are setting up local ‘caring communities where people (some are working carers) take it in turn to provide in-home respite in their house for all the elderly people in their community. They don’t know how to access services and have a fear of government involvement have a fear of government involvement (having to have an ABN, policies/ procedures and formal processes etc). However, government involvement could build more capacity in the community; engagement with younger generations; assistance with space, transport, access to community facilities.”***

In-home respite was favoured by many carers of people with dementia because of the difficulties associated with using day centre respite, ranging from the care recipient feeling more comfortable at home; overcoming reluctance to attend a day centre, lack of transport and finding a program that suited the individual. At the same time, managing difficult behaviours, not being trained in dementia care and lacking knowledge about dementia limited the extent to which family members could be called on. Comments made in the on-line survey showed that the answer for many dementia carers was a mix of in-home and day-centre respite. The importance of social engagement and activities was also emphasised.

***“I believe one to one care in the home is more beneficial for someone who has dementia. However, isolation away from the community is not beneficial. More hours at a day centre should be available when needed.”***

***“Respite must provide stimulating and appropriate activities for the person receiving care.”***

***“Respite should have meaningful, interesting, and appropriate activities that suit the person’s interests and they should be treated as a human being with individual needs.”***

Access to respite for people with early onset dementia was a particular difficulty and rigid application of age-based criteria was an additional barrier in some cases.

***“Special knowledge is required when caring for an Alzheimer’s person. Most friends/ family members do not have appropriate training/expertise/understanding. There are also the OH&S & insurance implications.”***

***“There is an urgent need for younger onset day centres with specially formulated programs for this sub-group of dementia people. More intelligently thought out and diverse activities are needed as well as a greater ratio of properly trained personnel.”***

Many dementia carers reported problems in finding suitable respite services that could manage behavioural and psychological symptoms of dementia (BPSD) and provide activities tailored to their care recipients capacities and interests. Incidents of both day centres and residential respite services being unable to manage were not uncommon, and often lead to the carer being asked to take the care recipient back home. An alternative response is clearly needed and calling on the psychogeriatric outreach services is one step that all services could adopt to enhance their capacity to manage BPSD. Carers recognised the value of having staff with dementia care skills and ensuring that staffs are available in as many day centres as possible is another step.

***“Respite time should be utilised to the maximum, especially for clients with dementia. The respite should be planned to suit the client’s level of functioning. Doing a Life Story Book is a brilliant idea. It will not only provide a meaningful time for the client but it will also be an enjoyable time for the respite provider. The book will also be a treasure of memories for the family when the client passes away.”***

***“As Dementia has many forms - respite needs to be structured to suit. Perhaps different respite care for Alzheimer’s and vascular dementia as they are so different and needs are so different.”***

***“I think there should be more variety in dementia respite. Currently the respite that I access is for severe dementia cases with substantial cognitive loss, whereas my mother can still hold conversations, albeit not logical or historically factual (quite fanciful, really). There should be some sort of half-way house respite for those dementia sufferers who don’t like to spend time with ‘those people with dementia’”***



### 3.3 Overnight respite preferences

The difference between the large number of consumers using residential respite and the much smaller numbers using overnight cottage respite has to be taken into account in comparing experiences in overnight respite.

***“It’s having someone able to take mum to appointments when I am working and being able to access overnight respite care when needed that is most helpful for us”***

#### 3.3.1 Overnight cottage respite

Only a small number of respite cottages are operating and less than half as many respondents to the on-line survey had used this type of overnight compared to overnight respite in a residential aged care home. While overnight respite in a cottage setting was spoken of highly and seen as very appropriate for people with dementia, the small scale of these services with limited staffing restrict their capacity to cater for people with dementia. Another factor limiting the capacity of cottage respite to care for clients with high care needs was the lack of nursing staff and inability to manage medications.

Consumers’ comments reflected both sides of cottage respite: while the small group setting, staff familiarity and home like environment were seen as an advantage, especially for people with less demanding needs, it did have some limitations.

***“Cottage respite is a very good model.”***

***“Cottage is not as good as (the person being cared for) cannot remove themselves if they feel uncomfortable in the small intimate setting.”***

#### 3.3.2 Residential respite

Two major experiences with residential respite were reported many times by carers and providers. The first was the difficulty in finding a respite place, especially for care recipients with high care needs. Consumers could not find vacancies, reporting that they could have to book up to 12 months ahead, or they found that providers had closed their books. Permanent residents were seen to take priority over those wanting respite, and carers felt that beds meant for respite were not kept for that purpose.

Second, the time periods for which respite could be used were inflexible. Residential respite was commonly offered only in blocks of two weeks or more and did not suit carers who wanted short periods of respite, such as a weekend or a short break.

***“Cannot get in, must book really far in advance.”***

***“Beds are full of permanent people even though they are supposed to be respite beds.”***

Some concerns were also expressed about the quality of respite in residential care homes as respite residents were not given enough attention by way of activities and dementia care needs.

***“It is easier to cope as a carer and find respite for someone with low care needs, it becomes more difficult to care for someone as they start to have higher care needs, and respite becomes harder to find.”***

Three avenues for enhancing respite in residential care homes emerged from the consultations and evaluation studies. The first is to expand provision of day respite co-located with residential care homes so that consumers develop a relationship with staff and familiarity with the environment that can facilitate use of overnight respite. Second, residential respite could be enhanced by adopting positive features of cottage respite. Third, the

professionalisation of respite would lead to improved quality of care for care recipients. Good practice approaches to these kinds of development are discussed further in Part 6.

### 3.4 High care respite

The most difficulty was encountered when trying to access suitable high care respite. Whether it was in-home, in a community based centre or overnight cottage, or in residential care, the need for more one-off, ongoing and planned high care respite was cited in all the consumer consultations.

***“Mixed blessing leaving someone in a place over night for a period of time.”***

***“Causes distress to leave them there as they want to come home with you.”***

### 3.5 Carer support concerns

In addition to the concerns raised about the provision of care services and types of respite, three issues of carer support were raised more frequently than others: financial impacts and the cost of caring; emotional needs; and working carers.

#### 1. The financial impact and costs of caring

Concerns about the financial impact of caring were commonly raised in both the 2011 and 2012 consultations and in both on-line surveys. Two issues that attracted particular comments were:

1. The inconsistencies in charges for HACC services and packages
2. The marked impact of the costs of EACH and EACHD packages and of residential respite on households and other costs associated with care giving, which were not offset by the Carer Allowance.

The need for more uniform arrangements for charging fees for home support services is flagged for attention in LLLB, in particular in relation to increased transparency through the introduction of CDC to all packages. Addressing different charges will become more urgent with the expansion of packages and introduction of two new levels of packages as higher charges for packages present a barrier to access compared to continuing use of HACC services. In addition to resolving fee differences across aged care services, carer capacity to meet the extra costs of caring could be enhanced by treating pensioner carers and recipients of care packages in the same way as when a spouse is admitted to residential care: that is, both receive the Age Pension at the single rate, with means testing is applied accordingly.

***“At present, I am a 7X24 hr carer and not able to work. I would like to get a part time job so as I can stay in touch with the society and make friends. Since I left work, I lost all my work mates, contacts and friends.”***

There appears to be some confusion about the respective roles and conditions applying to Carer Allowance and Carer Payment in the wider social security system. Some criticisms were made of the way in which Centrelink supported carers, or failed to do so, especially in the case of carers who were not eligible for Carer Payment. Carers also raised the need for a superannuation contribution to be attached to the Carer Payment as part of the compensation for having to give up work. This issue is beyond the scope of the review but the Australian Human Rights and Equal Opportunity Commission has engaged the Social Policy Research Centre at the University of NSW to carry out an extensive research project into Valuing Unpaid Caring Work as part of the Commission’s work on redressing gender inequality and ensuring women’s lifetime economic security.



**“The person I care for does not want to accept the diagnosis of dementia and therefore do not want to access respite “**

## 2. Emotional needs

Addressing the emotional needs of carers was the second most commonly raised carer concern, and was raised particularly in the CALD consultations. Many positive comments were made about the benefits of counselling and information that had been received at the time of diagnosis, but this support did not appear to continue through all stages of the dementia journey. The difference between carers' use of counselling and respite in the figures presented in Table 2.1 show that six times as many carers used respite than has received counselling support.

There was a need for counselling to be available at the point where respite was being considered. In particular it was raised in relation to overcoming carers' concerns about reluctance or resistance to using respite on the part of the person they cared for as well as what some felt was the stigma associated with being a carer and feeling there was an expectation that they should be able to cope.

Ongoing counselling was also seen to be very helpful, and in addition when respite arrangements changed or came to an end when the care recipient was admitted to permanent care. Linking carer training and other support group activities to respite services was also raised.

Closer links between counselling and respite are a feature of good practice and are discussed further in Part 6.

## 3. Working carers

The main concerns of working carers raised in consultations were around their need for longer hours of operation in day respite, and being able to use respite on more days each week. The evaluation of the extended respite services initiative for employed carers not only reported similar needs, but found that increased access to day centres made a major contribution to supporting employed carers.

For many carers, the balance between staying at work or leaving was easily tipped, with social as well as financial costs. For a number of carers who wanted to return to at least part work, having more day respite would make the difference.

For both working carers and carers who wanted to work, access to on-going respite gave them an opportunity to take stock of their situation and to plan ahead, for themselves and for the person they cared for, including planning admission to permanent residential care. The extended services initiative especially gave carers a greater sense of control and choice over the respite services they wanted to use.

The evaluation pointed to the need for employed carer initiatives developed through the NRCP to be better integrated with the wider aged care system. Accordingly, no distinction is made between these initiatives and the rest of the NRCP in the proposals for a new program structure for respite discussed in Part 5.

