



## RESPITE RECONSIDERED:

A discussion of key issues and future directions for  
carer respite

"Where is my break?"

Carers NSW  
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## Acronyms

<b>ABS</b>	Australian Bureau of Statistics
<b>ACAT</b>	Aged Care Assessment Team
<b>ATSI</b>	Aboriginal and Torres Strait Islander
<b>CACP</b>	Community Aged Care Package
<b>CALD</b>	Culturally and Linguistically Diverse
<b>CCRC</b>	Commonwealth Carer Resource Centre
<b>CSTDA</b>	Commonwealth and State/Territory Disability Agreement
<b>DADHC</b>	NSW Department of Ageing, Disability and Home Care
<b>DoHA</b>	Australian Government Department of Health and Ageing
<b>DSP</b>	Disability Services Program
<b>DVA</b>	Australian Government Department of Veterans Affairs
<b>EACH</b>	Extended Aged Care at Home
<b>FACSLIA</b>	Department of Family and Community Services and Indigenous Affairs
<b>HACC</b>	Home and Community Care
<b>NCCP</b>	National Carer Counselling Program
<b>NGO</b>	Non-Government Organisation
<b>NRCP</b>	National Respite for Carers Program
<b>OH&amp;S</b>	Occupational Health and Safety
<b>RACH</b>	Residential Aged Care Home

## **Executive Summary**

Unpaid carers provide the majority of assistance that enables people requiring support (due to disability, illness or frailty) to live in the community. Respite is a vital service for such carers. This is because it provides them with essential short breaks from their caring role. In this way respite is one of the services that enables carers to continue caring (and thus supports the community care system). Living at home is not only the wish of most people with significant need for assistance but it is also the goal of government policies.

### **Introduction**

The impetus for this research was the significant number of issues raised by carers with whom Carers NSW has contact about access to respite and the quality, appropriateness and availability of respite services.

There is research to indicate that respite services can deliver considerable benefits to carers and to those they support and that it can also be a cost-effective service. However in terms of its nature, availability and quality it is highly variable across the state. In this paper we discuss these variations as well as some of the factors that prevent positive respite experiences and outcomes. We also offer recommendations to improve respite experiences for carers.

The paper discusses the concept of respite in the context of demographic and social trends; in particular an ageing population, the greater longevity of people with disabilities and the changing role of women and the diversity of family forms. It covers respite across a range of sectors and programs including ageing, disability and mental health.

The information contained in this paper was obtained primarily from nine focus groups of carers conducted in 2005 - 2006 and an on-line survey of carers and service providers. Each focus group comprised distinct populations. These were carers who had not used respite; carers using community-based respite; carers using residential or overnight respite; carers from CALD backgrounds (2 groups); and Aboriginal carers. The total number of carers included in the focus groups was 50 and in the on-line survey 80. There were 24 service providers in 3 focus groups and 48 providers who participated in the online survey. These methods enabled indicative, rather than exhaustive findings to emerge. Other sources of information for this paper were relevant ABS statistics, surveys of members of Carers NSW and other secondary sources.

### **The use of and need for respite**

There are 750,000 carers and 150,000 primary carers in NSW. Currently many of these carers are providing high levels of care and support in an unpaid capacity. For example, there are around 67,500 carers in NSW providing 40 hours or more care per week, equivalent to a full time job. The percentage of carers providing this level of care has increased by 6% since 1998.

Despite the high levels of care provided, statistics indicate that around 87% of carers in Australia have never used a respite service and that most of them (62%) do not identify a need for respite. It must be noted however, that these figures contradict the understanding that Carers NSW has of the need for respite. A survey of our members showed that two-thirds of carers expressed a need for some form of respite. Furthermore we hear from many carers who say they need but cannot access respite.

Some of the main barriers carers raised in the focus groups were

- that carers do not identify their need for breaks with 'respite' services;

- that there is not a clear understanding in the community of what respite is; and
- that carers see respite as a last option so, while they perceive a future need, they do not express a present need

Service providers perceived insufficient funding and high costs of providing services as the main barriers. Other barriers raised included accessing particular population groups of carers.

### **Analysing respite**

Ongoing concerns about the low use of respite services by carers, despite its vital role have led us to reconsider respite. This has involved looking at what respite is, what the aims of respite are, and to determine whether the existing respite system can meet these aims. In addition we recommend measures that could be implemented to improve outcomes for carers and the people they support through the provision of respite.

#### a)What is it?

Respite is one aspect of carer support. A snapshot of the respite system shows that it is complex and has evolved as a 'stopgap' system whereby new programs and services have been layered on top of existing ones to address identified gaps. It is therefore not surprising that there is little understanding in the community about what respite is.

#### b)What are its aims?

Respite aims to support caring relationships by providing carers with short term breaks from their caring role. In doing this it enables the people carers support to continue living in the community. Different definitions of respite and its aims are developed for different programs that fund respite, contributing to the complexity of the respite system.

#### c) A critique of the existing system

Carers who use respite services often report satisfactory experiences in that respite enables them to balance caring with other aspects of their lives. Others, however, feel that services are inflexible, inappropriate or not able to meet their needs in some other way. Carers also report that the service system is complex and can be difficult to navigate.

From our research, we conclude that there are four main barriers to accessing respite:

1. lack of information or understanding about respite;
2. practical barriers such a lack of appropriate respite in the area;
3. emotional barriers such as guilt or anxiety;
4. lack of expressed need for respite (which can be related to perceptions about what respite is).

In many cases a crisis or emergency can trigger carers to override these barriers. Such triggers could include lack of informal support; relationship breakdown; increased intensity of caring role; poor health and well-being; and lack of support from other services.

Service providers can also experience barriers to delivering effective respite. Insufficient funding, inflexible guidelines, high and increasing costs of service delivery, staffing and workforce issues, difficulty engaging carers, lack of understanding in the community about respite and unrealistic expectations about what respite services can offer are some of the barriers.

### **Recommendations**

Systemic and service delivery responses are needed to address the issues raised by carers and respite service providers. We make a series of recommendations to Government about the need to accurately measure need for respite; clarity around what respite actually is;

monitoring the systemic effectiveness of respite and better planning and coordination of respite services.

We also make recommendations to service providers about carer assessment to respond to changing needs and principles for effective respite delivery.

The concept of respite for carers does not necessarily manifest as one service type or another. Therefore defining and measuring the effectiveness of respite should not be based only on how it is delivered. We recommend that it must involve the *outcomes* of that service for carers as well as those they support.

A range of responsive, flexible models of service delivery are required as suggested by carers and service providers. It must be recognised that every care relationship is different, from an elderly man caring for his wife to a young couple caring for a child with a disability. Yet all carers should have access to breaks in a sustainable community care system.

## Section 1: Introduction

Respite is a service that allows carers to take breaks from their caring role. Yet recent statistics demonstrate that a very low proportion of primary carers (only 13% according to the Australian Bureau of Statistics 2004) use respite. In attempting to unravel the reasons for low take up, we believe it is pertinent and timely to reconsider this key carer service. We will consider questions such as:

- Is there a misfit between the aims and outcomes of respite for carers?
- What different ways is 'respite' interpreted both in policy and in practice?
- How can respite be more effective for carers and the people they support?

The purpose of this paper is to document the current range of respite options for carers, to consider their function and effectiveness in supporting carers and to offer a new approach to this vital support for families in NSW. It is aimed at government bodies, both state and national that fund and deliver respite as well as services providing respite.

It makes recommendations to these agencies on how to increase the effectiveness of respite in terms of outcomes for carers and the people they support, as well as cost effectiveness and the effectiveness of the respite system.

### 1.1 Background

Carers are usually family members or friends who provide support to someone with a disability, chronic condition, mental illness/disorder or who is ageing. They are unpaid and may be parents, partners, siblings, children, neighbours or friends of any age. There are estimated to be at least 750,000 carers in NSW and 2.6 million in Australia.

Carers provide all levels of support, physical and emotional, from intermittent and short term to full time and long term care. We know that they too need to be supported, including the assistance to take breaks so they can fulfil their personal goals, maintain personal relationships their own health and well-being through social and community involvement. This is provided by respite delivered many different ways, from short-term emergency breaks to longer breaks in a residential setting.

Carers often report to Carers NSW that they need more respite or that they would like to see changes to the current respite system in terms of:

- **Availability:** more respite in their area or reduction in waiting lists
- **Quality:** better levels of care or communication by staff
- **Appropriateness:** services that are more appropriate to the needs or the lifestyle of the person needing care

In the most recent survey of Carers NSW members (Carers News Survey 2004), almost two-thirds of respondents expressed a need for respite to enable them to take a break from caring, to "recharge the batteries" or to be able to continue caring at home.

Some reasons that carers identified need for services in 2004 were clearly related to their own quality of life:

"I have limited time to shop – and never see friends – never get to church – have had to give up all my interests – and I get very tired." (carer of person with disability).

"I'm tired of providing full time care 24 hrs a day 7 days a week with only small amounts of respite which I often beg for". (carer person with disability, regional NSW).

"I am 65 and very energetic and social. Now I am confined to the house as I need to stay with my husband most of the time". (carer of partner with disability).

"(a) I am exhausted much of the time; (b) I don't cope with even routine housework; (c) I'm not able to maintain friendships and interests very easily". (carer of frail aged person).

Feedback about respite from carers has been consistent for many years. It comes to Carers NSW through a number of channels including the Commonwealth Carer Resource Centre and Carers NSW project staff as well as other sources of research. In many cases the issues that carers raise with us about the respite system in 2006 (availability, appropriateness and quality) mirror those identified by Interchange Respite in 1999 (Parmenter 1999) or the Disability Council in 1989.

We hear from carers with an entire range of experiences of the respite system, from those who are not coping and are unable to access respite to those who have sufficient, good quality respite that supports them in their caring role.

## **1.2 Structure of this paper**

The evidence for this paper comes from a number of sources, both primary and secondary. These are a review of the literature (Appendix 1) which is referred to throughout the paper, focus groups conducted by Carers NSW both with carers and with service providers and an online survey on respite that was completed either by carers or service providers (details in appendices 2 and 3).

Section 2 of this paper contains a broad look at the context of carer support, of which respite is one aspect. It then gives an overview of respite programs including what the statistics on carers and respite tell us. Section 4 presents the findings and key issues raised by carers in our research and Section 5 the issues for service providers. Analysis and policy implications of these issues ensues in Section 6 and Section 7 presents the recommendations emerging from this paper.

## **Section 2: The context and organisation of carer support**

The development of supports for carers, including respite, is influenced by changing demographics and an evolving social policy setting in response to the increasing longevity of care relationships in the community.

### **2.1 The context of carer support**

The number<sup>1</sup> and longevity of informal care relationships in the community is increasing. Macro social and demographic trends indicate that this is due in part to increasing longevity (particularly of males), which heightens the likelihood of partners becoming carers. Technological advancement is also contributing to increasing longevity of people with disabilities. This involves the accompanying impacts of early ageing for people with disability (for instance early onset dementia for people with intellectual disability) (AIHW 2000). As a result there is a greater need than ever to support carers.

Looking to the future there will be even greater need to accelerate policy development and investment in community care to support caring relationships. A significant increase in the future demand for informal carers has been highlighted in a report on informal care and the ageing population (NATSEM 2004). The number of carers available will increase but not as fast as the number of older people who need care. It is projected that the ratio of carers to older people requiring care will drop from 57 per 100 in 2001 to 35 per 100 in 2031.

The intensity of caring roles is increasing. Analysis of carers statistics for NSW in 1998 and 2003 demonstrates a 6% increase in the number of primary carers caring for 40 hours or more per week in that period (Carers NSW 2004, unpublished). Many carers (particularly parent carers) are also caring for extended periods of time. The AIHW (2005) recently reported that 23% of parent carers had provided support for a son or daughter for 10 to 14 years, 10% for 15 to 19 years and 17% for 20 or more years.

Social policy responses to disability, ageing and caring include the shift from institutional care (or devolution) to community care in Australia. As a consequence we have seen significant growth in funding to the community care sector through programs such as the Home and Community Care Program. This involves growth in support for families providing care at home. However the slow development of alternative options such as community-based supported accommodation for younger people with disabilities has also increased the pressure on families to provide high levels of care for longer in the community.

While staying at home for longer is the choice of many people with disabilities, ageing people and their carers, it is not a cost-free alternative to residential, institutional or acute care. It has been estimated that the value of carers' work equates to around \$19 billion in savings to government annually (AIHW 2003). However many costs are borne by family carers. These include (CA 1998; ABS 2004b; CA 2001; CA 2000; SPRC 2004:

- Financial costs of disability and ageing including increased household spending on transport, special equipment and food, medications, home modifications and general household expenses;
- Lost opportunities for employment and study at a young age resulting in barriers to entering and staying in the workforce;
- Diminished health and well-being; and

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<sup>1</sup>According to the ABS Survey of Disability, Ageing and Carers, the number of carers nationally increased from 2.3 million in 1998 to 2.6 million in 2003. In NSW however there was an estimated decrease from 798,300 in 1998 to 748,000 in 2003. Carers NSW analysis of the ABS data suggests that a sampling error is the most likely cause of this anomaly.

- Social isolation, negative impact on relationships and reduced leisure time.

These trends have posed some significant challenges to government, the community and families. As a result, there has been increased policy focus on family carers over the last five to ten years which has translated into a number of supports, services and programs for carers emerging from various human service government departments. Improved data on informal care is now collected by the Australian Bureau of Statistics and there has been a greater research focus on carers by organisations such as the Australian Institute of Health and Welfare, the Social Policy and Research Centre and various community based organisations.