The importance of supporting working carers and non-employed carers who want to work is evident in a report on barriers to mature age employment prepared by the National Seniors Productive Ageing Centre (2012). Much lower workforce participation among caregivers compared to all mature age workers (aged 45 and over) had significant impacts on current earnings and future incomes in retirement. More flexible work arrangements were the main means to enabling carers to work more hours or to return to the workforce.

## Recommendation 4

That flexibility in the provision of respite be promoted through:

- Removing boundaries between types of respite and allowing providers to adjust the types of respite they deliver within their allocated funding to meet consumer demand.
- Accountability that is achieved by reporting, not by the application of detailed service types in funding agreements.
- The allocation of additional funding to respite in *Living Longer. Living Better.* to meeting the high demand for centre-based day respite and in-home day respite, with a priority to deliver respite to:
  - People with dementia and other high and complex care needs.
  - Carers and care recipients from culturally and linguistically diverse backgrounds, particularly through recruitment and training of staff with cultural skills that match local community populations.
  - Supporting meaningful social engagement and activities that meet consumers interests and preferences and takes into account their age, gender, location, health, care needs and level of physical ability.

## Recommendation 5

That attention is given to ways of reducing direct and indirect cost barriers to the use of respite by:

- Uniform arrangements for charging fees under the Home Support Program
- The Age Pension for carers and package care recipients being assessed and paid at the single rate on the same basis as a couple with one partner in residential care.
- A focus on growth funds targeted at supporting caring families to participate in employment.



# 4. PROVIDER EXPERIENCES IN DELIVERING RESPITE

As a preface to reviewing provider experiences in delivering respite, brief accounts of the nature of respite provided in each program and the providers involved are given to provide some background to the scope and nature of change that might be required under alternative program structures. These accounts demonstrate the fragmented nature of provision that underlies the need for a new program structure to facilitate access for consumers and streamline management for providers.

## 4.1 Provider involvement in multiple programs

No comprehensive account of provider involvement in more than one of the programs delivering respite is available. One indicator of the extent of involvement in multiple programs is available from the reports on package programs and the NRCP in the 2008 Community Care Census which detailed the number of service outlets that served clients of those programs only, or clients of more than one of these programs.

Delivery of services only to clients of the respective program was much more common for NRCP and CACP outlets:

- 270 (55%) of the 490 NRCP outlets and 526 (55%) of the 943 CACP outlets delivered services only to clients of the respective program; the balance of 45% of outlets of both programs were involved in multiple programs.
- In contrast, less than 5% of the 302 EACH and 185 EACHD outlets delivered services only to those clients; the great majority of these outlets also delivered CACPs.

Many outlets delivering these four programs also delivered other programs. Most notably, 47% delivered HACC services, and 23% delivered DVA services (on a much smaller scale).

Only 12% of the outlets delivered residential care. This relatively low figure is due to counting on the basis of service outlets, so involvement in multiple programs is only identified where the residential care home is the outlet for the community care program. Counting on the basis of provider involvement shows much more extensive involvement in multiple programs, through outlets that may be co-located or at different sites. Thus, the 54 CRCCs operating as at September 2012 came under the auspices of 40 provider organisations. Excepting HACC, these 40 providers were identified as being involved in other programs in addition to NRCP as follows:

- 15 were involved in packages and residential care
- 7 were involved in package programs
- 3 were multi-purpose service providers
- 1 was involved in residential care only.
- 5 were carer organisations
- 9 were other providers whose involvement in other programs could not be identified but they appear likely to be involved in at least HACC and possibly disability services.

The extent of overlap of providers involved in NRCP, packages, HACC and residential care has important implications for designing and implementing a new program structure for delivering respite. A comprehensive account of the current involvement of all providers in the four programs is an essential

pre-requisite to monitoring changes in respite and other arrangements as the implementation of LLLB proceeds.

The AIHW would be the most suitable agency to conduct an audit of all providers currently delivering all forms of respite to provide a baseline account of the delivery of respite against which progress and outcomes of the consolidation of the NRCP into the Home Support Program can be monitored.

- The audit should begin with an analysis of all data and information currently held by the Department of Health and Ageing.
- Further data on respite provision should be collected as part of a Community Care Census that replicates and extends the Community Care Census conducted in 2008 to include all HACC providers, to provide a comprehensive account of community care provision and provider roles in delivery of different services at the beginning of the Home Support Program.
- The audit should clearly distinguish providers delivering respite directly from those using brokerage to avoid double counting and to enable monitoring changes in the balance of direct delivery in relation to brokerage.
- The Community Care Census should be repeated in three year time to track the effects of implementation of the Home Support Program on service provider roles and structures and delivery of respite and all other community care services.

## Recommendation 6

That the Australian Institute of Health and Welfare be commissioned to conduct an audit of all respite providers to provide baseline data on which respite in the Home Support Program can be monitored.



## 4.2 The need for a new program structure

The review consultations gave providers the opportunity to identify aspects of current programs which were working well and areas for improvement. While the findings reported below are broadly consistent with provider views reported in the research and evaluations studies already cited, it should be noted that the majority of discussions in the consultations focused on the NRCP.

Therefore, comments and experiences may not reflect the views of providers delivering respite through other programs, and the client group these providers serve may not be representative of all users of respite. However, they provide a more in depth view of NRCP providers and services and how any changes to NRCP might affect the wider aged care system.

Providers identified five main barriers to delivering flexible respite, and changes to make respite more responsive to consumer needs focused on addressing these barriers. For the most part, provider views reflected carer concerns, although from a different perspective, but this was not the case on all issues and there were some differences of views among providers.

### 4.2.1 Inflexible funding rules

The major barrier faced by providers in responding to consumer need was the very limited scope they had for shifting funds allocated to some types of respite to other types. Even within the one program, only narrow margins were allowed for shifting funds between categories of respite, a problem compounded by numerous and narrow categories, some of which accounted for very small shares of clients and funding.

With eight out of 10 providers delivering more than one type of respite, and almost all brokering at least some services, it is evident that these problems were widespread. Almost all the providers participating in the consultations delivered in-home day respite, with about half providing centre-based day respite. The next most common types were overnight respite in cottages or other settings, and far fewer provided in-home overnight respite or day respite in a residential care home. It should be noted that these reports were for whether or not the provider delivered each type of respite and do not take account of the volume of respite or the numbers of clients using each type.

When asked about demand for different types of respite, in-home day respite rated highest. Interestingly, while demand for overnight respite was lower, residential respite rated equally with cottages and other settings, and in contrast, demand for in-home overnight respite was minimal. It was surprising then that when asked how, given the opportunity, they would move funding between different types of respite within their current funding, one third would increase in-home overnight respite, the same proportion as would increase in-home day respite.

Nine out of 10 providers used some funding for brokerage and half reported that brokerage gave them much more flexibility in meeting the needs of all or most of their clients. At the same time, these providers had only limited experience of counselling and other carer support services. Taken together, these problems point to the need for any changes in program arrangements for NRCP and other respite to move away from narrow specification of types of respite and instead to allocate funds to a broad stream of respite.

### 4.2.2 Administration and eligibility criteria

Only one in five providers reported that flexibility in service delivery was inhibited by current administrative arrangements and reporting requirements other than the restrictions on how funding could be spent, as noted above. Aspects of administration attracting comment were the mismatch between reporting categories and actual expenditure categories, and too much time having to be spent on documentation.

### *“NRCP is the most bureaucratic of all programs.”*

Eligibility criteria, other than age, were identified as a source of inflexibility by around one third of providers, but no comments were made that expanded on the nature of the criteria that were problematic. Confusion over age criteria arose in cases where an older carer was caring for a younger relative, particularly when the relative was in their 50s, and did not fit readily into programs for much younger people.

The single change that would do most to streamline administration was having standard processes and forms for assessment and referral for all services. Electronic transfer of forms was also called for, with recognition of the need for consent before records were shared with other providers. Any change to program arrangements needs to address this area as consumers also identified concerns with differing practices for assessment and referral, including being required to fill out multiple, different forms.

Further streamlining is needed in brokerage arrangements. Brokerage was seen as providing flexibility, but often involved very complex contracting for relatively small amounts of service. Brokerage was particularly valuable in securing services for clients with special needs, such as engaging a support worker with the same language and culture as a client, and its continued use might focus on such cases rather than becoming a more widespread model.

A further source of inflexibility as to how funding could be spent at the individual client level rather than at the program level was identified in the differing fee schedules for care package clients compared to those accessing respite through HACC and NRCP. Almost half of the providers experienced such restrictions that ‘pushed them to be creative’ to meet care recipient needs. Evidence that perverse incentives were at play came from a number of providers who observed that package clients would be provided with in-home respite ahead of a preference for day respite because of a higher level of cost recovery from the package provider.

Providers strongly supported package clients being able to access respite over and above their package funding as well as within their package to ensure their respite needs were fully met. As noted above, instances of package clients accessing NRCP were infrequent, and the implementation of the new Level C packages should obviate the need for care recipients to access respite outside their packages to meet needs that required services that exceeded CACP funding.

In contrast to increasing flexibility in eligibility, stricter criteria appear to be required within residential respite to preclude the use of respite beds for post acute, transition care or individuals waiting for long term care beds. A number of instances were reported of post acute clients taking precedent over respite clients in gaining access to residential care beds or beds already being occupied by those waiting for a long term bed, when neither respite nor transition care beds are clearly designated and reserved for specific use. This problem was compounded in rural areas where respite, along with post acute, transition and long term residential beds were all co-located in the hospital.

### 4.2.3 Responding to special needs

Providers were aware that they could not always respond to special needs. Some four out of ten providers identified persisting problems in finding staff with language and cultural skills to match all carers and care recipients from diverse backgrounds. In addition to finding adequately skilled staff with relevant language skills, providers noted the difficulties in finding staff who can transcend and move between different community and cultural needs. As noted above, brokerage may provide a solution to some of these problems, depending on location, availability of skilled staff and brokerage services available.



Somewhat different limitations were encountered in Aboriginal and Torres Strait Islander communities. Traditional respite models are not wanted and ways had to be found to support carers from Aboriginal and Torres Strait Islander communities who focused on finding respite through their own networks, and intergenerational programs were also found to work well.

#### 4.2.4 Experience with Consumer Directed Care

Providers present at the consultations had limited experience of CDC; only one in four had any involvement with the CDC trials and few had any other experience.

Against this background, support for options involving cash payments was mixed. Providers were asked to indicate their level of support for the options of giving consumers cash instead of services, and for enabling carers to pay family members or friends to assist in providing respite. The even spread of responses across the four categories that ranged from 'strong support' to 'do not support' suggests that many providers are undecided on these issues. The small number of further comments suggests that providers had not formed views on these options, and had insufficient experience or information to express informed views.

Comments on paying family members pointed out that this approach occurred in the disability field and in the Victorian Transport Accident Commission, and that experience should be drawn on. Other comments raised the question whether such payments would affect means testing for the Age Pension, and flagged risks of financial abuse of the care recipient.

While some saw considerable benefits in cash options by way of giving consumers greater control and greater transparency overall, others expressed uncertainty about the capacity of carers to manage cash in lieu of services, and commented that take-up of a cash option could create uncertainty as to demand that could adversely affect service provision. The potential impact of providers having to bear hidden costs of CDC was also noted.

#### 4.2.5 Anticipating change

When asked about possible options for a new program structure for delivering respite care, there was no clearly preferred new approach. Maintaining the present arrangements was however very clearly the least preferred option. Many of the comments made on changes that would facilitate delivery of more flexible respite called for respite to become more of a mainstream service and core business for providers. As one provider put it, "respite is always the bridesmaid and never the bride." Three features that new program arrangements should strive for were flagged:

1. Staff roles need to be enhanced at all levels, with examples including:
  - Case managers need the knowledge, skills and time to take both carer and care recipient needs into account to make respite more couple and family oriented.
  - A shift in the role of brokerage towards advocacy for the consumer rather than just purchasing of services.
  - Staff with special skills, such as language and cultural skills, need to be shared across agencies to make the best use of resources in providing consultancy support as well as direct services.
  - An increase in more specialised respite training and an increased focus on respite in Certificate 3 training.
  - Considerable training will be needed to advance the implementation of CDC.
2. Carer counselling should be available and provided on an ongoing basis, for carers who wish to access it, in conjunction with respite to assist them overcome reluctance or resistance on the part of the care recipient to receive care, cope with separation issues, provide emotional support as well as providing day to day support to maintain carer health and wellbeing. The view of respite as being for the care

recipient as well as the carer endorsed the adoption of a wide definition of respite. Recognising that respite was a common step towards possible admission to permanent care if dependency and care needed increased further, counselling in conjunction with respite had a particular role to play in helping carers and care recipients plan ahead for such eventualities.

3. Increased attention needs to be given to ensuring cost effective options are developed ahead of more expensive options. While rigid funding of different types of respite can limit supply of lower cost options and push consumers into higher cost options, funding that is not restricted in any way might not necessarily lead to the most effective use of total budgets or allocations to individuals. In this regard, one advantage of increased consumer direction was that it would increase transparency as to the cost of different choices. While cottage respite was well received by those who used it, its limitations precluded use by others, particular those needing higher levels of care. The small scale of cottage respite also means it is a relatively costly option and further development of this option should have to demonstrate cost effectiveness.

Realising these features in new arrangements for respite requires a professionalisation of the management of services, a shift towards respite as a core part of provider business models, the development and promotion of training and career opportunities for respite workers and industry recognition.

Promoting good practice as a main means to this end is taken up in Part 6.





# 5. PROPOSALS FOR A NEW PROGRAM STRUCTURE FOR RESPITE

## 5.1 Aims of developing a new program structure

The overall aim of any alternative program structure is to eliminate, or at least substantially reduce, the boundaries between types of respite to give consumers more choice of the types of respite they wish to use and to give providers more flexibility in the types of respite that they can offer in responding to consumer needs. The key questions to be answered in considering a new program structure are:

1. Should all respite from HACC, NRCP and residential respite be brought together (a) to form a single Respite Program or (b) be part of the Home Support Program?
2. If all respite is delivered through the Home Support Program (option b above), should it be amalgamated with the rest of the services or maintained as a separate service stream?
3. Further to (2), should Package clients and their carers continue to be able to access respite both within and outside their package, or should the scope of packages be narrowed to focus on direct client care services, mostly personal care, nursing and domestic assistance, and respite be accessed outside the package?
4. Does a proposed ratio for funding of respite in the aged care planning process give rise to any further considerations that need to be addressed in a new program structure?

Consumer, provider and policy perspectives present some different considerations to be taken into account in answering these four questions.

### From the consumers' perspective, the key considerations in increasing flexibility are:

- Access to a wider range of respite services within a single program, with consequent simplified arrangements for access, assessment and referral;
- Access to other community care services that clients and carers may be using at the same time as using respite, including Home Care Packages;
- Opportunities for further development of CDC, taking account of the balance of preferences for accessing respite services.
- The availability of more person centred care that provides and meaningful social engagement and activities that meet consumers interests and preferences and take into account their age, gender, location, health, care needs and level of physical ability.

### From the providers' perspective, the key considerations are:

- Flexibility to diversify their provision of respite in response to consumer preferences, for example, by removing boundaries between different types of respite and enabling trade-offs between residential respite places and increased day centre places and/or in-home respite, with all types of respite able to incorporate more activities in the wider community. Providers who already deliver more than one form of respite, including day respite through centres co-located with residential care homes, are especially likely to be interested in such trade-offs.
- Feasibility of delivering respite, which will depend on many factors such as the range of respite currently provided,

capacity to set up other respite services, and the capacity to enhance the range of respite delivered through existing outlets compared to setting up new outlets. A central aspect of feasibility is the extent to which an alternative program structure can promote diversification of respite services by drawing on providers' existing infrastructure, both physical and organisational.

- Efficiency and reduced administrative costs in both managing client records and program reporting for different kinds of respite and in conjunction with other programs. It should be noted that increasing flexibility for providers does not reduce accountability as any new program structure will include reporting requirements, wherever respite is placed in the overall aged care program.
- The implications for respite services in States that have not transferred HACC to the Commonwealth.

### From a policy perspective, the key criteria are:

- Consistency with the broader reform strategy as set out in LLLB.
- The extent of change involved in implementation and complexity of transition arrangements, including possible incentives and disincentives for further development of respite services.
- Changes in several other aspects of the delivery of respite that would require further policy decisions are beyond the scope of this review. Such areas include user charges, total funding levels, the continuing role of existing providers vis-a-vis entry of new providers, and ACAT assessment for access to packages and residential respite.

## 5.2 Answering the key questions

### 5.2.1 A single Respite Program or amalgamating all respite with the Home Support Program?

Question 1 asked whether all respite from NRCP, HACC and residential respite should be brought together (a) to form a single Respite Program or (b) should respite be part of the Home Support Program?

#### Strengths of a single Respite Program

The main strength of a single Respite Program is that the identity of respite in the aged care program would be clearly maintained and increased.

For consumers, other benefits would come from access to all forms of respite through providers who participated in the Respite Program, with a single set of eligibility criteria and conditions. Choice of the type of respite would also be enhanced, particularly with CDC using personal budgets that would enable consumers to compare the cost of different combinations of respite services and decide what they considered best value for the resources available for their care.

For providers, a single Respite Program would maximise flexibility in the use of funds for different kinds of respite. Increased opportunities to deliver more types of respite directly could reduce the need for providers to broker different kinds of

respite from other providers, but would not remove the option of using brokerage as required to meet consumers' needs.

In policy terms, this option is consistent with CDC approaches in delivering respite. However, requiring all respite to be accessed through the Respite Program would limit flexibility to choose respite within packages and from the Home Support Program.

### **Limitations of a single Respite Program**

Against these strengths, there are a number of conceptual and practical limitations in designing and implementing a single Respite Program. A central difficulty is that respite as a service specifically for carers has to be separated from services that also benefit care recipients. This separation runs counter to the wider definition of respite as a service that has benefits to carers and the care recipient, and in many cases, it would be difficult to decide whether the primary beneficiary of respite was the carer or the care recipient.

A number of more specific limitations are also identified. A new boundary would be created for consumers using community based respite together with other services delivered through the Home Support Program; these consumers would potentially need to access respite through the Respite Program and other community services through the Home Support Program and/or packages.

The further limitations for providers are that many would continue to be involved in administration of up to four programs: Respite, Home Support Program, Home Care Packages and Residential Care, and there will be added administration in separate accounting for respite used by carers of package clients.

The main practical implementation concern is the considerable and complicated scale of change from present arrangements in excising all respite services from HACC and packages. The number and volume of these providers exceeds the number of providers currently involved in the NRCP; as estimated above, HACC accounts for around one third of all respite funding.

From a policy perspective, maintaining a separate Respite Program is inconsistent with amalgamating NRCP and HACC into the Home Support Program and will require continued administration of four programs.

In States that maintain HACC as a joint Commonwealth-State funded program, a separate and fully Commonwealth funded respite program will achieve benefits of increased flexibility within respite but not across the wider service spectrum and will impose an additional administrative burden on providers.

On balance, the limitations of a single Respite Program outweigh the benefits, and placing respite in the Home Support Program emerges as the stronger option.