## **2.2 Brief overview of carer support in NSW**

Respite is just one of the supports that carers require and is the focus of this paper. This section demonstrates how it fits with other carer supports.

Of the 475,000 primary carers in Australia, 37% or 176,000 carers reported a need for more support (than they were receiving) in 2003 (ABS 2004b). This figure was similar regardless of whether the carer lived with the main recipient of care or not. It represents a significant perception by carers that they are under-supported, both by formal and informal networks.

### *2.2.1 Informal support*

"During this time we had lots of support from carers, family and friends. Often my friends would sit with mum at home while I ran errands, did shopping, visiting my grandchildren, or just got out of the house for a while. This really helped me cope with mum's illness and refreshed me" (carer, Carers News December 2005).

Informal support for carers is often the mainstay of carer support or it can be used to fill the gaps left by formal services. It is considered by carers to be a vital source of support in their caring role (Carers News Survey 2004).

Most often primary carers reported in 2003 that a relative or friend was their main source of assistance (34%) (ABS, 2005). Just over half of all primary carers (55%) reported having a fall-back carer, usually the daughter (30%), father (19%) or son (15%) of the person requiring support (ABS 2005; 43).

There are great benefits to having strong informal supports for carers. These can include maintaining family relationships, confidence about the standard of care, privacy and convenience for carers.

Barriers to using informal supports include not wanting to 'burden' other family members and perceptions that family members are too busy, don't have the capacity to assist with caring activities or are too geographically distant from family (Payne forthcoming). While it is the preference of some carers to use only informal supports, others rely on formal services for a host of reasons.

### *2.2.2 Formal support and services for carers*

The formal carer support system can be complex for carers to navigate. Ideally carers should benefit from the services delivered to the person they support as well as from carer-specific services that support them in their caring role.

TABLE 1: BRIEF OVERVIEW OF CARER PROGRAMS

Program	Funding		Target group				Type of service available to carers						
	State	Commonwealth	People with disabilities	Ageing People	Carers	Respite	Emotional support	Counselling	Financial assistance	Education/ Training	Advocacy	Information	
NRCP		✓			✓	✓							
- CCRC		✓			✓	✓	✓					✓	
- NCCP		✓			✓			✓					
- Resource Centre*		✓			✓		✓					✓	
Carelink**		✓	✓	✓	✓	✓						✓	
HACC	✓	✓	✓	✓	✓	✓					✓	✓	
Centrelink		✓	✓	✓	✓				✓				
NSWCP***	✓				✓		✓			✓			
CSTDA	✓	✓	✓			✓							
DSP	✓		✓			✓							
CACP		✓		✓	✓	✓							
EACH		✓		✓	✓	✓							
ACAT		✓		✓	✓							✓	

NOTE: List of Acronyms at beginning of document.

\*Commonwealth Carer Resource Centre

\*\* Commonwealth Carelink Centre<sup>2</sup>

\*\*\* NSW Carers Program

<sup>2</sup> Recently merged with CCRCs as part of the Commonwealth Government's strategy for streamlining community care services.

Broadly the formal supports available for carers in NSW include:

- Information;
- Respite;
- Advocacy;
- Emotional support, counselling;
- Education and training;
- Carer support groups;
- Health care (acute, primary and community health);
- Community care services (practical assistance, aids and equipment etc); and
- Financial assistance.

It is apparent from the snapshot in Figure 1 that, while there are undoubtedly supports available to carers, they constitute a complex and fragmented system. There are no identifiable pathways for families to move between the various supports and services. As we shall see, carers find it difficult to navigate these services and many are unable to access any support from services at all. For example, although carers are a legislated target group of the HACC program, they constitute only 1.7% of HACC clients in NSW according to most recent figures (DoHA 2004).

Respite is one component of carer support and, as demonstrated in Table 1, is provided through a number of different programs.

### 2.3 Respite Programs in NSW

Respite provides carers with breaks from caring. However there is no clear definition of respite, nor is there a common understanding of this service across policy makers, service providers, consumers including carers and the broader community.

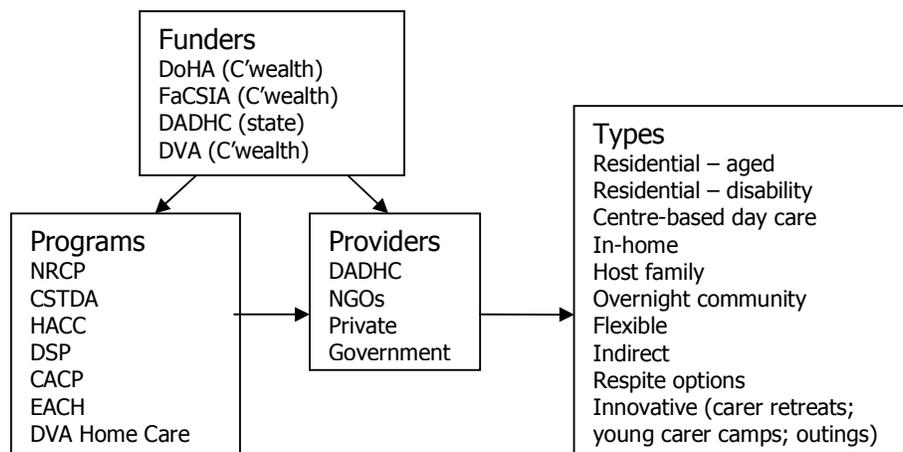
The purpose of this section is to provide an overview of the respite system in NSW as a background to the discussion which follows. The section outlines what respite is, who uses respite, how it is funded and the difference between respite services and respite outcomes.

This section is not a comprehensive documentation of all respite options as programs change frequently and various pilots and time-limited projects run at different times in different areas. Rather it provides an indication of the types of services generally considered as 'respite' and how they are funded and delivered.

#### 2.3.1 The respite system in NSW

The basic structure of the respite system in NSW (that is at least in part funded by a government agency) looks like this:

FIGURE 1: RESPITE IN NSW



### *2.3.2 Types of respite*

Typically there are four main types of direct respite funded in NSW. These are in-home, centre-based, host family respite and residential (in an aged care facility or disability group home). These can be classified as residential or community respite models. In addition 'indirect respite' is offered by CCRC's, funded by the National Respite for Carers Program.

**Residential respite in aged care homes:** The purpose of residential respite in aged care homes is to provide short term accommodation in nursing homes or hostels for people requiring support, giving their carers a break, and delaying or avoiding permanent admission to aged care facilities. However NSW has the lowest rate of return back to the community following a respite episode (60% compared with 88% in Tasmania). The policy target for residential respite (around two places per 1000 people aged 70 and over) has typically been under-utilised owing to the high administrative cost of providing respite and high cancellation rates (Niedzwiecki and Pierce 2003). In response to this the Commonwealth Government recently introduced (in January 2006) incentives for respite provision. This type of respite is typically less flexible for carers than others as it must be booked in advance and usually for a minimum period of time (eg two weeks).

**Respite in disability group homes:** This type of respite enables carers of younger people with disabilities to take breaks of several nights at a time. Families of over 2000 people with disabilities accessed this type of respite in 2005. The availability of respite fluctuates. For example in September that year, of the 400 DADHC-run respite beds for young people with disabilities, 77 were permanently 'blocked', or used for people who required ongoing accommodation. In April 2006, 50 respite places were occupied by people requiring ongoing accommodation (GPSC 2, September 2005; GPSC 2, April 2006).

**Community respite:** Day centres, in-home respite, host family respite and overnight community respite<sup>3</sup> are typical community respite models (although this is a limited definition) according to program definitions of respite. Other respite models that are variously funded as respite for carers of people with disability include peer support, vacation care, out of school hours care and family day care. The NRCP provides emergency or "one-off" respite. This type of respite provides carers with breaks of up to several hours at a time which may enable them to catch up on various activities, to attend work or study.

**Indirect respite:** The CCRC guidelines contain the provision to fund 'indirect respite'. This enables CCRCs to provide financial assistance with some aspect of a carer's duties such as equipment or assistance with costs incurred. Essentially it enables them to purchase services. In this way, 'indirect respite' can be used to relieve carers from some aspect of their caring tasks that aren't associated with the caring role, for instance shopping and cleaning. While this is not a service delivery model it can provide a "respite effect" by reducing the need for carers to spend respite time on carer-related chores such as cleaning or cooking for the person they support.

### *2.3.3 Program definitions and aims of respite*

Each program has its own definition and purposes of respite. There are some common aspects of program definitions across the Australian Government Department of Health and Ageing and the NSW Department of Ageing, Disability and Home Care, for instance that respite is a short-term or time-limited break. However, due to the multitude of service models, the aims differ as shown in Appendix 5.

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<sup>3</sup> Also referred to as the Community Respite House or Community Cottage model.

### *2.3.4 Distinguishing between respite services and respite outcomes*

Importantly the aims of respite services can be achieved through use of other services which are not specifically funded as respite but still provide a “respite effect”. This occurs when disability, aged care or general community services support a family and as a result provide them with a proper break from their usual caring role.

While it is not expected that all of these services should be captured in planning and funding for respite, it is vital that the effect of these services for carers is recognised. This may influence carers’ need for respite.

Additional benefits to getting a break from caring can be achieved from respite and often carers find a combination of supports to be very effective. For instance organised carer holidays, retreats or camps can provide breaks, emotional support and education for carers. Courses for carers can have similar benefits provided the appropriate supports are in place so they can attend without having to worry about the well-being of the person they support.

### *2.3.5 A stopgap respite system*

Since the 1980’s new programs have been developed in order to address identified gaps, resulting in a stopgap respite system. Previously only ongoing respite was available through the HACC, DSP and residential respite funds. In the 1992-93 Federal Budget funding for the Commonwealth Respite for Carers program was announced. This was intended essentially to supplement HACC services (DHFS 1996) and there was little difference between the service delivery provided under the various programs.

A number of different programs have been layered on top of the initial respite programs to address various gaps that have become apparent in the system over time. Funding packages<sup>4</sup> have been introduced in recent years to address the specific respite needs of young carers, carers of people with dementia, working carers, carers of young people with disability, ageing parent carers and carers in palliative care situations.

While these are all important and respond to identified need, there are unanswered questions. How can we measure their effectiveness? How do we know if the carers they are targeting understand that there are respite packages for them? How do we know if they are meeting the need that they were designed for?

Respite, as it is currently defined, can either be planned and preventative in focus (ie the HACC respite program) or used for crises and emergencies (NRCP, brokerage model). It can be for as little as a couple of hours a week or a number of weeks at a time. These factors impact on the understanding of respite in the community and by carers.

The complexity of the system and variation between programs and departments on the definition of respite and assessment and eligibility for services creates a complicated picture of respite for carers which may impact on the use of respite by carers.

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<sup>4</sup> Most have been introduced by the DoHA. FaCS introduced respite for young carers.

## Section 3: What the statistics tell us about respite use

Data on respite use are collected nationally by the Australian Bureau of Statistics (ABS) and by each program providing respite.

### 3.1 ABS data

The ABS conducts a survey of carers (as part of the Survey of Disability, Ageing and Carers) every five years. It distinguishes between all carers and primary carers (those providing the most support to a person). Where primary carers are identified a further in-depth survey is conducted, one aspect of which is use of and need for respite<sup>5</sup>. There are estimated to be nearly 450,000 primary carers in Australia. Nearly 150,000 of those reside in NSW.

The statistics for 2003 present the following picture of respite use (ABS 2004b)<sup>6</sup>.

- **87% of primary carers had never used respite.**
- Of those who didn't use respite, **62% reported 'no need'**; 23% said the main recipient of care did not want it; 4% said available respite was not affordable/suitable; 2% said service was unavailable; 9% gave other reasons.
- The **number of primary carers who needed more respite increased** by 8,900 from 1998 to 2003.
- Of the 80,000 primary carers who said they needed respite, 63% had never used respite, indicating **unmet need**. These may be carers who reported that the main recipient of care did not want respite or gave other reasons for not using respite.
- Of those who reported a need for respite care, 70% needed it on **weekdays**; 34% on **weeknights**; 70% needed more access to respite on **weekends**.
- Of those who reported a need for more respite care, 70% needed it on **short notice** or on an **irregular** basis; 30% needed it on a planned or regular basis.
- 55% of primary carers have a **fall-back informal carer**, 35% do not, 10% don't know.

### 3.2 Carers NSW data

In 2004 Carers NSW collected statistics on its members through the Carers News Survey. In stark comparison with the ABS statistics, two-thirds of respondents identified some form of respite as a service that they needed. Reasons behind the variation will be further explored later in this paper.

### 3.3 Program data

Service user data from the programs delivering respite demonstrates a number of characteristics about the people most likely to use respite. There is limited information about the characteristics of carers as most programs collect data for the person requiring support.

- People who always need assistance with one or more activities of daily living are most likely to be respite clients (CSTDA 2004-05).
- 2.4% of the NSW population is indigenous yet indigenous people make up only 0.5% of residential respite clients in aged care facilities. In comparison a greater percentage (3.5%) of CSTDA or HACC respite clients are indigenous. .
- A low proportion of clients from CALD backgrounds access respite services. Only 6% of CSTDA service users were not born in Australia, 8.6% of HACC clients spoke a language other than English at home, 11% of respite residents in aged care facilities had a preferred language other than English. This compares with estimates that 24% of the population is from a CALD background (MDAA 2005).