### **5.2.2 A separate respite service stream within the Home Support Program**

If all respite is brought into the Home Support Program, the second question is whether respite should be maintained as a separate service stream, or amalgamated with the other services in the Home Support Program? The answer to this question will depend on the extent to which current service streams of NRCP, HACC, Day Therapy Centres and Assistance with Care and Housing for the Aged are maintained in the Home Support Program in general.

### **Strengths of a respite stream within the Home Support Program**

The advantage of a separate respite stream is that the identity of respite as an important component of aged care would be maintained. In addition, funding would be earmarked or ring-fenced, enabling monitoring of use and annual adjustments in line with changes in consumer needs and preferences, as occurs to some extent in HACC currently.

Creating a single respite stream would allow funding boundaries to be collapsed between program types, reducing administrative

processes, and give flexibility to providers to adjust the types of respite they deliver within their funding to meet consumer demand.

For consumers a single respite stream would give access to a wider range of respite services from a single program allowing simplified arrangements for access, assessment and referral and would maximise consumer choice of types of respite in line with CDC.

A separate stream would also be in line with the National Carer Strategy in recognising the importance of carers and their access to respite services.

### **Limitations of a respite stream within the Home Support Program**

While maintaining a separate respite stream within the Home Support program would give consumers and providers more flexibility within respite, it could limit choices between respite and other services in the Home Support Program.

Moving the major share of funding of community based respite that is in the HACC program to a separate stream would raise much the same practical problems as excising it and moving it to a separate Respite Program.

The strengths of creating a separate respite service stream within the Home Support Program outweigh the limitations. On balance, the review sees some short term advantage in ensuring the prominence of respite as a component of the Home Support Program, pending a decision on whether the totality of Home Support Program funds are to be accessed on assessed needs basis in response to client needs, including respite.

### **5.2.3 Access to respite within and outside packages**

The third question is whether package clients and their carers should continue to be able to access respite both within and outside their package, or should the scope of packages be narrowed to focus on direct client care services, mostly personal care, nursing and domestic assistance, and respite be accessed outside the package?

Conceptually, taking carer respite out of packages runs counter to the goal of packages being to provide integrated support to the care recipient that requires recognition that carers play an integral part in supporting many care recipients to remain at home. Similarly, it would be difficult if not impossible to separate services that have a respite function for carers from use of the same services by clients who do not have a carer.

Both these difficulties are evident in the case of CACPs: almost 60% of CACP clients have a carer, and respite for these carers would have to be accessed outside their package, but at the same time, CACP clients who do not have a carer would continue to access day centres and related services through their package. Higher proportions of EACH and EACHD clients have a carer, but the same difficulty arises.

Limiting packages to direct client care services and taking access to respite for carers out of packages is also inconsistent with a wide definition of respite that encompasses care recipients as well as carers. This move would create a new boundary for package clients and their carers seeking to access respite, and this new boundary may be a complication for package providers who currently deliver respite to their clients.

In practical terms, the extent to which package clients access to NRCP respite outside their package appears limited. The report on use of different services by package clients in the 2008 Community Care Census is informative on this question: respite was used by only some 5% of CACP clients, 25% of EACH clients and about 33% for EACHD clients, whereas over 80% of CACP clients and over 60% of EACH and EACHD clients used domestic assistance, and the proportions using personal care were 40%, over 80% and around 75% respectively.



Use of HACC respite by package clients is however not known. The differences in the use of respite by CACP clients and EACH clients suggests that once needs for personal care, nursing and domestic assistance have been met, a considerable share of the additional funding that is available through the higher level packages goes to respite. It might be expected that some of the additional funding in the proposed Level C care packages might go to clients using more respite than was available in CACPs, and would obviate the need to access additional respite through HACC or NRCP.

Requiring all package clients to access respite externally risks a considerable cost shift if funding allocations were not adjusted between programs and package levels. While freeing package resources for use on other services, there could be a considerable cost shift to the Home Support Program for respite used by package clients.

On balance it would seem preferable to leave access to respite within packages, and allow access to additional respite outside the package when necessary, noting that the new Level C packages should reduce the need for accessing respite outside the package.

#### **5.2.4 Implications of amalgamating residential respite funding with the Home Support Program**

Recommendation 2 opens up the opportunity to amalgamate residential respite funding defined by a ratio in the aged care planning process with the Home Support Program. Such a funding transfer presents opportunities to address concerns raised about the availability, flexibility and quality of residential respite raised in the course of the review. These opportunities would not arise if this funding remained as part of the residential care program.

#### **Strengths of amalgamating residential respite with the Home Support Program**

Flexibility in respite provision through Recommendation 2 would be furthered by transferring funding for respite from the residential care program to the Home Support Program. Providers would be able to develop a full suite of types of respite to respond to consumer needs. Consumers would increasingly be able to access the mix of respite most appropriate to their needs without having to go to different providers. At the same time, integration of respite with other services delivered by the same provider would enhance continuity of care for clients using different types of respite and other services over time.

Many providers already receive funding from HACC, NRCP, packages and the residential care program to deliver a variety of respite services and other services. Amalgamating residential respite with the Home Support Program would further motivate them to develop respite as a major component of their community care services rather than operating it as a sideline to permanent care. The quality of respite would be enhanced by three broad opportunities that would be opened up. First, providing overnight respite in a designated wing or unit rather than in scattered beds is recognised as more effective. Second, developing day respite that could support overnight respite clients alongside day respite clients rather than expecting them to fit into the routines of permanent care residents. Third, adoption of features of cottage models that are seen as good practice is discussed in Part 6.

For both consumers and providers all respite administration would occur from one place, making the system easier to navigate and allow more flexibility in respite provision.

The application of a ratio for respite funding in the aged care planning process would facilitate the transfer of funding by defining an aggregate amount to be transferred, with block funding to providers based on allocated places rather than the current claims based approach to funding residential respite.

#### **Limitations to amalgamating residential respite funding with the Home Support Program**

Transferring residential respite to the Home Support Program would narrow the scope of the residential care program to permanent care only and could risk continuing growth in provision of residential respite. In assessing provider responses to changes in program structure, it has to be recognised that a proportion of all residential care homes do not provide any respite currently and are not likely to do so under any program arrangements. On the other hand, those providers who are already committed to respite provision are likely to respond positively to a program structure that offers them scope to expand and diversify their respite services.

A new program structure will have most effect on residential care providers who currently make only limited provision for respite. While some may decide to hand back existing allocations for respite beds and provide only permanent care, changes in the sector suggest that providers are increasingly moving in the opposite direction and expanding into community care. The LLLB package overall offers providers a number of new opportunities for such development and integrating residential respite funding with the Home Support Program furthers these objectives.

Figure 2.1: Current Program structure for provision of respite

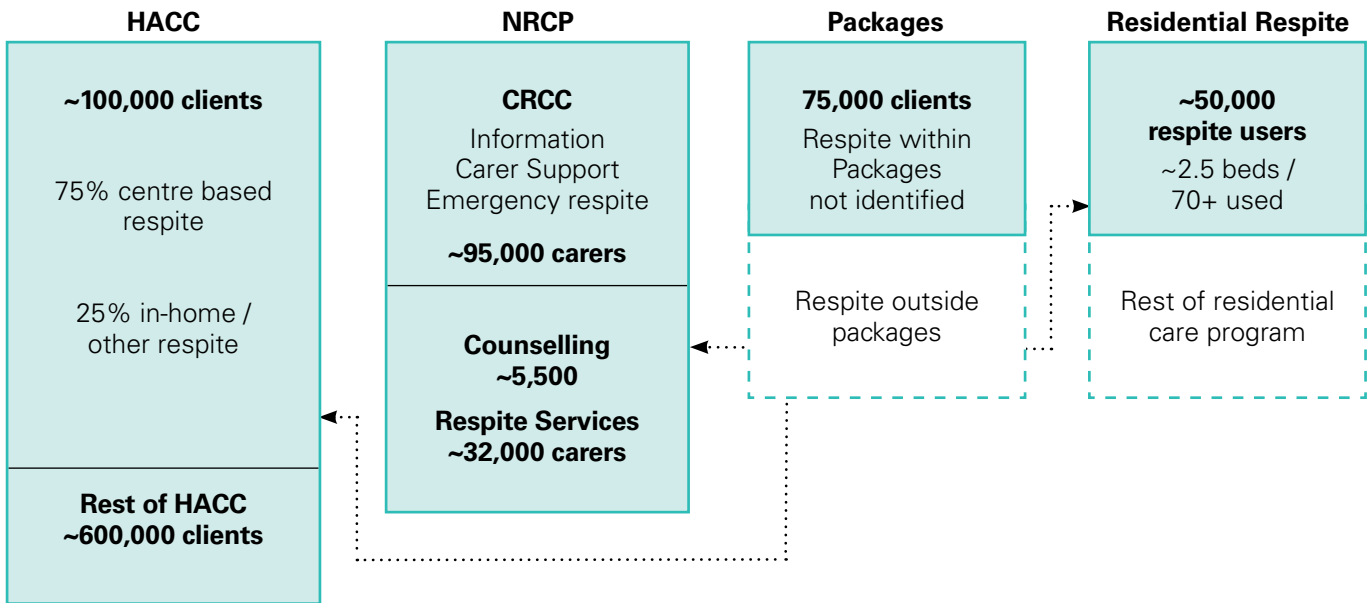
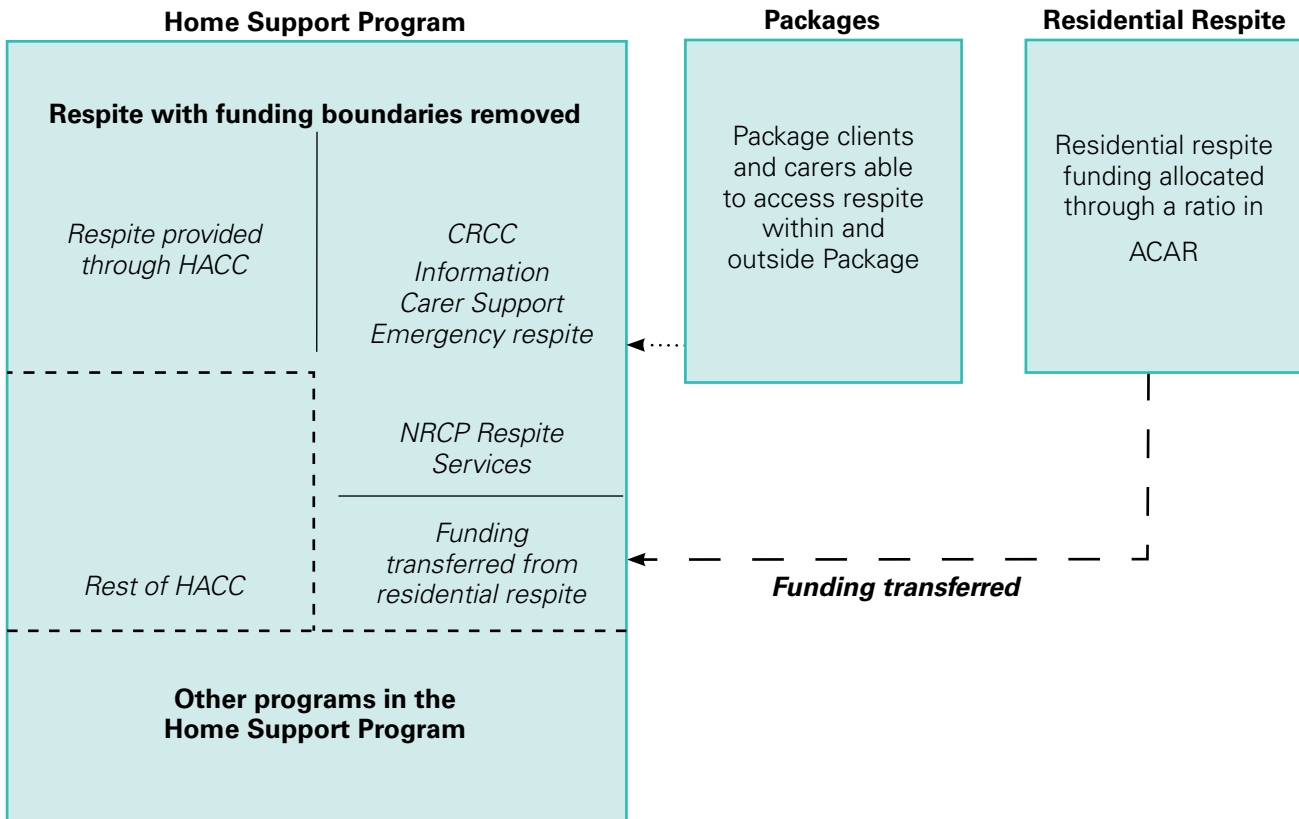


Figure 5.1: A new program structure for respite from 2015



### 5.3 A new program structure

Based on the answers to the questions posed above, the most effective new program structure for the delivery of respite is to have all respite from NRCP, HACC and residential respite integrated into the Home Support Program, as set out in Figure 5.1 (Figure 2.1 provided for comparison to current structure).

This new program structure has four main strengths for consumers:

- It provides increased consumer choice not only between types of respite, including respite in a residential aged care home, but between respite and other services within a single program.
- Package clients retain the choice of respite within or outside their package.
- The scope for CDC is maximised.
- Improved quality of residential respite through more flexible funding options along with the adoption of good practice.

Gains for providers are:

- Increased flexibility and reduced administrative processes in delivery of respite in conjunction with other community services and in response to changes in consumer demand.
- Package providers can continue to deliver respite as part of packages.
- Administrative efficiencies from having to be involved in only three programs: Home Support Program, Home Care Packages and Residential Care for permanent care.
- In policy terms, the new structure allows:
- Changes that are consistent with the wider reform agenda of consolidating the NRCP and HACC in the Home Support Program.
- The approach to packages, combined with the scope of respite services within the Home Support Program, to be consistent with the broad definition of respite that recognises benefits to clients as well as carers.

Increased consumer choice in line with CDC.

### Recommendation 7

That funding for the National Respite for Carers Program, a defined ratio of residential respite places, and respite provided through HACC, be consolidated as a component of the Home Support Program at the commencement of the program in 2015.

This program structure is designed to:

- Promote flexibility in the types of respite provided in response to consumer needs and preferences, in line with Recommendation 4.
- Enable Package users to access respite within and outside their package.
- Enable all consumers to choose the mix of respite and other services that best meet their needs across the full spectrum of services in the Home Support Program, in line with Consumer Directed Care.
- Provide opportunities for residential care providers to participate in the Home Support Program and diversify their respite services and adopt good practice approaches to enhance quality of services.

Two main avenues for furthering flexible respite provision and consumer choice were raised in the consultations, by both consumers and providers:

1. Developing options involving direct cash payments that enable carers to pay family members or friends; receiving cash instead of services, and trialling a CDC approach that included the option of direct payments; and
2. Promoting good practice in all forms of respite.





# 6. FURTHERING FLEXIBLE RESPITE PROVISION AND CHOICE

## 6.1 Options involving cash payments

Consumer Directed Care is aimed at giving consumers greater choice and control over the services they use, and cash payments are one means to this end. Rather than seeing the choice as being between provision of services or cash however, it is more useful to consider several points along a continuum. Such a continuum developed in 1999 by the Roeher Institute, a disability agency in Canada, demonstrates the spectrum of control that ranges from the state as fund-holder to individual control. The schema was designed to have wider applicability, and Figure 6.1 is based on it. Application to the current Australian scene in aged care shows that:

- A number of options that are fully consistent with individualised funding and offering a high degree of CDC do not require direct cash payments to individuals; conversely, cash payments are only one of a number of possible approaches.
- Practices in place in Australia can be fitted along the continuum, with a number already being consistent with principles of individualised funding.
- There is not just one but many approaches to CDC that offer consumers a range of choices as to how far they wish to manage the funds allocated to their care.

A range of options offered in schemes in England involve setting Personal Budgets and Direct Payments, and for convenience, the English terminology is used here.

The trials of CDC packages and respite conducted in 2010-11 involved setting personal budget and providing increased consumer choice over how their budget would be spent, but did not provide cash payments. The review aimed to extend the discussion of CDC to options involving direct cash payments by asking two questions in the consultations and the on-line survey:

1. If you had the option of paying family members or friends to assist you in providing care, would you make use of this option?
2. If you were given money instead of services, would this be helpful?

***“Familiarity is all important to someone with dementia so family and friends more appropriate and reliable. Also understand Mum’s needs/ interests better.”***

***“Peace of mind knowing that I do know and can trust the person in my home to care for my vulnerable family member.”***

### 6.1.1 Paying family members or friends

Half the survey respondents reported that they would take up an option of paying family members and friends if it was available, and half did not. Three out of four who answered this question made further comments and these showed some ambivalence and qualifications rather than simple support or not for this option.

#### Reasons for supporting paying family members and friends

The overwhelming reason for supporting this option was that the person engaged to provide care would be known to the carer and care recipient and familiar with their needs and situation; carers said they would be happy to have the person in their home and trust them.

Being able to pay family and friends was also widely seen as having benefits for the carer and the care recipient by way of being more flexible and easier to arrange, with family being partners in care, giving increased choice of respite options, and being able to reward those who gave support.

At the same time some consumers saw risks and in particular resistance from the care recipient. Others would only want to pay family or friends in particular situations such as an emergency. A number also saw considerable contradictions: why should family and friends have to be paid, why should they be paid when the carer was not paid, and blurring boundaries between formal and family care.

***“Over time mum has made friends, people from her own country, neighbours, friends she’s made in church. Mum’s been able to help these new friends over the years and would be more receptive to their help in return. She would be more willing with the idea of respite in the care of familiar friends. I know she would feel safe, be more relaxed and happy. This care could be provided in our home, where she is familiar with her surroundings allowing her some independence. This would also have a positive impact on the dynamics between us all at home too. I know she would have trust and confidence in such a situation, as we would too. I’d much rather leave mum in the care of someone who was well known to us than someone unknown.”***

***“I have some very good friends and I know they would help if needed but I wouldn’t ask them unless I could pay them something.”***

**Table 6.1: A continuum of approaches to Consumer Directed Care, Personal Budgets and Direct Payments**

Conformity with principles of individualised funding	Relationships between government and individual for allocating and accounting for funds	Some current Australian approaches
Arrangements that do not conform	Individual service costs identified, but only as accounting exercise within block funding	Unit costing of HACC services
	Services costed and allocated individually but accessed and controlled by fund-holder.	
	Standard allocation of vouchers issued to individual for 'purchase' of services	
Marginally consistent	Individually determined credits which individuals can trade for services from authorised providers.	Most case management, including case management using brokerage.
	Responsibility for service planning and funding requirements notionally passed to the individual but overseen by 'broker' answerable to government fund-holder.	
Fully consistent	Individual allocation passed to fiscal intermediary, to be spent according to the person's requirements, but subject to contractual constraints from government fund-holder.	CDC Package and CDC Respite as piloted in 2011.
	Individual allocation of money, passed to the individual, subject to binding conditions of use, with monitoring arrangements.	Victorian Transport Accident Commission
	Individual allocation of money passed to individual with no imposed conditions of use.	Carer Allowance

Source: Modified from Table 1 in Dowson, S. & Salisbury, B. (1990) *Individualised funding: Emerging policy issues*. Paper prepared for the Roeher Institute. Toronto.