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<sup>5</sup> The ABS defines respite care as: "Respite care services provide alternative care arrangements for persons with one or more disabilities, or older people, to allow carers a short-term break from their care commitments. Respite care may be provided on a regular, planned basis, or in an emergency or crisis situation. Respite care services may be in a facility such as a nursing home or community centre or in a person's home.

<sup>6</sup> No statistics are available for NSW however it can be assumed that the national statistics are reflected in NSW.

### 3.4 How many carers access respite services?

Given the data in Table 2, it appears that there are potentially around 56,400 people using respite services in NSW. However this does not mean that 56,400 carers are benefiting from these services. For a number of programs the 'client' of the service is the person requiring assistance, not their carer. Many of the clients do not have carers. Furthermore many people, we know, access more than one type of respite and therefore are captured in multiple data sets.

If there *were* 56,400 carers receiving respite from these services, this would equate to just 7.5% of carers in NSW or 38% of primary carers. It has been estimated by the ABS that just 13% of primary carers had ever used respite services. These figures on the use of respite are roughly in keeping with a smaller community sample in Australia (Schofield et al 1998) of which 12% of carers had used respite.

Our online survey of carers demonstrated that carers used an average of 1.5 respite service types. This further consolidates the evidence that respite programs are distributed amongst a smaller group of carers.

It should be noted that more respite places are planned as announced by the NSW Government in 2006 for carers of people with disability and carers of people with mental illness. In the coming years these will affect the number of 'clients' in Table 2. However it is not clear whether these respite places will reach carers who currently do not access respite services or carers who are already using respite but need more.

TABLE 2: RESPITE DATA FOR NSW 2003-04

Funder	Program	Type	Out-lets	Clients*	Client Age (majority)	Has a carer (%)	Major city	Inner regional	Outer regional/remote	ATSI (%)	CALD (%)
DoHA DADHC	HACC <sup>7</sup>	In-home/Host family respite		3,056	65+	61.4	61%	26%	13%	2.8	8.6
DoHA DADHC	CSTDA - DSP	In-home	1	12	15-59	86	64%	24%	10%	3.5	6
		Centre based/respite homes <sup>8</sup>	63	2,268							
		Combination/flexible	65	1,925							
		Host family/peer support	8	276							
		Other	6	99							
		Total	143	4,129							
DoHA	NRCP <sup>9</sup>		432	33,000 national	65+	N/A	N/A	N/A	N/A	N/A	N/A
DoHA		Respite in RaCH		18,588	65+	N/A	67%	24%	9%	0.5	11.2

Sources: AIHW (2006) Residential Aged Care in Australia 2004-05; AIHW (2006b) Disability Support Services 2003-04; DoHA (2004) HACC MDS 2003-04

\* For the HACC respite program (in-home/host family) the client is considered the carer, for all other programs the client is the person requiring support.

<sup>7</sup> Geographical distribution for all HACC services, not only respite.

<sup>8</sup> Includes group homes or 'residential' respite services for younger people with disability which are funded and operated by DADHC.

<sup>9</sup> Limited data available for NRCP program. National figures only.

## Section 4: Key Issues for Carers

The following are results from the six carer focus groups and the online survey that were conducted by Carers NSW. In total 130 carers in NSW were consulted for this paper, including fifty carers participating in the focus groups and 80 carers responding to the online survey (outline and results in Appendices 2 and 3). There was representation of different caring situations including types of relationship, age of carer (with the exception of young carers<sup>10</sup>) and cultural diversity.

Most of the carers that were consulted for this paper were likely to have had prior contact with services or support groups or to know about Carers NSW as recruitment for focus groups and advertisements for the online surveys took place through these channels. This affects the representativeness of respondents as we have not been able to access many 'hidden' or extremely isolated carers.

The focus group questions and online survey questions mainly addressed two issues regarding respite, in line with the purpose of the project. These were:

1. Questions relating to the use and non-use of respite by carers; and
2. Its effectiveness in meeting the needs of carers.

The major issues to emerge relate to:

- Why carers do not use respite
- What leads carers to use respite
- What carers see as 'good' respite

### 4.1 Four reasons that carers do not use respite

The ABS statistics outlined in Section 3 indicate that most carers do not use respite and the main reason for this is that they have no need. While many carers in our consultations reported that they had no need for respite there were other reasons stated as well.

*Reason 1: Carers do not use respite because they don't know about it*

"Don't know much about [respite services]" (carer of person with chronic condition)

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"I understood that it was almost non-existent and was impossible to access" (carer of person with mental illness)

Due to our methodology, most carers had already accessed information on respite. The group of carers who had the least understanding of what respite was and had little information about respite services were CALD carers. However a number of other carers felt they had insufficient information, or misinformation about respite.

"It was all those events, the Base Hospital, nursing hospital, Age Concern and mum's GP that helped to build up the body of knowledge. It started basically with the GP. That made it easier to get on the phone...I now have a regular relationship with [the ACAT Manager] and I ring up every time I need to know something. She has given me a lot of support and vital information. Lutheran care is another link I have got information from." (Carer, regional NSW).

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<sup>10</sup> The online survey was advertised through the Carers NSW Young Carer Website however only a small number of young carers responded. None attended focus groups.

Often carers received information in a fragmented way and they had to piece it together themselves. For some carers this was effective (as above) however others felt frustrated that they did not have the “full picture” of what they were eligible for and could access.

*Reason 2. Carers do not use respite due to practical barriers*

“...sometimes I reject respite...knowing respite services [are] unable to cope with serious illnesses of caree as respite services have no medical training!!” (carer of person with chronic condition).

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“We don’t think respite services in our area take in to account the whole family. We don’t feel sending our child to a respite centre meets our needs as a family. In house respite would benefit us a lot better but is not offered”. (carer, online survey).

Practical barriers to accessing respite included:

- Lack of ongoing, appropriate respite. Carers reported that they could not find services that could manage complex health care or support needs, or that they knew their family member’s needs were ‘too hard’ or unable to fit eligibility criteria for any local services.

“I booked but then didn’t have the heart to send her. It was a long way from where I live. Amazed that the only two high care respite beds were over an hours drive away when I live in a Sydney suburb.” (carer of a frail aged person, online survey).

- Lack of services that could meet the needs of the whole family.
- Information did not assist with access. There was an expectation by carers that if they had the information the services would be available when needed. Carers usually had not been informed that respite services could be difficult to access or that they may need to try a number of times or through a number of different avenues before they were successful.

“I haven’t been able to get any respite. I wrote a letter to [the Respite Centre] and that was two years ago. When my wife was in hospital one of the nurses said I would need to get help but I said I could do it on my own... One of these nurses said to me “you’re not going to manage all the time on your own. Ring this number and ask for help”... When I got through the person said “ring me back in three months and tell me how she’s going”. I couldn’t drop the phone fast enough.” (carer, regional NSW).

- Carers were often reluctant to ask for help. Many viewed respite as a last resort.

“When you get the courage to make the phone call you never say how dire straits (your caring situation) is. When you get a person on the other end who says they can’t do anything, it’s the funding, it makes you give up.” (Parent carer, regional NSW).

- Carers were often told by service providers that funding constraints or high costs of respite were barriers to service provision. One carer had made a deliberate decision not to use respite owing to **“recognition that limited funding [is] available so I have not used it for myself”**. Another carer commented, “[I] had no one else to take over for a couple of days and know I could not cope much longer. There are a lot of people who need it more than me, but **it would be nice to use [respite] again without feeling guilty that I was taking the space of other people”**. One Aboriginal carer

said of a brokerage model: "They paid for it but let [the carer] know that it cost them \$2000 so the next 2 times I took (the children with disability) for the weekend. They put her on a guilt trip so I used to take them."

### *Reason 3. Carers do not use respite due to emotional barriers*

Emotional barriers to using respite included:

- Negative first experience of respite.

"I took a holiday and put my mother into respite for two weeks, however she begged to come home after our return in 10 days. Though she was assessed as [low level care] there were several dementia people in the same hostel due to lack of a dementia facility...After the first experience she refuses to even entertain the idea again, and frankly I don't blame her, it was appalling" (carer of frail aged person).

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"As an Official Community Visitor I saw what respite houses are like. There is often little gentle 'mothering' and staff may not always treat the children in a way I would like (at all). I would not feel confident that my child would [be] happy and safe" (online survey).

- Anxiety, which was mostly related to the carer's perception about the level and quality of care and support for their family member.
- Resistance by the person they support and carers' own feelings of guilt. This often led to cancellation of respite services, particularly residential and centre-based day respite.

"It is particularly hard to put a person into care when they don't wish to go and much easier to just not bother" (email from carer 1/2/06).

- Many carers felt they should be able to cope with their caring role without assistance, or that they could provide better care than services.

"I did not want to be seen as not coping and I did not want strangers to care for my daughter" (parent carer, online survey).

### *Reason 4. Carers do not use respite because they do not have a need for it*

Carers usually indicated they had no need 'yet' but anticipated that they would in the future. This was attributable either to the diminishing physical or cognitive condition of the person they were supporting or their own health issues relating to ageing or increasing stress of their caring role.

Other reasons associated with the expression of need included carers':

- perception that respite is not meant for them/their type of caring situation;
- perception that there is no respite available;
- misunderstanding of what respite means.

Some carers also reported that they had adequate informal supports and that this was their preference and therefore did not need services.

Carers were also asked about their need for breaks. Almost all reported a need for breaks owing to the high intensity of their caring role, lack of other supports or their own health and other needs. This included carers who did not express a need for 'respite', indicating the importance of terminology for carers.

"I was ill and DADHC came to me and said "I think you need some respite". I thought "Why didn't I know?" It was a big secret at the time...Because I was quite ill we got a high score [in assessment] so we got into the system. But you have to be really in a crisis to qualify to get in." (Parent carer, regional NSW).

#### 4.2 What leads carers to use respite services

Carer focus groups indicated that the advent of a crisis was the main trigger for accessing respite. Carers would only seek out those services, or be referred to them by a GP or other service provider, when it was clear either to themselves or others that they were not coping.

Carers identified a range of triggers that led carers to access respite. In summary these were:

- Lack of informal support (including recognition, practical and emotional support from family and friends)
- Relationship breakdown (with other family members or in the caring relationship)
- Intensity of caring role increases (challenging behaviours; health of person requiring care deteriorates)
- Poor health and/or wellbeing of carer
- Lack of support from other service types including health and community services

#### 4.3 What carers see as 'good' respite

"The experiences with respite have been uniformly good. There's been no wash up except a positive wash up from respite. When mum went out in the bus each day, when she came back she was always in a good condition. She was happy to see us as well. When the [care worker] came to the home to look after her...we had a list of activities that she might like to do with mum...and we'd often get the same person to come back again" (son carer, Sydney).

Carers referred to the outcomes of effective respite, the factors contributing to effective respite and some of the barriers to a positive respite experience.

##### 4.3.1 Outcomes of effective respite

"As a chronic fatigue syndrome sufferer caring for my wife with developing dementia and severe balance difficulty requires me to be with her all the time. Our family lives overseas and interstate and without respite my health would collapse" (carer, online survey).

Some carers reported reduced stress, more time for other relationships and prevention of deterioration in their own physical and, particularly, mental health as the positive outcomes of respite. Some reported that respite enabled them to work, others emphasised the importance of having time to relax or 'recharge the batteries'.

Other positive outcomes of respite identified by carers included:

- Positive experience and continuity of care for person requiring assistance
- Ability to maintain important activities (including employment) as the intensity of the caring role increased
- Maintaining relationship with spouse and other family members or friends
- Having a good night's sleep
- Improved health
- Improved relationship with person requiring support
- Ability to continue caring for longer at home (coping with caring)

- Preventing carer and family breakdown (as one carers said "It keeps us above water")

"(Respite) is very important otherwise mentally we would possibly be both having a mental breakdown by now, there would be mental tension on the boys which would come across into their behaviour as they copy behaviours (role modelling all the time)...Respite definitely helps us and is appreciated but also we do see the benefits for them." (Parent carer, online survey).

#### 4.3.2 Factors of effective respite

Those carers who were satisfied with respite identified a number of factors for effective breaks:

- Benefits for the care recipient (eg social participation, quality care)
- Entering the system before crisis point
- Sharing care responsibilities through good family/informal support
- Knowing or planning in advance (with assistance) what activities both the carer and the care recipient would do in the respite time
- Involvement in planning for respite service and adequate communication between the carer, the person requiring support and the service provider
- Knowing and having confidence in the support worker and the service provider

#### 4.3.3 Barriers to effective respite

Carers also reported on the aspects of respite that prevented a good break. These included:

- Inconsistency or unreliability of respite care workers
- Lack of understanding from providers about the carers' needs and sometimes poor quality care
- Deterioration in the condition of the person requiring support during respite, leading to increased levels of care that carers were required to provide upon return home

"In last case in 2004 wife came home with nappy rash after being kept in nappies for 6 weeks. Not given any exercise and was hardly able to walk." (online survey).

- Use of respite time for caring tasks such as cleaning equipment or being required to be present and active in their caring role during the respite period (eg for transfers).

"It takes me an hour and a half to disinfect the lenses every day and I do that when the respite comes for them cos that's the only time when they're being minded that I can do that, because since [Home Care workers] leave I have to keep my eye on the kids. It's called respite and personal care but when it comes to it I can't leave the house because the hours I get for [one child] are different to the hours I get for [the other child]...**Where is my break? It's just a name there, it's just a service...**I've got the hoist at home but they can't really use the hoist for everything so I have to be there." (carer of two children with disabilities, Sydney) (emphasis added).