***“If there was a different funding model - this would be the best option. I would like not to impose of trusted family and friends to stop gap me - but for payment. Bear in mind that as a carer for \$300.00 per wk plus \$100 allowance and utilities - one has to be there 24x7 and report nights and days away to Centrelink.”***

***“Excellent option I have had experience of this. It provided a good match as often the care recipient knew the person and were familiar with their family situation and preferences. Difficulties are with insurance and risk management, training, liability in some forms of personal assistance.”***

***“I care for my wife who is very anti care from strangers and institutions. To have a friend to assist would be very helpful. Though this type of care could be fraught with dangers, especially from the point of accidents, work care etc.”***

**Reasons for not supporting paying family members and friends**

Reasons for not supporting paying family members and friends fell into three groups, with some responses raising more than one issue. First, many respondents gave reasons associated with family relationships, both from the side of the carer and the other family members: paying did not fit with values of family care, it was not necessary, and it could create potential for conflict.

***“My mother would be insulted to think her friends or family would be paid to care for her - she would***

***think they do it for her because of their loving/friendly relationship with her.”***

***“This causes a concerning imbalance in a family relationship. I don’t want my relative being my boss - and what happens if they are unhappy with the paid care I provide and they want to sack me? Because it creates conflict. Other family and friends who help and are supportive withdraw their help if another family member or friend is being paid (from experience in a former caring role).”***

The second set of reasons were associated with limited availability of family members: family did not have time due to other commitments, the carer had no family or they were too far away.

The third set of reasons focused on the nature of care, the skills required and responsibilities: caring was too demanding and would impose too much responsibility on family and friends who did not have skills and might not be able to manage, and the need instead was for workers with skills and knowledge, especially of Alzheimer’s disease.

***“Too much of an imposition on the family’s time. Also, too emotionally draining for all concerned. Care needs to be provided by someone who is experienced. It becomes too hard for family or a friend to do this job.”***

***“My answer is a resounding NO if it means giving up the informed and committed professional carers who have worked with my mother for approx 4 years.”***

### 6.1.2 Money instead of services

One in three respondents to the review on-line survey answered yes to the question "if you were given money instead of services, would this be useful?" This level of interest points to carers wanting to explore approaches that could offer more personal and individualised services.

#### Reasons for supporting money instead of services

By far the most common reason for supporting this option was that it would enable more personalised respite, choice of workers and purchase of respite that was better suited to needs, with a number of comments referring particularly to needs of care recipients from different cultural backgrounds.

*"Could be used where and when the need arose... to purchase services privately and not have to apply or go through a service provider."*

*"To arrange respite to suit mum's needs at times and with workers that are appropriate and to help pay for 3 or 4 days of day centre so that I can continue to work."*

*"I would use it basically the same way mum's package is used. The only difference is that I would choose respite workers from among our own family, friends and neighbours that mum is comfortable with and pay them for their help; e.g. among our friends we have a Greek woman in her early 50's whose husband recently passed away leaving her a widow who needs to work to provide for her family. She is more than willing to help but I'm not comfortable to ask her for unpaid help. Being a carer for such a long time has had a financial impact on my family and I'm not in a position to make her an offer. It's such a shame because her circumstances and our circumstances are a perfect fit."*

Purchase of different services (other than respite) was also mentioned. Some further comments mentioned that it would enable family and friends to be paid, or help with paying for services.

Several respondents said this was a difficult question to answer, said 'yes and no', or indicated that they were not sure. Some also said it was hard to envisage such an option.

*"I would use it to make changes to accessibility in the home to make things easier for my father and less stressful for me in caring for him."*

*"Receiving money would not have solved any difficulties, but it would be very helpful for us to pay the fee for respite."*

#### Reasons for not supporting receiving money instead of services

Reasons for not supporting this option were that services were preferred, that it would place more demands on the carer to organise services, and that money would not compensate for the costs associated with caring, nor overcome some of the other barriers faced when trying to access respite.

*"Money will not buy you a vacancy."*

*"Not sure, but it would be good to have a choice or a bit of both."*

*"Difficult to answer as personnel available to access respite are not always available in a small town. It is just one more task I would have to do."*

*"Please, think carefully, this is just another job I would have to do, and then you would ask me to do a balance sheet every year, just let me support my loved one and get the Case Manager to manage the funds."*

*"In my experience of receiving money e.g. continence scheme, subsidised respite, carer payment etc is that it devalues whatever it supposedly compensates. No amount of money can ever make you feel worthy or respected. Money doesn't even compensate, financially what you have to spend, scrimp, do without. It's almost a poke in the eye - makes you realise how much it doesn't compensate."*

### 6.1.3 Provider experiences and support for cash options

While cash payments are only one of many approaches CDC, it is evident that providers have limited, and seemingly varied, experience with Consumer Direct Care of any kind. Support is also varied, probably reflecting experience and understanding of CDC approaches.

#### Provider Consultations

Of the providers participating in the consultations, around one in four reported they had been involved in the Commonwealth trials of CDC respite and packages, but very few had any other CDC experience. Support for a CDC approach that provided cash instead of services was fairly evenly divided between those who supported or strongly supported the idea, and those who did not support such options.

It is evident that considerable work will have to be done to advance CDC practices as proposed in the LLLB package. While LLLB only specifies that CDC will only apply to Home Care Packages, it is difficult to see how CDC could be constrained in practice. Consumers are likely to want to exercise choice beyond a limited range of services and practitioners are also likely to modify their practice in assessment and case management for all care recipients, whether or not they are to be offered support specifically on a CDC basis. A number of service providers are already experimenting with CDC approaches, short of a cash option, and in these circumstances, there would be considerable value in a well structured trial of a direct payments. Some of the key features of such a trial are outlined in Section 6.4 below.

### 6.1.4 Carer Allowance

A large component of cash payments already exists in the Australian aged care system by way of the Carer Allowance. Total expenditure on Carer Allowance is now about the same as expenditure on HACC. Take up of Carer Allowance is also high. Just on three out of four of those responding to the review on-line survey received the Carer Allowance currently or had received it at some time when a carer. This level of take up is consistent with take up among all primary carers; not all primary carers as defined in the ABS surveys meet the eligibility criteria for Carer Allowance.

Use of Carer Allowance is totally at the discretion of the recipient. Most survey respondents did not use the Allowance to purchase services, and of those who did, services were purchased only occasionally.

### 6.1.5 Other cash payments

Other cash payments that are made under transport accident insurance payments were noted in the consultations. It is also expected that the National Disability Insurance Scheme which is currently being piloted will provide cash payments, but only in very exceptional circumstances.

While both these cases are limited to particular circumstances, they have one particular implication for aged care: one on hand, insurance based funding does not automatically confer entitlement to cash payments, and on the other, direct payments can be made through any funding system and do not require insurance based funding.

Whatever the funding arrangements, the Roeher Institute emphasises that central and local fund-holding agencies not only have responsibilities for ensuring that personal budgets provide individuals with adequate assistance, but must also demonstrate financial responsibility for public expenditure and services. The latter responsibilities imply the need to monitor the actual use of funds and quality of services, noting that a number of market failures mean that market forces alone will not ensure that services are effective in responding to need or that they are delivered efficiently or equitably.

### 6.1.6 Trialling Direct Payments

The level of interest in direct payments indicates that a trial is warranted. The trial and evaluation of CDC packages and respite, other experience in the field and the growing body of research and evaluation findings calls for careful planning for such an exercise.

A trial of direct payments should begin with a scoping study of the benefits that such an approach may hold compared to budget holding by the service provider, and drawing on evaluations in Australia and overseas. Consideration should be given to offering a range of choices in the trial, including personal budgets with case management as well as direct payments. The findings of the scoping study should then inform the decision on whether to proceed with a trial, and if so, how. The trial should have a robust design, including proper control groups, and be on a sufficient scale and duration to allow outcomes to be compared and assessed.

## Recommendation 8

That a scoping study be conducted for a trial of direct payments as an option within Consumer Directed Care approaches in the second half of 2013.

## 6.2 Good practice in respite

A wide range of good practices in respite were nominated by consumers and providers and many specific services were identified as offering high quality respite that was responsive to carers and care recipients. At the same time, it is apparent that some community respite providers have limited contact with residential respite services, and vice versa. When seen as part of continuous quality improvement, good practice can be achieved in all services, and the task is now to promote good practice. Features of good practice were identified in consultations, the on-line survey, in research and evaluation reports, and in a number of services named as providing high quality respite.

This section begins with a summary of the elements of good practice that were common to all types of respite, and then outlines approaches that are specific to one or other form of respite. With the prospect of more providers being able to offer a range of types of respite, careful consideration has to be given to the balance between centre-based and in-home respite, including cost-effectiveness. The different types of respite are best seen as complementary rather than competing and consumers need to be able to choose the mix of services that suit them best rather than having to make an either-or choice.

Particular attention is given to translating good practice from community centre-based day respite and overnight cottage style respite to day and overnight respite in residential aged care homes.

In the longer term, ensuring that the findings of the Australian Human Rights Commission work on valuing unpaid carers are taken into account in developing aged care programs that provide support for carers.

### 6.2.1 Common features in good practice across respite settings

A number of features of good practice for carers, care recipients and staffing were common across all forms of respite.

#### For carers, these features were:

- Sufficient availability to allow choice of when and how the respite is provided based on assessed need.
- Delivering flexibility to both carer and care recipient, with both seen as active clients rather than carer only, so that both feel comfortable with and supported by support staff.
- Accurate care planning with carer and care recipient so consistency with usual activities can be maintained and needs met.
- Good communications so that carer drives the respite effort and makes it worthwhile; good communication is enhanced by having written documentation, shared between the carer and provider so both are 'on the same page'.
- Respite linked to access to counselling, and more education for carers about the importance of looking after their own mental health by taking a break.
- Ability to care for other family members in addition to the primary care recipient, to provide a full break for the carer.

#### For the care recipient, common features of good practice were:

- An individually focused, person centred approach that gives the care recipient and carer choice of meaningful activities from a variety of programs that offer recreational, sporting and cultural options, that is, a holistic approach to care.
- It is appropriate in terms of matching language, skills, gender and interests of care recipients and care workers.

#### For respite staff, the ability to deliver good practice respite care is characterised by:

- Having training and qualifications to engage in meaningful activities with care recipient, not just sitting with or minding the care recipient.
- Being able to provide the carer with knowledge, including knowledge of enablement approaches.
- One key worker who identifies with the carer and care recipient and is the right person to provide respite and foster continuity of care.
- Skilled care staff with appropriate training, and matching workers and care recipients as a means to developing trust between the workers, the care recipient and their carer and family.
- The carer and care recipient are involved in selection of the worker.
- Not wearing uniforms.

#### For providers, developing good practice in respite requires:

- Seeking consumer feedback and involving carers and care recipients in designing programs.
- Consultation with other stakeholders so that providers work together rather in isolation and therefore have greater capacity to respond to a wider scope of community needs.
- Links to counselling services and support groups that can assist potential and actual users take up different types of respite as their needs change and especially overcome barriers to using respite that arise from reluctance or resistance on the part of care recipients.



### 6.2.2 Good practice in centre-based respite

A large number of respite day centres have been in operation for many years and serve very diverse communities across Australia. The review could not encompass the full range of day centre respite, but promoting good practice focuses on ensuring that programs in all day centres are responsive to consumer needs, and keep up with changing needs among the consumers they serve and in wider communities. A good practice to this end is for each centre to have a service development and quality improvement plan and to exchange ideas with other providers. The consultations identified the following features of good practice that could be included in such plans.

The continuation of the pilot of day respite in residential aged care homes provides particular guidance for residential care providers interested in establishing or expanding their respite services. This model of day respite was found to offer a bridge between community and residential care for consumers and offered a number of advantages that are not always available in other day centre respite services. It was also apparent in the consultations that exchange between day respite in residential aged care homes and other settings could enhance knowledge and skills for both groups of staff, and was necessary to ensure that those presenting options to consumers were well-informed. In particular, the evaluation noted that negative perceptions of residential care can deter consumers and that measures had to be taken to establish a distinct identity for the day respite service.

#### For care recipients and carers

- Interaction in small groups.
- Enabling care recipients to do things they are interested in, and to join in groups and try hobbies, to meet up with other people and engage in groups and activities of their choosing.
- Providing opportunities for participation in both in-centre activities and external outings so as to increase confidence, well-being and social inclusion.
- At a convenient and accessible location, with transport provided.
- Familiarisation with a residential care setting meant that carers and care recipients could more easily access residential respite.

#### For staff

- Need to be aware that the care recipient is out of their usual setting and routines and try to meet their needs without disruption to usual routines and rituals.
- Work within guidelines so they know what is possible without being unduly restrictive.
- A high degree of continuity of staffing.
- Exposure to and exchange with a range of day respite centres, including centres in residential aged care homes.

#### For providers

- Undertaken a risk assessment of the environment, especially physical accessibility.
- Assessment has been carried out to ensure the care recipient is able to enjoy community activities.
- Initiatives to provide dementia specific day respite.
- Ensuring that hours of operation meet carers' needs to the greatest extent possible.
- In small communities where few in any other opportunities may be available, residential care providers need to consult with key stakeholders, including consumers, about options for co-location of day respite.

### 6.2.3 Good practice in in-home respite

NRCP provides more in-home respite than HACC, and the consultations included consumers and providers with considerable experience of in-home respite. The good practices identified are especially informative for other providers considering offering or expanding in-home respite services.

#### Activities

- In-home respite should incorporate value-adding activities, for example, opportunities to maintain social inclusion and interaction in the community, reading, and playing cards, etc.
- Workers should be able to take the care recipient out, with transport available, possibly with the carer if they need assistance to manage outings for social and other activities.
- In-home activities such as gardening and carpentry need to be covered by insurance.

#### For providers

- Monitoring and good knowledge of brokerage services.
- Capacity to be flexible in providing different levels of respite with volunteer and support workers, at different times throughout the day.
- Increased funding for overnight in-home respite.
- Recognising that just sitting with the care recipient is not meaningful to them nor is it a meaningful job for the worker or volunteer, feedback should be sought from volunteers and workers regarding what they would like to be able to do in order to better respond to carer and care recipients needs.

### 6.2.4 Good practice in overnight cottage style respite

Overnight cottage respite attracted more comments than other forms of respite in the review. While many positive features were identified by consumers and providers, there were also many limitations. A number of tensions were evident; for example, while the small scale of cottage settings was seen to be well suited to people with dementia, few cottages had sufficient skilled staff to manage people with dementia and other high care needs. Similarly, while small scale offered a home-like setting, high operating costs limited operation to week-nights only for some cottages, and notwithstanding positive acceptance, under-occupancy added to costs.

The comprehensive evaluation of the overnight community respite initiative, conducted by Urbis (2009), points to a number of areas in which cottage models could be strengthened, particularly with regard to cost-effectiveness, and concluded that their future development needed to be more closely integrated in the wider aged care system. These conclusions mean that as well as promoting good practice within cottage models, opportunities should be taken to promote the positive features of cottage models in residential respite.

#### For carers

- The carer is able to stay at the cottage if they wish to, at least to see that the care recipient has settled in.
- Transport is provided if necessary.

#### For care recipients

- Social interaction and inclusion is emphasised.
- Preferable for relatively younger care recipients, especially those with early onset dementia.
- Activities are individually tailored, including the option of not participating in activities if this is what is desired.
- Usual routines, skills and social activities are maintained, such as news discussions, with attention to physical and psychological well-being.
- Able to participate in running aspects of the cottage, such as cooking, cleaning, tidying up etc. under supervision.

#### For staff

- A sufficient staff to care recipient ratio; low staffing limited the capacity of respite cottages to cater for people with high care needs, including many of those with dementia.
- Staff did not wear uniforms.
- Policies, procedures and guidelines that set some boundaries, but are not too restrictive, and which gave guidance on action to be taken in case of adverse incidents.

#### The environment

- A familiar, home based environment.
- Nutritious and nicely presented food.

### 6.2.5 Good practice in residential respite

While cottage style respite was very well accepted by those who used it, a number of limitations constrain its growth. Some of the limitations, especially around the presence of skilled staff, are less present in resident facilities. However, other features associated with the large scale of residential aged care facilities, such as less person centred care, and less home-like settings are a drawback to using residential respite. The 'best of both worlds' could be realised by making residential respite more cottage-like.

The need to enhance the respite role of residential care homes rests on four considerations:

- Many large not-for-profit providers are already delivering several forms of respite and other kinds of community care, including packages, and so provide a model for other residential providers who want to extend their roles in community care.
- As residential aged care homes operate in all but small and remote communities, they offer existing infrastructure for extending the range of respite available in many communities in a way that draws on experienced staff, organisational infrastructure and physical facilities. Using existing infrastructure is critical in rural and remote communities that have a small service base to build on and where developing new infrastructure is most difficult
- Such approaches are likely to be more feasible and cost effective in the face of growing demands on the aged care system; there are some 3000 residential aged care homes in operation compared to 80 respite cottages.
- Such development is in line with offering consumers greater choices across the service spectrum rather than a limited either/or choice of community or residential respite, with increased opportunities for continuity of contact with a single provider.

#### For carers

- Respite in a residential aged care home is the only option that is likely to be available in an emergency and a clearer definition of notice of emergency is needed, as the same day or up to two or three days, otherwise carers can expect to be able to book at least a week or a month ahead.

#### For care recipients

- May not be suitable for younger care recipients, unless they are able to access age appropriate residential respite
- Recognised that care recipients may be in a larger group, so need to have activities in smaller groups and with some individual attention so that no individual is overlooked in a group.
- Continuing to attend the same day respite program as attended when living at home.
- Normal social, recreational and physical activities presented as such and not turned into 'therapies'.
- Meals at normal meal times.
- Mutual support from peers and buddies.

#### For staff

Welcome from designated reception staff.

- Allowing familiar staff from community, such as in-home support worker, to stay with care recipient in respite.
- Night staff needed for respite residents who are awake.
- Able to be flexible in routines for when get up, showering, when want o, not when staff want them to.
- Need a mix of staff, with registered nurses, enrolled nurses, personal care workers, diversional therapists and allied health staff.

#### The environment

- A small scale respite wing, suited to four or five residents.
- Home-like built environment, with smaller, domestic scale areas for meals and sitting rooms, rather than one very large open area and activity room meant for many activities but not suitable for any in particular.

- Single rooms with en-suites, with community living areas and shared kitchen close by.
- A home-like social atmosphere, including pets.

#### For providers

- Dedicate small areas for respite to enable more personalised care and interaction among respite residents.
- Must be accredited or going through accreditation.
- Residents well profiled to ensure compatibility and address carer concerns about care recipients being in company of others with much less capacity.
- Allowing a more fluid approach to respite care, separate from the facility's structures and routines.