- Difficulty accessing respite. Carers made comments like "after a while you think 'Oh buggler it! I'll just do it myself and it's easier'" (carer, Sydney).

"Too difficult to have breaks. Emotionally difficult. Logistics too difficult. Only go when I have to for work and that is very, very difficult for all of us (I care for two)." (carer, regional area, online survey).

- Lack of carer focus in services. Being listened to by respite providers was important for carers. They sometimes felt they needed to 'beg' or 'fight' for services and to constantly justify why they should be receiving services. They reported having to take whatever they were offered, with many services showing little flexibility.

"Respite means that you provide the service according to the carers needs, not according to the service needs because they give you hours and you've got nothing to do in that time. You don't need it in that time. I get so angry because they treat us like nothing. You take it or leave it." (Parent carer of adult child with a disability, Sydney).

#### 4.4 Different Carer Population Groups

While many of the key issues apply to carers generally, we found that some are more prominent for ATSI carers, carers from CALD backgrounds, carers of people with mental illness and carers in different life stages. These are briefly explored here.

##### 4.4.1 Aboriginal and Torres Strait Islander carers

"I didn't have family and friends to call on. Didn't know about services, didn't know they existed. I'll have a different approach this time than what I did last time...I wouldn't go through the welfare. That's why my boy's not with me now."

A group of nine Aboriginal carers were consulted. The views of this group of carers are not necessarily representative of all ATSI carers. However they provide some indication of ATSI carers' needs. The notable issues included:

- Carers felt that information was not readily available. Among many suggestions was the key message that a range of mediums should be used to promote services;
- Aboriginal carers do not recognise themselves as carers, which can present a significant barrier to effective targeting, advertising and promotion about respite services to the Aboriginal community;
- Better access to transport and emotional support were identified by Aboriginal carers (and service providers) as crucial to improving access to respite.

"Transport is a big problem. More people would access respite if transport was available in the package deal. It would be one less thing to worry about" (Aboriginal carer).

- While it is a common perception that ATSI carers are supported more by informal networks than other carers, Aboriginal carers remarked that they didn't always like asking family and friends to help them.

"I ended up ringing my friend and she came down but didn't have a good time. She ended up telling me "don't ever ask me to do that again". You can't plan for funerals, emergency surgery etc. I couldn't leave my daughter with a stranger anyway. I can't go to my mum because she's schizophrenic."

- Carers expressed reluctance to access mainstream respite services. This was based on negative perceptions, often founded on past negative experience (sometimes not respite-related).

#### *4.4.2 Carers from culturally and linguistically diverse backgrounds*

Two separate focus groups were held with carers from Greek and Vietnamese backgrounds, most of whom were linked in some way with day care centres and therefore had access to bilingual workers and services. One or two of the seventeen carers who attended the two focus groups spoke a small amount of English.

The main issues raised by these carers were:

- Lack of information and knowledge about services and how to access them;
- Not knowing or understanding the meaning of respite (despite their links with services);
- All had significant caring roles and many carers reported that they were not coping well at home and were in need of assistance. Many cited their own health problems to exemplify this fact;
- Those carers using services acknowledged the key role of their English-speaking relatives, not only in accessing the service, but in ongoing communication with the service provider.

Demonstrating that CALD carers are not an homogeneous group, there were also marked differences between Vietnamese and Greek carers. For example many of the Vietnamese carers did not immediately identify with the need to have breaks from caring. One Vietnamese carer stated that as long as he is still alive he will do everything himself. Greek carers on the other hand were more likely to recognise their need for breaks but they preferred to access family members rather than services. The carers in this focus group who were receiving respite services were generally happy with the services. They were not ethno-specific services but the carers had mostly been linked to them through a Greek worker.

In summary there was a common feeling that carers would not ask for assistance until there was an emergency. Usually their first choice would be to get assistance from family. Failing that, most carers wanted to know the number they should call if they required help. Some reported that they would either call the bilingual worker that they knew or the ambulance service if they required urgent assistance.

#### *4.4.3 Carers of people with mental illness*

There was representation from carers of people with mental illness in the focus group for carers who do not use respite services and nearly one-third of the carers responding to our online survey were carers of people with mental illness.

"Dealing with a child under 5 with anxiety and OCD along with his baby brother is quite a task, and at times, we are pushed over the edge, and really burnt out. If we were able to have some time away from the situation to do other things, it would help us to cope better making the home environment healthier for all of our family." (Carer in regional NSW).

Of the 25 mental health carers who responded to the survey, only six had ever used a respite service. Of those, two had used respite only once in the form of an organised holiday, two used it less than once a year (one reported using it "when we are at breaking point") and one used it about once a year to get support to go to work.

Interestingly, the sixth carer lived outside NSW and reported that they accessed respite every three to six months to go shopping etc when the person was unwell and once had been financially assisted to take a short holiday. We received no reports from carers of people with mental illness getting this type of respite support in NSW.

"Current respite services are unsuitable for a mentally ill person...They need someone to check up on them, make sure they have taken medication and gotten out of bed and showered etc." (carer of person with mental illness in regional/rural NSW).

Many carers (as above) indicated that respite services were not suitable for people with mental illness. Other carers reiterated the suggestion that different service delivery models (such as drop-in support) would be more effective. This type of service would give the carer a mental break, as well as a physical break, from their current caring role which, for many carers of people with mental illness, takes a heavy emotional toll.

Comments were also made about the value of combined respite and carer education that assists with coping mechanisms. For many family carers of people with mental illness this type of support gives them a break, emotional support, and skills for coping at the same time. However others commented that they required respite so they could attend courses, social groups and other activities that enabled them to think about and do things other than caring.

#### *4.4.4 Carers in regional and remote areas of NSW*

Forty-one percent of people who responded to our online survey were from regional, rural or remote areas and we also conducted one focus group with carers from a regional area of NSW.

Carers from regional and remote areas were likely to express the same need for respite services however some of the issues they raised differed from carers in metropolitan areas. They were less likely to find a respite service (particularly out-of-home) appropriate for their needs or those of the person they supported. They were likely to be providing significant amounts of transport in order to access respite with significant costs in time and money.

Regional NSW carers felt that they were left out of planning processes and forums where they could have expressed their concerns and unmet needs and that regional staff did not actively seek consultation with families.

### **4.5 Carers in different life stages and relationships**

The varying needs of carers in different relationships and life stages have been explored in the 'Carer Life Course Framework' (Pagnini, 2005). Drawing on this framework, we will highlight some of the identifiable distinctions between caring relationships and life stages that have emerged throughout consultations around respite specifically. We will discuss here only those types of carers that were represented at our focus groups. For this reason we have not included sibling carers. The purpose is to demonstrate the differing needs of caring relationships. It may be useful for service providers in targeting their respite services appropriately.

#### *4.5.1 Parent carers*

"We're at the stage of our life where we want the child out of the house. One part of us wants to take off and have fun but we also want to just relax in our own home." (Parent carer).

A significant issue for parent carers was the impact on their relationship with their spouse or partner and the feeling that they should be able to cope with the caring responsibilities. Many reported losing a lot of their own friends as a result of their caring role. This was often

the combined effect of lack of respite to visit friends and lack of understanding from friends about their caring role. They also referred to the importance of respite in helping them maintain their identity.

"Having respite helps me to resume my identity. I'm no longer Rebecca's mum. I'm Deb. Having respite's also good to get some sleep. It aides me to give the best possible to the disabled person." (Parent carer, Sydney) (Names have been changed for confidentiality).

Parent carers were generally frustrated by the amount they had to 'beg' or 'fight' for services. They were often critical of the quality of the service and expressed concern about the skill level of workers. Some carers found mainstream services more accommodating however there were barriers associated with these too. For out-of-home respite they often reported that they had to provide transport themselves which reduced the time left for a break from caring.

Some carers had found it very difficult to access respite because their child did not 'fit' any of the available services and they were continually referred on. Parent carers of children with disability also expressed a perceived inequity between the amount of respite available in the aged care sector compared with the disability sector.

#### *4.5.2 Partner carers*

"We've been married 53 years now and I'd find it very difficult to go away and enjoy myself. I can't leave her" (Partner carer).

Most of the partner carers were ageing themselves. They were supporting partners with a range of conditions including dementia and physical disabilities. These carers saw their caring role as part of their married life and for some this had inhibited their access to respite.

They generally felt uncomfortable asking other family members for support. Comments such as "I have a son but he and his wife have their own lives and they are too busy to help us" were not uncommon.

The impact of caring on carers' own health and capacity to care was a major concern to them. In many cases failing health had led the carer initially to access respite.

Many older partner carers commented that they would most like to take breaks with their partners but without the stresses of constant caring (ie dual respite). The inappropriateness of some respite models was apparent amongst these carers.

#### *4.5.3 Daughter and son carers*

All of the children caring for parents in our focus groups were adult children. A number of them were also caring for their own child with disability and in a couple of cases they were all living in the same household.

Many son and daughter carers have trouble dealing with the changing roles in their relationship with their parent and taking on a key decision making role. As one carer put it "it's hard telling a parent what to do". This group particularly valued emotional support and assistance with using respite for the first time. Some had given up their own retirement or work plans to care for their parents. Relationships with siblings and partners were also affected as demonstrated by the quote below.

"It's got to the stage where my rest time is when I can go out...cos I sleep in the truck now, I got sick of the doors opening at 1 in the morning, or you're out in the lounge room and she comes in and says "I've got to pay for this electricity. Who are you?"...So I just go and hop in the van and sleep in there of a night. It's a bit different to the house..." (son-in-law caring for mother-in-law). (His wife interjects) "You need time for your relationship. You need time with your husband or you can't keep caring for long".

#### **4.6 Summary of key issues**

The reasons that carers do not use respite are:

1. They don't know about it
2. They can't access it due to practical barriers
3. They don't access it due to emotional barriers
4. They don't have a need for respite

A good respite experience for carers involves:

1. Positive outcomes for them and the person they support
  2. A range of factors regarding access such as entering the system before a crisis, knowing the care worker etc;
  3. Addressing a range of barriers that can arise which prevent a good respite experience
- There are a number of triggers that may lead to respite use including relationship breakdown, poor health and wellbeing of the carer or increased intensity of caring role.
  - It is important for policy makers and service providers to recognise that while different population groups of carers may have the same expressed need for respite, their specific needs may vary.
  - Different models of respite will be appropriate for carers in different life stages and relationships.

## Section 5: Key Issues for Service Providers

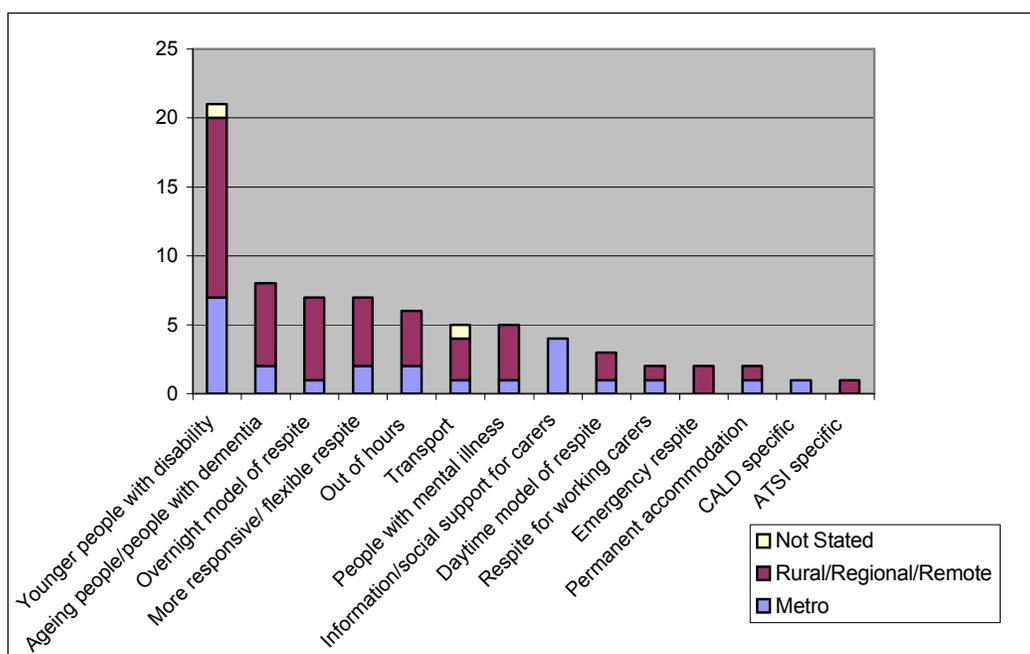
A total of seventy-two service providers contributed to this research, including 24 who participated in focus groups and 48 respondents to the online survey. They were asked to comment on gaps in the system and the challenges of providing effective respite to carers.

They were from metropolitan, regional, rural and remote areas of the state. They received funding from a range of sources including HACC, DSP, NRCP and local government amongst others. They provided all types of respite including in-home, host family, social support, centre-based day care, community overnight respite and residential respite.

### 5.1 Gaps in respite

The gaps identified by service providers varied, reflecting in part the inconsistency of available respite across the state. However some gaps were repeatedly raised. While Figure 2 represents a small sample size, these results were consistent with feedback from the focus groups.

FIGURE 2: GAPS IN RESPITE IDENTIFIED BY SERVICE PROVIDERS



Source: Carers NSW Online Respite Survey

As shown in Figure 2, several types of service gaps were identified in our research, including:

- Respite for carers of different population groups (eg carers of younger people with disabilities; carers of people with mental illness; working carers)
- Types of respite or models of service delivery (eg overnight respite; flexible respite). Models of respite that need more funding were raised by providers as gaps in the system including twilight respite, dual respite<sup>11</sup>, family holiday, overnight in-home and respite that is suitable for people with mental illness and their carers.
- Services that enable respite or impact on respite availability (eg transport; permanent accommodation).

<sup>11</sup> Dual respite refers in this paper to respite provision that enables both carer and care recipient to remain together during period of respite. It has been trialed successfully in Victoria for ageing partners.

## 5.2 Challenges for service providers

"Lack of time and money. High staff turn over. Carers do not have time to make it to support groups. Clients have high needs so a lot of energy goes into the care recipient." (Service provider, online survey).

The main challenges to providing respite raised by service providers were:

1. Insufficient funding to meet carers' needs;
2. High costs of providing services (including high cost of providing transport);
3. Workforce issues (lack of appropriately trained staff, lack of volunteers, high staff turnover);
4. Lack of understanding in the community about respite services and unrealistic expectations about what services can provide;
5. Resistance from carers and resistance from people requiring support to use respite;
6. Difficulty engaging CALD and ATSI communities;
7. Inflexibility in funding agreements. [One response from an NRCP-funded provider highlighted this by giving the example that **"respite money can't be paid for carers to stay in a motel when it's most appropriate"**. Some people commented that while there was flexibility there were still constraints. For instance one provider reported "we are able to be flexible with the way we present our day program but until we get a purpose built day centre we cannot provide all the services we would like to".]

"Most funding agreements are very narrow and do not give scope to provide a totally flexible service." (service provider, online survey)

8. The use of respite beds for permanent accommodation, or 'blocked' respite beds;
9. OH&S issues diverting resources away from families needing respite. [One worker commented that **"the focus of the organisation has shifted from rights under the Disability Services Act...(to) looking after your workers under the OH&S Act"**, adding that demonstrating compliance with OH&S legislation was a significant strain on the service's resources. Increased provision of in-home respite means that family homes must also comply with OH&S regulations. Families may be required to modify their homes or purchase equipment in order to access in-home respite.]

"We've had to exit two consumers from our service because of OH&S issues around challenging behaviours, which would never have happened before, but the risk is just too great to our workers...Both those two consumers have now been forced to move into respite houses and are 'blocking' beds because the mothers could not cope without respite." (Service provider in Sydney).

10. In terms of regulation, one Commonwealth-funded provider reported that "too much time and energy is taken up accounting for every dollar we spend, every km we drive, every hour staffed. Boggled down with paperwork justifying our existence to the funding body".
11. Lack of transport. Service providers are increasingly calling on carers to provide the transport themselves (at the carers' cost and in their respite time) or providing transport with the respite funding which means that the amount of respite is reduced.

It was recognised that these factors have a cost to the family. In many cases the barriers presented are simply too much and families opt for no service. As one service provider commented **"It's not respite any more, it's a hassle"**.

### 5.3 Service responses

Service providers were asked how they could or do respond to the challenges identified. A key issue raised was the limited availability of avenues to feed back information to funding bodies, particularly in relation to insufficient funding to meet carers' needs. They also reported that government funding bodies did not appear to hold information on carers' needs.

Across the state there is not consistent collection of information on local unmet need which can be fed back to funding bodies for planning purposes. It is not known. One provider made the following comment about trying to access information on unmet need:

"When I started with this respite pilot, I went to DADHC [in my region] to get an idea of the unmet need for respite and they had no data". (Service provider, regional NSW).

One provider commented, citing the minimum data set collection for his project, that **"Government funding bodies don't tend to have a tool for [collecting unmet need data]. They want to know what you've done but they don't necessarily want to know what you haven't done."**

There was a perception amongst participants that smaller organisations may have less influence in reporting unmet need and consequently getting increased funding to address it. In regional and rural areas this could mean that entire communities could have unaddressed needs for respite. It was generally agreed that larger, better resourced organisations had a 'direct line' to their funding bodies, particularly if they were able to employ a planning officer or person whose dedicated role is liaising with the funding body.

Some service providers reported that local responses to the limited infrastructure to record, report and address unmet need for respite have developed. Good practice examples of these include the RAPID (Respite Allocation Process in Disabilities) scheme in South East Sydney and the pilot of the Central Referral System in South West Sydney and TAB 2 in the Inner West. Local forums, such as HACC forums, provide valuable opportunities for respite organisations to network and initiate local responses such as these. They not only provide a picture of which carers cannot receive services in the area but also helps to address the needs of carers by enabling a consortium of providers to share waiting lists.

### 5.4 Working with diverse population groups

As program data shows, certain population groups are less likely to access respite services than others. Therefore, services were asked about their work with some of these groups. The diverse population groups discussed included ATSI and CALD carers; carers of people with mental illness; carers living in regional, rural and remote areas; and young carers.

**ATSI carers:** The lack of consistent partnerships and communication between mainstream and Aboriginal services was raised as an issue. Also lack of knowledge from providers about how to target and access ATSI carers and lack of knowledge about the availability of ATSI-specific services or workers in the area were apparent issues for mainstream providers. ATSI providers had mixed responses, reflecting the different partnerships in different areas. Many perceived the biggest problem as getting Aboriginal carers to identify themselves as carers.

**CALD carers:** A significant barrier to meeting the needs of carers from CALD backgrounds was getting them to access the service in the first place. There was very little engagement with carers from CALD backgrounds expressed by providers in regional areas for this reason.

**Carers of people with mental illness:** While most service providers remarked that they could provide respite to people with mental illness and their carers, there were a number of issues preventing them from doing so including lack of appropriately trained staff. Several Respite Centres operating under the brokerage model reported that there were very few services where they could broker respite for carers of people with mental illness. Some reported that monthly carer support groups was the main strategy they used for these carers.

**Carers in regional/rural areas** It was apparent that service providers in regional areas were more likely to know what others in the area were doing and what services they could provide. However this did not necessarily lead to improved service delivery for carers. The regional focus group highlighted some significant gaps in services. Most notable was the lack of respite in the mental health sector. As one service provider commented “young adults can only go to the psychiatric hospital” if their carers require respite.

**Young carers:** In terms of addressing the needs of young carers through respite most service providers reported that they did not know of many young carers. Feedback from some of the CCRC’s<sup>12</sup> suggested that they considered the most appropriate supports for young carers to be flexible service delivery, young carer camps, peer support, emergency support and assistance with continued education such as tutoring and recreational activities.

### **5.5 Summary of key issues**

There are a number of gaps in respite service provision, depending on the area, including:

1. Respite for carers of younger people with disability.
2. Respite for carers of ageing people/people with dementia
3. Overnight respite
4. Regular/occasional/ongoing/flexible/appropriate respite
5. Out of hours respite
6. Transport for respite

Some of the systemic challenges for service providers are:

1. Insufficient funding to address local levels of need
2. Increasing costs of providing services
3. Lack of transport
4. Workforce issues
5. Inflexibility in guidelines
6. Competing priorities such as compliance with OH&S guidelines, reporting requirements

There are also societal factors including:

1. Unrealistic community expectations of respite services
2. Resistance from carers and people requiring support to access respite

Services responded to these challenges in different ways. In terms of addressing unmet need many service providers felt that local networks could be more effective in planning and coordination of respite services.

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<sup>12</sup> Commonwealth Carer Respite Centres are funded through the NRCP to provide respite for young carers.

## Section 6: Analysis

A number of domains for analysis in regards to improved respite services for carers emerge from our research. These include:

- Investigation of the low reported use of and need for respite by carers;
- Service delivery of respite including its effectiveness, better defining respite based on outcomes, coordination and planning of respite services.

Some future challenges for policy makers and service providers are also identified.

### 6.1 Why is there a low use of respite by carers?

Many carers who need respite do not use it, despite the positive effects that it can have on individuals and caring relationships. We have seen from the findings of our research, from the review of the literature and from the current statistics on respite use that, for a range of reasons, a low level of need for respite is expressed by carers. Yet we know that most carers express the need for breaks from their caring roles.

Table 3 illustrates the range of reasons that carers do not use respite services juxtaposed with their explanations of the need for breaks from caring.

TABLE 3: NON-USE OF RESPITE AND THE IMPORTANCE OF BREAKS

Type of carer	Reasons carers don't use respite	Do they think breaks are important?
Mental health carer	"I haven't put any time into looking at the info"	"I get very exhausted being the counsellor as well as making the decisions."
Carer of person with disability, regional area	"It is impossible to find the right type of respite care, I want respite to support my need to work and to facilitate breaks for our family in our home"	"I believe the breakdown of my marriage is directly related to the lack of support for parents and families who care for their disabled children at home...When your child has disabilities you constantly have to own up to failing to get help."
Mental health carer	"I was not aware of it"	"I am a single mother in full time work. I am finding it increasingly difficult to cope..."
Carer of person with disability, regional area	"My son is only four years old so I have not seen it as appropriate to send him away by himself. Maybe respite that we can all enjoy together would be more appropriate"	"it is important that a family with a child with a disability can have a break together as a family however financially this is not possible."
Carer of person with disability, regional area	"..because I know my son is too capable for us to qualify – even though he has a significant intellectual disability"	"Absolutely – because we all need a life of our own away from family members and constantly being on duty to care for other people."
Mental health carer	"I don't think about it"	"Yes. Just to have a break from the tension."
Mental health	"When very unwell usually ends up in clinical care. When I needed it I was	"It gives you and the person you care for the opportunity to have a

Type of carer	Reasons carers don't use respite	Do they think breaks are important?
carer	never made aware it was available"	fresh outlook to each other and the illness."
Mental health carer	"I understood that it was almost non-existent and was impossible to access"	"Yes, physical and emotional exhaustion and the fact that I cannot afford to take holidays."
Carer of frail aged person	"Mainly my mother's attitude towards respite. At times I have put her into hospital for valid medical reasons and this has given me a 'little' respite. Mum would see respite as me trying to get rid of her."	"Yes it is important to have a break. Both mentally and physically...but more mentally..."

Source: Carers NSW Online Survey 2006

Statistics from the ABS (2004b) demonstrate that the greatest percentage of carers who don't use respite report no need for respite. However Table 4 demonstrates that even these carers may have a need for breaks.

TABLE 4: CARERS WITH NO NEED FOR RESPITE

Type of carer	Reasons they don't use respite	Do they think breaks are important?
Mental health carer	"I have not yet felt the need. I have asked for one of my family members to come and stay with me or I go home (Canada) to be with my family, when I feel I need respite."	"without a break away from my loved one, I find myself becoming depressed and unwell. Even going to work is a break for me."
Carer of person with chronic condition	"Don't feel I need it yet. May possibly consider it at a later date."	"It is important but I have to admit my breaks usually consist of doing the grocery shopping etc. Would like to have a few days on my own ...the person I care for thinks he should come too!"

Source: Carers NSW Online Survey 2006

It is important to note that in Table 4 these carers expressed no need 'yet'. The information gained from our research indicates that many carers do not feel that they need respite before they are in an emergency situation. This is further reflected by the ABS (2004b) statistics which demonstrate that seventy percent of carers with a need for more respite need it on a short notice or irregular basis.

A number of explanations have emerged from our research to suggest why the majority of carers surveyed by the ABS report low use and low need for respite, despite our understanding that there is considerable unmet need for respite. As reported in Section 4, we found that:

- Many carers have perceptions about respite that may prevent them from accessing it. These perceptions may include that it is mainly centre-based or residential respite; that it cannot cater to their needs or the needs of the whole caring situation.
- Carers from CALD backgrounds in particular may not understand the concept or terminology relating to respite and therefore do not understand that it is a service for them;

- Whilst many people use small amounts of respite to assist them on a weekly basis, others view seeking respite as a last resort and admission that they are not coping with their caring role and therefore report that they do not need it 'yet'.
- Our methodology, compared with the ABS methodology, favours carers who are likely to be familiar with the service system and terminology to the extent that they identify a need for respite. Our carer sample is not representative of the total carer population, of which only one-third are likely to identify as a carer (SPRC 2004).

As discussed by Payne and Ehrlich (1998) carers are less likely to express a need if they are unaware of the services available. In the case of respite there are misconceptions and a lack of general understanding about respite and its availability. This lessens the likelihood that carers will express a need for this service.

The lack of understanding in the community about both the concept of respite and how this translates into services has two main implications. Firstly there needs to be a better understanding across policy makers, service providers and service users about what respite is and there needs to be more effective communication to the community about carers and the services that can support them.

## **6.2 What makes respite effective?**

A better understanding of what makes respite effective requires a more consistent approach to defining the purpose, aims and outcomes of this service. While there is not total agreement (as shown in Sections 2 and 4) there appear to be some commonly held views amongst service providers and across programs about respite. Based on our research these are:

- Purpose: The purpose of respite is to provide carers with a break from their usual caring role. The intention is that the caring relationship is maintained throughout the respite episodes and continues after the episode is complete.
- Aims: Respite should support carers and the people they support in their home, in the community or in a residential setting; Respite includes planned and regular short breaks for carers (ranging from one hour to several weeks); All carers with significant caring roles need support and breaks. The way these breaks should be received varies in every caring situation. Respite, while important, is just one of the services required by carers and the people they support and must be delivered as a component of family support.
- Outcomes: Respite should have positive outcomes for both carers and the people they support; Carers and the people they support should have choices about the support they receive and about the extent of their 'caring' relationship.

Two questions posed in the introduction to this paper were whether there is a misfit between the aims and outcomes of respite and how respite can more effectively meet the needs of carers and those they support. We have seen from the findings of our research that often the aims and outcomes of respite do not correspond largely due to the effectiveness of respite.

There are two interrelated aspects of effective respite. They are:

1. Individual outcomes (for carers and the people they support);
2. Systemic and cost effectiveness.

### *6.2.1 Individual outcomes of effective respite*

The key aspect of a respite service that distinguishes it from other services is that it must provide positive outcomes for family carers and these should be measured and reported on.

Hirst (2004) has identified four dimensions of outcomes for carers using services. These can be adapted as a tool for measuring effectiveness of respite. The four dimensions are:

1. quality of life for the cared for person (including safety, independence, stimulation);
2. quality of life for the carer (including health, wellbeing, choice; social involvement positive relationships);
3. recognition and support in the caring role (includes being informed, satisfaction, ability to manage); and
4. service process outcomes (includes being valued and respected, consulted, responsive and accessible services).

From our consultations with carers it is clear that respite is not effective unless it is delivered in the context of holistic support for carers. Many of the barriers to accessing respite indicate lack of other relevant supports (Appendix 4). For example lack of transport and emotional support were inhibiting factors raised by ATSI carers.

Therefore an effective respite system involves the placement of respite in a package of family support which must include relevant and timely information and referral, emotional support and health and community care services. It may also include advocacy, counselling, case management, education and training and financial assistance for carers. This is explored by Arksey et al (2004) in their study on effective respite for carers of people with dementia. The study identifies two tiers of support services that are required in order to achieve a 'good break'. The bottom tier of factors that underpin effective respite includes for example knowledgeable and supportive doctors; accessible information; helpful family and friends. The next tier involves characteristics of effective respite such as assessment and ongoing review; and ability to maintain or improve the well-being of the care recipient, amongst others.

In order to achieve the outcomes for carers suggested by Hirst, we have developed a set of *principles for effective respite*, based on consensus from the literature (Kilner 2002; StollzNow 2005; Coopers and Lybrand 1996) and carers who were consulted for this paper. These are:

- Timely, relevant and culturally appropriate information and referral
- Emotional support and assistance with access
- Flexible service delivery that is appropriate to the individual cultural and lifestyle needs of the care relationship
- Appropriately trained staff for the needs of the care recipient
- High quality, reliable care and support
- Affordable
- Appropriate length of time
- Planned and developed in consultation with carer
- Choice of options for the carer and the person they support
- Responsive to identified needs of the carer and the person they support

The weighting of these principles in terms of their importance will vary according to the needs of different groups of carers as set out in Section 4.

### *6.2.2 Systemic and cost effectiveness of respite*

The systemic effectiveness of respite has not been measured in NSW. However there are some available measures. For example the extent to which respite beds for younger people with disabilities are 'blocked' or used by people requiring ongoing accommodation is one measure. The extent to which people using residential respite in aged care homes return to their community is another. It can be seen from the data in Sections 3 of this paper that,

using these measures, NSW has a degree of respite system ineffectiveness. This impacts on consumers wishing to access respite as the entire allocation of respite is not available. Systemic ineffectiveness generally indicates lack of available services such as accommodation support. There is no measure of how much respite is used in place of other services such as employment/education services for younger people with disabilities. These issues were raised by service providers (Section 5).

There is variable literature on the cost effectiveness of respite (Arksey et al 2004; Jeon et al 2005) and many of these studies have not viewed the overall benefits of respite making it difficult to draw conclusions. Effective respite in terms of individual outcomes is likely to be cost effective as it supports carers to maintain their health and wellbeing and enables the continuation of care in the community. The way carers use respite influences its benefits overall. For example respite may enable carers to continue working, to take preventative measures in looking after their own health and wellbeing and essentially to continue caring.

Apart from these benefits the cost-savings of community care versus residential care for people with high support needs are significant. A recent report (Access Economics 2005) found that the cost of care in the community (including replacement costs of carers) is 60% less than high care residential care.

The overall cost-effectiveness of respite could be measured by comprehensive research on the impacts of the full range of respite models on caring relationships in the community. Development of a cross-government NSW Carers Policy could provide a framework for setting benchmarks and measuring carer outcomes from respite services.

### **6.3 How can respite be better defined?**

'Respite' (as it is currently used) can be anything from a one-off break to an indefinite period of care when the care arrangements at home break down. We have suggested above that respite is better defined by the outcomes it produces rather than the specific service delivery model, as flexibility in respite services is a key principle of effective respite. We hope to reach a clearer shared understanding between government, service providers and carers about what respite is and what it aims to achieve. It may be necessary to rethink terminology used when referring to respite.

Respite should have positive outcomes for carers and the people they support and accordingly, should have positive outcomes for the community and may carry cost savings to government. Therefore we propose below, based on the outcome domains suggested by Hirst (2004), some specific outcomes for respite services in NSW. Ultimately these outcomes will not be achieved unless carers have a range of supports including respite.

#### *Carer outcomes:*

- Maintenance or improvement of health, well-being and quality of life
- Improvement in ability to cope with caring role
- Reduction of stress in the long term as well as the short term
- Improvement of relationship with person they support and other relationships
- Maintenance of cultural beliefs and practices
- Linked with other required services and supports
- Able to balance caring with other parts of their life

#### *Outcomes for person requiring support:*

- Maintenance or improvement of health, well-being and quality of life
- Improvement of relationship with carer
- Positive experience in terms of (age and cultural) appropriateness of service

*Systemic outcomes:*

- Prevention of inappropriate or premature admission to residential facilities
- Reduced pressure on generic services including acute care and emergency services resulting in cost savings to government.

It is a fundamental aspect of carers' rights and the rights of people they support that they should have choices about continuation or cessation of their caring role and about how and where they live. Therefore respite should be delivered on the premise that continuation of the caring relationship is the choice of both parties.

Each caring situation is unique and needs change over time. Carers are likely to require more than one type of respite depending on a range of factors that will be apparent to service providers through ongoing assessment and review. The triggers for accessing respite identified in Section 4.2 are a useful guide (ie availability of informal supports; relationship breakdown; changing intensity of caring role; health or wellbeing of carer; changing levels of support from other services) to factors that may influence need for respite.

The types of 'respite' support that can achieve respite outcomes for carers and those they care for are:

- **One-off or episodic support** – enables carer to attend events such as courses, weddings, holidays etc and enables continuity of support for person needing assistance.
- **Frequent, small amounts of support** – enables carer to 'catch up' on household and other activities on a regular basis and enables continuity of support for person needing assistance. Where individual planning is undertaken both carer and care recipient can have positive, appropriate experiences.
- **Regular blocks of time for relief, rest or a break from caring** – enables carers to plan time off from their caring role. It should provide the person requiring care with positive, appropriate experience and good quality care and support. Options for dual respite for couples, or holiday respite could produce positive respite outcomes.

In all of these cases respite should be provided in a setting that is appropriate and flexible manner.

There are a number of other services that should be available to people when needed. These include emergency support (eg where carer needs to go to hospital at short notice); transition to supported accommodation or residential care (where both carer and person requiring support can adapt over time); ongoing accommodation for people requiring support. Respite services are sometimes used when these specific types of support are unavailable. However it must be noted that by using respite in these ways the individual and systemic outcomes specified above are unlikely to be achieved.

The following scenarios demonstrate the ways in which a particular respite service delivery model can be effective for one caring situation but ineffective for another. Similar scenarios could be drawn for all respite models.

*Different scenarios for outcomes of in-home respite model*

Scenario 1: An elderly man caring for his wife who has early signs of dementia and limited mobility applied for respite to enable him to take weekly visits to the doctor, to the bank, to the park for a walk. He loves spending time with his wife and they have quite a few friends but they can no longer do everything together and the weekly respite time enables him to get things done or just have some 'time off'. His wife enjoys the company of the respite

worker who often just sits with her for a cup of tea and chats. On occasion the respite worker takes her out for short walks and sometimes to the shops or to visit a neighbour.

Outcomes: The carer is able to balance caring with other activities, to maintain his health and wellbeing, to reduce stress and to keep a happy relationship with his wife. The care recipient's needs are met, her health and wellbeing is maintained, as is her relationship with carer. The couple is able to remain living at home and they know who to contact if their support needs change.

Scenario 2: A single working mother in her fifties cares for her 20 year old son with a physical disability who attends a day program. They had been trying for years to access supported accommodation. The carer applied for respite because she felt she could no longer cope without help and her own health was getting worse. She received in-home respite each Thursday from 4.30pm – 6.30pm, during which time she could do the weekly shopping and catch up on some housework. She spent much of her weekends providing transport and personal care so could not catch up with friends. Having tried to get more support without luck she continued to be the sole carer for her son until her health deteriorated. She was admitted to hospital during which time she received 'emergency respite' where a worker lived-in at her house for eight days as it had been suitably modified.

Outcomes: Respite provided was not sufficient to enable the carer to balance caring with other activities, to maintain her health and wellbeing, to reduce stress in the long term, or to improve her ability to cope with caring at home. Care recipient did not have improved quality of life or a positive experience that was age appropriate. This led to avoidable use of generic health services and costly 'emergency respite'.

Analysis: One service delivery model of respite could be appropriate for one caring situation and inappropriate for another. It can be seen that in scenario 2 respite was ineffective on two levels. In-home respite enabled the carer to catch up on essential chores but not to have a proper break from caring. Emergency respite was delivered while she was in hospital receiving treatment, therefore not delivering any of the benefits of respite. These scenarios demonstrate that 'respite' services do not always deliver 'respite' outcomes. Weekend respite could have enabled a better balance in the carer's life<sup>13</sup>.

There is an important distinction to be made between 'one-off respite' and emergency support. Emergency support is an essential service for carers and should be available without affecting the amount of respite they receive. However they do not receive many benefits as they may be in hospital or another crisis situation. 'One-off' or intermittent respite may be useful for carers wishing to attend weddings or go on holidays. It enables them to balance their caring role with other important aspects of their lives (as long as they have adequate ongoing supports). It has the potential to be a cost-effective option as it provides an alternative to hospital or residential care and enables ongoing care in the community.

By proposing an outcomes-focussed definition of 'respite' we hope that these services will be more effective for carers, not less flexible.

#### **6.4 How could respite be better planned, coordinated and delivered?**

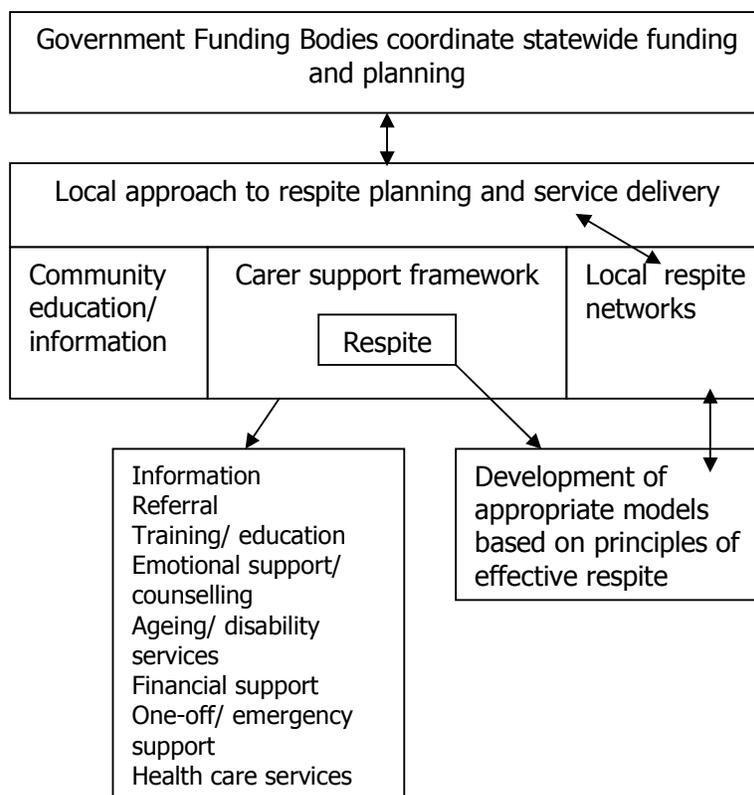
There is no simple formula for planning respite services. In some regions respite services need to reach a small, dispersed population. In others they need to cater to a higher-density population within a small area. Different models of respite will be suitable for different areas. Demographic variation also means that some areas will need to develop better strategies for

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<sup>13</sup> Although these scenarios are fictional, they mirror the types of issues raised by carers in our research.

working with ATSI carers, for example, while others will need an increased focus on a growing number of ageing carers. In 2007 planning bodies will have access to local area data on the number and characteristics of carers from the 2006 census which will aid planning.

FIGURE 3: LOCAL RESPITE FRAMEWORK



Using a localised approach to planning and coordinating respite shown above as well as the principles of effective respite and its location in a context of comprehensive support, the respite system could be much more beneficial to carers. Local networks for different types of respite (eg targeting carers of people with disability, mental illness or frail aged people) would need to collaborate as shown in Figure 3 as well as having a central mechanism for all respite providers to identify gaps in services and unmet need.

The central role in this representation of a more responsive respite system is the regional planning and service delivery role. Local respite networks provide the infrastructure for better collection of data on unmet needs and to provide a centralised referral system to ensure that families needs, where possible, can be met by existing resources but still provide them with choices about the services they access. The infrastructure needs to be put in place to facilitate data collection and communication with funding bodies.

In communication with local respite networks, a clearer picture of what is needed in any region can be communicated to the State and Commonwealth funding bodies. This way, when gaps are identified in an area, respite funding can be used more effectively to address these gaps.

Local networks can also identify gaps in the carer support system or generic services that are impacting negatively on the respite system, for instance need for supported accommodation, one-off/emergency support or case management.

Innovative models that address specific needs of the community can be proposed and developed through the local respite networks, in consultation with families in the region. Resources are likely to be used much more effectively where there is local collaboration and planning is made in consultation with families.

A host of pilot respite programs and innovative models have been developed in NSW, nationally and abroad. It is problematic that many successful respite pilots and innovations do not receive ongoing funding, an issue that must be addressed in planning for respite services. It is important that any new respite models are developed according to the principles of effective respite (Section 6.2).

As suggested by Hirst (2004), assessment and ongoing review of the carer's needs as well as the changing needs of the person requiring support are vital to the effective delivery of respite services appropriate to those needs. Given that carers who express a need for respite and who access respite are most likely to have higher intensity caring roles than other carers (as shown in Sections 3.3), carer assessment by service providers is particularly important for carers accessing respite services.

Community education and information about respite and the type of information that is outlined in Appendix 4 will help to address the low use of respite services by carers who would potentially benefit from these services. This information would need to be delivered through a range of mediums, available in relevant community languages and formats and appropriate for the cultural diversity of each region.

### **6.5 Policy Implications**

There is little evidence from the literature or consultations that carers are involved in planning for respite services, at a local or statewide level. There is also limited evidence that outcomes from respite services are readily being assessed or recorded and there is no consistent, statewide tool for doing this.

The effectiveness of respite is seriously jeopardised by lack of other supports and services particularly for those caring for younger people with disabilities or people with mental illness. If respite is being used as a proxy for other services (such as accommodation support) then carers are not actually benefiting from these services and the respite system as a whole is negatively affected.

In addition the lack of funding leads to problems already identified including long waiting lists and poor levels of access. As shown in Section 4, the service system tends to be crisis-driven and service-focussed rather than carer-focussed.

There are important benefits to be gained from investment in the respite system at this point. The potential benefits to carers and the people they support have been identified in Section 6.2. The benefits to government include continued care in the community for longer periods of time, increased coping of families and improved health and wellbeing of carers.

There are significant implications of an ineffective respite system on other areas of government policy as well. These include an over-reliance on generic acute care and emergency services by families that cannot cope and are unable to access the appropriate supports. Also carer stress, exhaustion and ill-health stemming from unavailable or inappropriate supports will impact on the primary, acute and emergency health systems. Lack of appropriate, preventative respite will also lead to increased future pressure on an accommodation support system that is already failing to meet the needs of NSW families.

## **6.6 Challenges for the future**

In this paper we have taken a practical view of respite, considering what it is in the context of carer support and how effective it is from a carer and systems perspective. We have also outlined some of the approaches to respite that could improve the outcomes for carers and for the people they support.

Underlying these practical issues is the environment of demographic change and social policy development. As identified in the introduction, the population is ageing. People with disabilities are living longer and society has growing expectations that all people should be able to exercise their rights to choose where and how they live.

The economic pressures inherent in these trends are apparent. In 2006 the NSW Government released a Budget Paper entitled 'NSW Long Term Fiscal Pressures Report' in which it identified the health and disability services budgets as key growth areas over the next forty years.

Given that respite needs are likely to increase it is pertinent now to consider how respite needs to be planned differently for the future. The need for 'respite' will be never-ending if carers are expected to continue caring for long periods of time without other adequate supports. The distinction between a need for respite and a need for other types of support will become more difficult to determine unless adequate processes of ongoing carer assessment and review are in place.

Presently three quarters of carers in NSW are of workforce age (ABS 2004c), yet their rates of employment are very low because there are not adequate supports to allow them to balance work and caring. These considerations must be incorporated into future planning by the government. By encouraging flexible workplace practices in combination with improving ageing and disability services the NSW Government could assist those carers who want to return to work or remain in work to do so.

The effectiveness of respite services needs to be better documented including outcomes for individuals as well as systemic outcomes of respite. The effectiveness of new or existing programs in reaching their target populations should be recorded, including the extent to which targeted carers are already known to the service system.

The desire of the NSW Government to assist people with disabilities to continue living at home has been strongly emphasised in recent policy developments particularly in mental health and disability in NSW. There is a similar emphasis in care for frail aged people and people with other conditions.

There is clearly a strong economic imperative for this policy focus in light of the high costs of residential and institutional care. However these costs cannot be shifted into the home without ramifications. Without adequate planning for future carer support there will be impacts on economic and health outcomes for carers.

## **Section 7: Recommendations**

### **For NSW Government:**

1. *Increase funding to address identified gaps in respite services, including respite for carers of younger people with disabilities and respite for carers of people with mental illness.*  
(see Section 5.1)
2. *Increase funding for transport to enable more effective use of respite services by carers.*  
(see Section 5.1)
3. *Address inadequate levels of supported accommodation available to people living in the community and other services that impact negatively on the respite system.*  
(See Section 5.1; 6.5)
4. *Funding for outreach and information services for CALD carers and ATSI communities particularly in geographical areas where there is likely to be a high level of unmet need.*  
(see Sections 4.4.1; 4.4.2)
5. *Urgently address the issue of inappropriate respite use, primarily the 'blocking' of respite beds in disability respite houses for people requiring ongoing accommodation.*  
(see Section 6.2.2)
6. *Trial and resource local coordination networks (based on existing best practice models) that enable improved planning for respite services including improved data collection and reporting on unmet need..*  
(see Section 6.4)
7. *Develop improved community education and information about 'respite'. This may involve reconsidering terminology and clearly identifying the benefits of respite, who it is for and what type of service it is.*  
(see Section 6.4)
8. *Revisit existing respite guidelines in light of the principles of effective respite and outcomes for carers and the people they support.*  
(see Section 6.2)
9. *Ensure the inclusion of measures for effective respite in terms of outcomes for carers in the NSW Carer Policy development.*  
(see Section 6.2)

### **For Commonwealth Government:**

10. *Increased funding and program development for emergency carer support.*  
(see Section 6.3)
11. *Urgently address the low rate of return to the community for respite residents in aged care facilities.*  
(see Section 2.3.2)

12. *Work with NSW Government to ensure that an improved system of local coordination and planning for respite services including improved data collection and reporting on unmet need and outcomes for carers using respite is developed.*  
(see Section 6.4)
13. *Ensure that there is adequate funding to states to provide comprehensive package of support for carers including respite but also emotional support, practical services and financial assistance.*  
(see Section 6.4)

**For service providers:**

14. *To participate in local and regional networks of information sharing and planning and feed data on unmet need back to funding bodies*  
(see Section 5.3)
15. *To conduct comprehensive carer assessment and where relevant recognise a carer's needs for additional supports and make the appropriate referrals*  
(see Section 6.2; Appendix 4)
16. *To understand the different needs of different groups of carers and have strategies to respond to their needs developed, where appropriate, with ATSI and CALD specific organisations and mental health service providers.*  
(see Section 4.4, Section 5.4)
17. *To conduct ongoing assessment that ensures respite is achieving positive outcomes for carers and to ensure respite is a positive experience and that carer involvement in planning and ongoing consultation about the respite service.*  
(see Section 4.3, Section 6.2)
18. *To provide a variety of respite options and deliver services with maximum flexibility, in line with the 'principles of effective respite'.*  
(see Section 6.2)

## **Appendix 1: Literature Review**

There is a significant amount of literature on respite from around the world. Conceptually this area of carer support has been explored in the UK, America, Canada and Australia. This review of the literature focuses on respite from the carer's perspective, canvassing three thematic areas concerning respite outcomes for carers. These are the use and non-use of respite services, the effectiveness of respite for carers and the conceptualisation of respite.

### **Use and non-use of respite services**

There is broad agreement in the literature that respite services are under-utilised by carers despite the great need for respite, which is often considered to be under-reported. Some of the literature identifies aspects of the service system that make respite inaccessible or inappropriate and therefore contribute to non-use by carers.

A range of issues preventing use of respite services including service fragmentation, inadequate assessment, inconsistent fees policies, the use of respite beds for ongoing accommodation and the inequitable distribution of respite services have been raised in NSW (ADD 2000; CSC 1998) and elsewhere. An Australia-wide review of respite services (DHFS 1996) highlighted many systemic problems with respite and called for greater carer focus in assessment and service models. It recommended more innovation and flexibility in funding and delivery of services in response to these systemic issues.

There are other reports that focus on which carers are more likely to need and access respite care. This is usually linked to the level of support a carer provides, the type of person they care for and other demographic factors (SPRC 2003; Schofield et al 1998). The ABS (2000), for instance, identifies carers who provide at least 40 hours of care per week, care for someone with a profound disability, give continuous care, have no back up carers and/or are female, caring for someone other than their partner, as most likely to access respite.

There are several reports highlighting the reasons why carers are unsuccessful in accessing respite, leading to non-use of services. These include lack of information, flexibility and choices (Niedzwiecki and Pierce 2003; Liu and Choi 1996; Carers WA 2002). Lack of identification as a carer is a significant barrier to the reporting of need for services and it is known that many carers, even those the ABS would define as primary carers, do not identify as such and are therefore less likely to access services (SPRC 2004).

In two recent surveys of carers (Carers News Survey 2004; Bennett 2005), when asked what type of assistance they most require, carers have reported needing assistance to take breaks from their caring role.

There is also literature to show that carers are most likely to access respite through certain pathways. An AIHW report on Residential Aged Care (Karmel 2005), found that there was a greater likelihood of people accessing the HACC Program or a CACP to enter residential respite. For the period examined, up to 60% of residential respite residents had used either a CACP or HACC service before their admission to residential respite.

Unmet need is largely un-recorded. It is estimated by the Australian Bureau of Statistics that over one-third of all primary carers need more support in their caring role. It is also estimated that nearly 81,000 carers in Australia needed more respite (ABS 2004b). However it has also been suggested that many carers do not recognise their own unmet need for services unless information has been tailored to the individual carer's situation (Payne and Ehrlich 1998).

### **CALD and ATSI carers**

There is limited literature that discusses respite for Aboriginal and Torres Strait Islander (ATSI) carers. There is evidence, however, that ATSI carers have a need for respite similar to other carers (Pearson and Associates 2001). The desirable characteristics of respite are flexibility and trustworthiness and cultural awareness of providers.

There is evidence in the literature that carers from CALD backgrounds have a need for respite. It has been identified in a number of reports from Australia and overseas (Schofield 1998; Jewson 2003; Nankervis and Rebeiro 2000) that, although the term 'respite' may not be used, the need for carers to have breaks from caring is prevalent in CALD communities. The literature suggests that this need may be amplified by issues relating to migration, social isolation and lack of informal supports in the local area.

There are a number of reasons why carers from culturally and linguistically diverse (CALD) backgrounds are less likely to access services than other carers. These include language barriers, insufficient coordination, inadequate income and lack of cultural awareness by service providers (MMHA 2004).

The Carers News Survey 2004, conducted by Carers NSW, found that carers from CALD backgrounds were more likely than other carers to express a need for information and outreach and as likely as other carers to express a need for respite. This is a very small sample survey and for this reason cannot be considered representative of all carers from CALD backgrounds. However it does indicate that there may be a greater need for information as a first step towards accessing services in CALD communities.

### **Effective Respite**

There has been a greater focus in recent years, both in Australia and overseas, on identifying what constitutes effective respite for a family living with disability or illness. This includes literature on 'best practice' as well as linking different support needs with different respite services.

Gray (1996) considers best practice models for respite in Australia and how respite should be placed in the continuum of community, in-home and residential services for aged people. Other research investigates how respite needs can be met in specific care situations. For instance respite ageing parent carers (CAA 2005), for carers of children with multiple disabilities (McConkey et al 2004), children with chronic conditions (Neufeld et al 2001), carers of people with advanced cancer (Strang et al 2002) or Motor Neurone Disease (Richter 2000). Jeon et al (2005) identified a lack of literature on effective respite, particularly for carers of people with mental illness.

One of the most comprehensive and significant reports to be written recently regarding effective respite is from the United Kingdom, by Arksey et al (2004). Its focus is on carers of people with dementia but the model used could be more widely applicable. 'The Effective Respite Pyramid' demonstrates all the components that lead to an effective break in three tiers, illuminating a picture of respite that is now becoming more widely accepted, that respite should not be an isolated service, but part of a whole system of support for families.

The question of whether or not carers actually receive breaks from using respite services is a contentious one. Conflicting results have been identified in a number of studies. There have been findings, for instance, that carers do not perceive a break because of the concern they have regarding the quality of care their family member is receiving in the respite service. Also the level of preparation that goes into a "respite day" outside the home can mean that a higher level of care is provided by family carers on respite days than on non-respite days (McConkey et al, 2004 Northern Ireland; Arksey et al 2004 UK; Neufeld 2001 Canada).

There have also been cases put forward for the effectiveness of respite in other areas of carers' lives including reduction of stress, coping, health and well-being of carers (Chan 2002).

There is some consistency in the literature on what constitutes 'good' respite. In many ways it reflects other services for carers in general. For instance affordability, accessibility, availability, flexibility and appropriateness are frequently raised as elements of good respite (DHFS 1996; Parmenter 1999; Nankervis and Rebeiro 2000; Disability Council 1989).

The perceptions of respite are also explored by these authors, for instance, Nankervis and Rebeiro (2000) write that carers often see residential respite as the "end of the road".

Constraints to flexibility from a service provider perspective include transport costs, inflexible funding, lack of resources and time, inadequate funding and staffing, lack of early intervention, waiting lists, lack of overnight respite, limited range of options, limited capacity to meet needs of carers from CALD backgrounds (AAV 2003).

It has been reported that there are opportunities for closer working relationships between providers in regional and rural areas than in metropolitan areas and that a range of innovative respite models have emerged from regional areas as a result (Shanley 2001).

### **Conceptualising Respite**

There has been an ongoing debate over what the role of respite should be in the community care system. One of the earlier pieces of work on respite in NSW (Disability Council of NSW 1989) recommended that respite should be "entitlements based" rather than viewed as a "quality of life" service, which is not essential but beneficial.

In 2000 a Respite Working Group reported to the NSW Minister for Disability on reshaping the respite system in NSW. It recommended that respite should be "promoted as support for the person with a disability and their family or carer/s; a planned, preventative service, not a crisis service; and one part of a total coordinated range of support services for people with disabilities" (ADD 2000).

For some time there has been debate that respite should be seen as an outcome as well as a service and recently more consideration has been made around reconceptualising respite entirely. It has been suggested that the word "respite" now has negative connotations and is seen as an economic alternative to early institutionalisation (Husayn, 2004). The emphasis on "carer burden" is still apparent in many of the studies on respite, contributing to this negative perception.

Chappell et al (2001) provide an explanation for the low utilisation of respite services by suggesting that service providers and policy makers define respite differently to carers. In their study 60% of carers identified respite as something outside of the service system. Also illustrating this point, Strang et al (2002) describe respite as a cognitive process rather than a service. They recommend that health professionals do not push carers to take breaks (from caring for people with advanced cancer). Rather they should encourage carers to do the things that make them feel that they are getting a break, even if that doesn't entail leaving the home or involve formal service use.

### **Gaps in Literature**

The Australian literature on respite indicates that systemic problems are widely known. Numerous reports have been commissioned by various tiers of government over a number of years (including ADD 2000; CSC 1996). They largely highlight access issues relating to blocked respite beds<sup>14</sup>, the complications of multiple funding sources and programs, lack of communication between various respite providers and so on.

While some authors have begun to investigate the effectiveness of, not only different respite models but the concept of respite services themselves, in meeting the needs of carers and the people they support, more research in this area is needed.

The varying needs and perceptions of respite by different population groups should also be considered including Indigenous communities and culturally and linguistically diverse communities. In addition the needs of different groups of carers including young carers, ageing carers and carers of people with different disabilities or conditions should be further considered.

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<sup>14</sup> This refers to the misuse of dedicated respite beds in supported accommodation facilities that are continuously occupied by people otherwise requiring long term accommodation options.

## **Appendix 2: Focus group outline**

This is a general outline of the questions that shaped the focus group discussions with carers and with service providers. They provided a guide to focus group discussions and each discussion varied slightly depending on the specific group. For example carers attending the focus group for people who do not use respite were not asked about the types of respite they used.

The focus groups were each two hours in duration and participants were asked to give a brief introduction at the beginning. They were also sent a short survey introducing some of the topics to be addressed in the focus groups prior to attending and asked to bring it with them. Participants were also followed up with a thank you note and further information about the research.

### **Focus groups for carers**

- Do you feel it is important to have breaks from caring? Why/why not?
- What arrangements do you currently have to assist you with breaks from caring? What different types of respite or other services do you or have you accessed?
- What types of things do you use these breaks for?
- Do you get enough support? What do you need more of?
- What helps to make a break good for you?
- What prevents you from having a good break?
- At what point in your caring relationship did you first try to access respite/ feel the need to take a break?
- How did you/ would you go about accessing a respite service?
- Do you get a chance to give feedback about the service you are receiving? How could services support you better to get breaks from caring?

### **Focus groups for service providers**

- From your perspective what are the significant gaps in respite for carers in your area?
- What types or models of respite are most needed in your area?
- How much flexibility do your funding guidelines allow you to address specific needs of families?
- To what extent does the level of funding you receive limit your ability to address carers' needs?
- How does your service work with ATSI carers/ CALD carers/ carers of people with mental illness?
- In your experience what other services and supports do carers need in order to get effective breaks when using respite?
- What innovative respite models or approaches to respite do you know of in your area?

## Appendix 3: Results of online carer and service provider surveys

<i>Results - online survey for carers</i>	<i>No.</i>	<i>%</i>
Total carers	80	100%
<b>Q1: Your age</b>		
Less than 18	0	0%
18-24	3	4%
25-34	6	8%
35-44	20	25%
45-54	28	35%
55-64	17	21%
65-74	6	8%
75+	0	0%
Not stated	0	0%
Total	80	101%
<b>Q2: Your gender</b>		
Male	9	11%
Female	71	89%
Not stated	0	0%
<b>Q3: Primary condition of the person you support</b>		
Chronic condition	7	9%
Disability	47	59%
Frail aged/dementia	6	8%
Mental illness	20	25%
Not stated	0	0%
<b>Q4: Area you live in</b>		
Metropolitan NSW	44	55%
Regional or rural NSW	33	41%
Remote NSW	0	0%
Different state of Australia	3	4%
<b>Q5: Are you an Aboriginal or Torres Strait Islander?</b>		
Yes	2	3%
No	78	98%
Not stated	0	0%
<b>Q6: Are you from a culturally or linguistically diverse background?</b>		
Yes	5	6%
No	72	90%
Not stated	3	4%
<b>Q7: Have you ever used a formal respite service?</b>		
Yes	50	62%
No	30	38%
Not stated	0	0%
<b>Q8: What type of respite was it (multiple responses allowed)?</b>		
In-home	23	46%
Host family	4	8%
Centre based day care	12	24%
Residential	26	52%
Other	10	20%
Not stated	1	2%

Total	76	100%
<b>Q9: How frequently do you use respite?</b>		
Only once	6	12%
Less than once a year	7	14%
About once a year	4	8%
Every 6 months to 1 year	4	8%
Every 3 months to 6 months	5	10%
More than every 3 months	25	50%
<b>Q11: Have you made a deliberate decision not to use respite?</b>		
Yes	10	33%
No	20	66%
Not stated	0	0%
Total	30	100%
<b>Q13: Have you tried to access respite but not been successful?</b>		
Yes	7	23%
No	23	77%
Not stated	0	0%
Total	30	100%

<i>Results - online survey for service providers</i>	<i>No.</i>	<i>%</i>
<b>Q1: Type(s) of respite provided</b>		
In-home	33	45%
Host family	7	10%
Centre-based day respite	18	25%
Social support	25	34%
Community overnight respite	15	21%
Residential respite (aged care)	10	14%
Residential respite (disability)	11	15%
Other	14	19%
Not stated	4	3%
Total	137	
Average no. of respite types provided by each organisation	2.9	
<b>Q2: Type of organisation</b>		
Not for profit/charity	28	58%
Government	12	25%
Private for profit	3	6%
Other	1	2%
Not stated	4	8%
Total	48	99%
<b>Q3: Is your organisation mainstream or ATSI/CALD specific?</b>		
Mainstream	37	77%
ATSI	1	2%
CALD	1	2%
Not stated	9	19%
Total	48	100

<b>Q4: From which source(s) do you receive your funding?</b>		
HACC	28	58%
NRCP	17	35%
CSTDA	4	8%
DSP	8	17%
Commonwealth Government (other)	14	29%
Local Government (other)	5	10%
State Government (other)	13	27%
Private	2	4%
Not stated	2	4%
<b>Total</b>	<b>93</b>	
Average no. of funding sources	1.9	

<b>Q5: What area do you service?</b>			
Metropolitan (Sydney/Wollongong/Newcastle)	NSW	14	29%
Regional or rural NSW		24	50%
Remote NSW		2	4%
Different state of Australia		0	0%
Different country		0	0%
Not stated		8	17%
<b>Total</b>		<b>48</b>	<b>100%</b>

Type of respite/service	Metro	Rural/ Reg'l/Remote	Not Stated	Total
<b>Q7: Gaps in service - Number of issues raised</b>				
Respite for carers of younger people with disability	7	13	1	21
Respite for carers of ageing people/people with dementia	2	6		8
Overnight model of respite	1	6		7
Regular/occasional/ongoing/flexible/appropriate respite	2	5		7
Out of hours respite	2	4		6
Transport	1	3	1	5
Respite for carers of people with mental illness	1	4		5
Information/social support for carers	4			4
Daytime models of respite	1	2		3
Respite for working carers	1	1		2
Emergency respite		2		2
Permanent accommodation	1	1		2
CALD specific respite	1			1
ATSI specific respite		1		1
<b>Total</b>	<b>24</b>	<b>48</b>	<b>2</b>	<b>74</b>

## Appendix 4: Respite as a component of carer support

Type of support	Key components	How it should be delivered
Information	<ul style="list-style-type: none"> <li>- Relevant and useful information about respite (what it is, what it will cost, what to expect when accessing it for the first time etc)</li> <li>- What other supports and services are available for carers</li> <li>- Changing information depending on changing needs over time</li> <li>- What to expect in terms of emotional impacts of accessing respite</li> <li>- Assistance with first time respite use</li> <li>- Support from family and friends</li> <li>- Opportunities to share experiences with other carers in similar situations</li> </ul>	<ul style="list-style-type: none"> <li>- From an early stage in the caring relationship (prior to crisis)</li> <li>- In culturally sensitive manner</li> <li>- Through a range of mediums to reach many carers</li> <li>- By professionals and workers that carers come in contact with</li> <li>- Accompanying information and referral</li> <li>- Throughout caring relationship</li> <li>- At important life course transitions</li> </ul>
One-off/emergency support	<ul style="list-style-type: none"> <li>- Available 24 hours a day</li> </ul>	<ul style="list-style-type: none"> <li>- In a place that the carer and person requiring support are familiar with (home or facility they have used before)</li> </ul>
Breaks for carers	<ul style="list-style-type: none"> <li>- As per principles of effective respite</li> </ul>	<ul style="list-style-type: none"> <li>- As required; early in the caring relationship; flexible models</li> </ul>
Training/education	<ul style="list-style-type: none"> <li>- Coping skills</li> <li>- Practical carer education and training</li> </ul>	<ul style="list-style-type: none"> <li>- As required</li> </ul>
Financial support	<ul style="list-style-type: none"> <li>- Carer Payment</li> <li>- Carer Allowance</li> </ul>	<ul style="list-style-type: none"> <li>- As required</li> </ul>
Community (including aged and disability) services	<ul style="list-style-type: none"> <li>- Quality support for care recipient</li> <li>- Transport (to and from respite)</li> <li>- Equipment as required</li> <li>- Home modifications as required</li> <li>- Home maintenance as required</li> <li>- Personal care and other support services</li> <li>- Case management</li> <li>- Supported accommodation</li> </ul>	<ul style="list-style-type: none"> <li>- Based on regular needs assessment</li> <li>- When needed</li> <li>- Focus on needs of carer and person they support</li> <li>- Respite effect of community services should be recognised</li> </ul>
Health care services	<ul style="list-style-type: none"> <li>- Regular health checks to maintain or improve carer health/wellbeing</li> <li>- Preventative health care</li> <li>- Acute care</li> <li>- Community health care</li> <li>- Therapies</li> </ul>	<ul style="list-style-type: none"> <li>- Preventative and as required</li> </ul>
Advocacy	<ul style="list-style-type: none"> <li>- Assistance to protect rights of carer and person requiring support</li> </ul>	<ul style="list-style-type: none"> <li>- As needed</li> </ul>

## Appendix 5: Program definitions of respite

Department	Program	Definition
DoHA	CCRCs, funded through the NRCP	<p>Respite care is defined as an alternative or supplemental care arrangement with the primary purpose of giving the carers:</p> <ul style="list-style-type: none"> <li>• <i>A short-term break from their usual caring role; and/or</i></li> <li>• <i>Assistance with the performance of their caring role, on a short-term basis.</i></li> </ul>
DADHC		<p>Respite programs provide planned short-term and time-limited breaks for families and other unpaid care givers of children with a developmental delay and adults with an intellectual disability in order to support and maintain the primary care-giving relationship. Respite also provides a positive experience for the person with an intellectual disability.</p>
	HACC	<p>Respite refers to services which strengthen and maintain the primary care relationships between a frail older person or a younger person with a disability and their carers through the provision of flexible and responsive alternatives to the usual care arrangements. Services will be preventative in focus, time limited, and generally provided on a planned basis.</p> <p>Whilst providing a respite effect for carers which is appropriate to their needs and circumstances, services will endeavour to ensure that respite options have positive benefits and outcomes for the frail older person, or person with a disability.</p> <p>Unless otherwise specified respite services will be provided in the home of the client or in a host family home and where the usual carer is not present during the incident of service. Respite services are provided on a one to one basis.</p>
	CSTDA and DSP <sup>15</sup>	<p>Services for relief or assistance, for a limited period of time and whether on a planned or unplanned basis to:</p> <ul style="list-style-type: none"> <li>• families of, and other persons who provide care for or assistance to, persons with disabilities living in the community, or</li> <li>• persons with disabilities living in the community.</li> </ul>

<sup>15</sup> Established under the *Disability Services Act 1986*, these programs provide services to people with disability. Respite care is defined in the Disability Services Act.

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