### 6.3 Furthering good practice in respite

Good practice in all forms of respite care should be promoted through a three part strategy that gives attention to:

1. Making flexible use of respite funding allocated through the residential respite program to diversify respite through an initiative to enhance the roles and responsibilities of residential care providers and realise their potential to deliver respite of all types that meets the needs of local communities, where few if any other providers have the capacity to operate respite services, especially overnight respite, and including the development of centre-based respite in aged care homes, with priority given to:
  - Multi-Purpose Services and residential providers in rural and remote communities.
  - Residential care providers delivering respite to particular cultural and linguistic groups.
2. Developing a more coordinated approach that links respite with timely access for carers to counselling and support services through:
  - Giving priority to use of additional funding for counselling services made available through the LLLB package for developing these links.
  - Facilitating access to support programs delivered by organisations such as Carers Australia and Alzheimer's Australia.
  - Promoting the use of available carer support resources, including the Outside Looking In package developed by Carers Victoria, as part of these initiatives.
3. Showcasing high quality services for all types of respite and promoting good practice in respite through funding a series of coordinated and ongoing Better Practice Events conducted by the relevant Agency, industry, professional or consumer body. This initiative should especially aim to foster exchange between providers of community centre-based and residential respite to increase understanding of the full range of respite options that can be developed in any community and ways in which different options can complement each other in responding to consumer needs.

### Recommendation 9

That good practice in all forms of respite care be promoted through a three part strategy that gives attention to:

1. Making flexible use of respite funding allocated through the residential respite program to diversify services with priority given to:
  - Multi-Purpose Services and residential providers in rural and remote communities.
  - Residential care providers delivering respite to particular cultural and linguistic groups.
2. Developing a more coordinated approach that links respite with timely access for carers to counselling and support services.
3. Showcasing high quality services for all types of respite and promoting good practice in respite.

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# APPENDIX I: ALZHEIMER'S AUSTRALIA RESPITE REVIEW CONSUMER SURVEY

## RESPITE SURVEY

Thank you for taking part in our consultation process on respite care.

On the 20th of April this year the Gillard Government announced the *Living Longer Living Better*. aged care reform package. As part of these reforms there will be a review into the way respite is provided in the community.

Alzheimer's Australia is undertaking a project looking at how respite is currently provided and making recommendations for changes to the current system that could be implemented as part of the *Living Longer Living Better*. reforms.

We would like to hear about your experiences of respite and what you think are the changes required to better meet your needs.

By completing this survey you will have the opportunity to:

- Provide your ideas for the future of respite
- Highlight any of your concerns; and
- Help us to inform the government on your views

### What is respite?

Respite is support that is given to you and/or the person you care for to support you both to continue to live at home in the community. Respite can be an enjoyable activity, a social event, or having someone else provide care to give you time away from your caring role.

The types of respite you may have received could include any of the following:

- Overnight respite in your home, a respite house, residential aged care facility, hotel or other location
- Day respite in your home, at a local community centre or residential aged care facility
- Counselling, support groups, or social event.

## Demographic Information

1. In which State and Territory do you live?

- ACT
- QLD
- NSW
- NT
- SA
- TAS
- VIC
- WA

2. What is your age?

- Under 40
- 40 – 50
- 50 – 60
- 60 – 70
- 70 – 80
- 80+

3. Are you?

- A carer?  Yes  No
- A person being cared for?  Yes  No
- Do you have dementia?  Yes  No
- Does the person you are caring for have dementia?  Yes  No

Others (please provide details below)

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## Types of Respite services that you have used

4. What types of respite services are you and/or the person you are caring for currently using or have used in the past? (Please tick all that apply)

- Day respite in your home
- Day respite at your local community centre
- Day respite at a residential aged care home
- Overnight respite in your home
- Overnight respite in a respite house/cottage
- Overnight respite in a residential aged care home
- Overnight respite in a hotel/motel
- Overnight respite at another location
- Counselling
- Support groups
- Social events

Others (please provide details below)

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5. Of the respite services that you and/or the person you care for have used, which ones would you use again?  
(Please tick all that apply)

- |   |                                    |  |                              |
|---|------------------------------------|--|------------------------------|
| • Day respite in your home                          | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Day respite at your local                         | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Day respite at a residential aged care home       | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Overnight respite in your home                    | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Overnight respite in a respite house/cottage      | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Overnight respite in a residential aged care home | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Overnight respite in a hotel/motel                | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Overnight respite at another location             | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Counselling                                       | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Support groups                                    | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |
| • Social events                                     | <input type="checkbox"/> Use again | <input type="checkbox"/> Would not use again | <input type="checkbox"/> N/A |

Others (please provide details below)

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### Access to Respite

6. What has kept you from using respite when you have needed it?  
(Please tick all that apply)

- services not being available within the timeframe you need
- service not being available at the time of day you need
- concern you or the person you are caring for will not benefit from respite
- being turned away from a respite service
- having a negative experience with a respite service
- not having sufficient funds to pay for respite
- service not being available in an appropriate location

Others (please provide details below)

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7. Have you ever tried to use respite but were refused?

- Yes
- No

If yes, what was the reason?

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**Changes to respite**

We would like to hear what you think should change to allow respite services to better meet your needs. Thinking about the respite that is provided in the community, in your home or in a residential aged care home. What would you like to see changed to help you and/or the person you care for get the respite you need.

8. What changes to respite are most important to you?

	Not Important	Somewhat Important	Important	Very Important	N/A
• The time(s) it is available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The day(s) it is available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The location(s) that is provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The availability of counselling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The access to support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The choice and sustainability of activities for the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The availability of dementia specific care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The choice of services available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The type(s) of care offered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Who provides the care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

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9. If you had the option of employing family or friends to assist you in providing care would you make use of this option?

- Yes
- No

Why?

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10. If you were given money instead of services would this be helpful?

- Yes
- No

How would you use it?

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11. Which would you prefer? (Tick box)

- More hours of care at a day centre
- Fewer hours of more specialised care in your home

Why?

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# APPENDIX 2: ALZHEIMER'S AUSTRALIA RESPITE REVIEW PROVIDER SURVEY

**OCTOBER 2012**

## Current service provision

### 1. What types of respite do you provide?

- Day respite in a person's home
- Day respite in a local community centre
- Day respite in a residential aged care home
- Counselling
- Support groups
- Social events
- Overnight respite in a person's home
- Overnight respite in a respite house/cottage
- Overnight respite in a residential aged care home
- Overnight respite in a hotel/motel
- Overnight respite at another location

Other \_\_\_\_\_

### 2. Of the types of respite that you currently offer, which has the highest demand?

- Day respite in a person's home
- Day respite in a local community centre
- Day respite in a residential aged care home
- Counselling
- Support groups
- Social events
  
- Overnight respite in a person's home
- Overnight respite in a respite house/cottage
- Overnight respite in a residential aged care home
- Overnight respite in a hotel/motel
- Overnight respite at another location

Other \_\_\_\_\_

### 3. Do you broker any services?

- All     Some     None

Does brokering services allow you to achieve greater flexibility for the client?

- For all/most clients     For some     No

### 4. What aspects of current arrangements and contractual reporting inhibit flexibility in the way you can deliver respite to clients?

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**5. What difficulties, if any, do you encounter with the current eligibility criteria for respite?**

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**6. What are the barriers to providing respite for diverse groups?**

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**Future options**

**7. What could be done to streamline administrative processes for you as a provider of respite?**

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**8. If you could move funding between different types of respite within your current funding, would this increase your ability to deliver a more flexible service?**

- Yes – a lot    Somewhat    No/Probably not much

If you could move funding around, what types of respite would you increase, what would you reduce?

Increase:

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Reduce:

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**9. Considering future options for funding respite, rate your preferences for each option.**

Please circle the number that indicates your preference	Highly preferred		Not preferred	
a) All respite delivered as an entirely separate program with a separate funding pool.	1	2	3	4
b) As part of the Home Support Program.	1	2	3	4
c) Maintain present arrangements (respite delivered through HACC, NRCP, Packages & Resi. Care Program)	1	2	3	4
d) Focusing on care packages, should respite continue to be accessed within packages (rather than limiting packages to direct care services and respite accessed outside the package)	1	2	3	4

**10. Consumer Directed Care – CDC**

CDC is being increasingly adopted as a way of giving consumers more choice.

- a) Have you been/are you currently involved in Commonwealth CDC programs, including the 2011 trial of CDC packages and CDC respite?    Yes    No
- b) Do you have any other experience of CDC approaches?    Yes    A lot    Some    None



Further options for CDC have been proposed. *Please rate your support for each option*

	Support strongly		Do not support	
c) Giving consumers cash rather than providing services so they can access the type of respite that best meets their needs.	1	2	3	4
d) Enabling carers and clients to pay family members or friends to assist in providing respite.	1	2	3	4
e) Do you have any other suggestions for CDC approaches?				

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**Better Practice**

We are keen to identify the features of better practice in respite, from both consumer and provider perspectives. Please use the space below to note what you regard as better practice, based on your experience as: *(you can tick more than one box)*

- A consumer
- Working with consumers as a case/care manager/broker
- As a direct provider of respite
- As a direct provider and broker

*Please use page over if not enough room.*

Better practice in in-home respite is characterised by:

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Better practice in community based respite is characterised by:

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Better practice in overnight/cottage model respite is characterised by:

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Better practice in overnight respite in a residential care home is characterised by:

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Do you have any suggestions as to how overnight respite in residential aged care homes could be made more like cottage models of respite?

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Visit the Alzheimer's Australia website at  
**WWW.FIGHTDEMENTIA.ORG.AU**

for comprehensive information about  
dementia and care  
information, education and training  
other services offered by  
member organisations

Or for information and advice contact the  
National Dementia Helpline on

**1800 100 500**

(National Dementia Helpline is a  
Australian Government funded initiative)

**FIGHT ALZHEIMER'S  
SAVE AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU