



# SUMMARY PAPER

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January 2007

## RESPITE RECONSIDERED:

A discussion of key issues and future directions for carer respite

Copies of the full report, *Respite Reconsidered: A discussion of key issues and future directions for carer respite* (October 2006) can be obtained from:

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## **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.*
2. *Increase funding for transport to enable more effective use of respite services by carers.*
3. *Address inadequate levels of supported accommodation available to people living in the community and other services that impact negatively on the respite system.*
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.*
5. *Urgently address the issue of inappropriate respite use, primarily the 'blocking' of respite beds in disability respite houses for people requiring ongoing accommodation.*
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.*
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.*
8. *Revisit existing respite guidelines in light of the principles of effective respite and outcomes for carers and the people they support.*
9. *Ensure the inclusion of measures for effective respite in terms of outcomes for carers in the NSW Carer Policy development.*

### **For Commonwealth Government:**

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

### **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*
15. *To conduct comprehensive carer assessment and where relevant recognise a carer's needs for additional supports and make the appropriate referrals*
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.*
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.*
18. *To provide a variety of respite options and deliver services with maximum flexibility, in line with the 'principles of effective respite'.*

## Acronyms

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ATSI	Aboriginal and Torres Strait Islander
CACP	Community Aged Care Package
CALD	Culturally and Linguistically Diverse
CCRC	Commonwealth Carer Resource Centre
CSTDA	Commonwealth and State/Territory Disability Agreement
DADHC	NSW Department of Ageing, Disability and Home Care
DoHA	Australian Government Department of Health and Ageing
DSP	Disability Services Program
DVA	Australian Government Department of Veterans Affairs
EACH	Extended Aged Care at Home
FACSIA	Department of Family and Community Services and Indigenous Affairs
HACC	Home and Community Care
NCCP	National Carer Counselling Program
NGO	Non-Government Organisation

## 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, Carers NSW conducted research including a series of focus groups and an online survey with carers and service providers during 2005 and 2006.

This is a summary of the final paper which considers 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?

Appendices to the complete paper include the literature review, focus group outlines, online survey questions and summary of responses. These are not included in this document, however the full list of references has been included.

### 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. 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; and

**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 continue caring at home.

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.

Carers NSW hears 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. This summary provides an overview of the background information, findings from the research conducted by Carers NSW and recommendations to government and service providers.

## **2. Overview of the respite system 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.

Carer support includes a combination (depending on the needs of individual relationships) of informal support (from family and friends) and formal support (from service providers and the government). The latter may 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.

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 that they need. As we shall see, carers find it difficult to navigate these services and many are unable to access any support from services at all.

### **2.1 Respite Programs in NSW**

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.

Funding packages<sup>1</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, it is not clear whether their effectiveness can be measured; if the carers they are targeting understand what respite is and that respite packages are available for them; and if respite is meeting the need that it was 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.

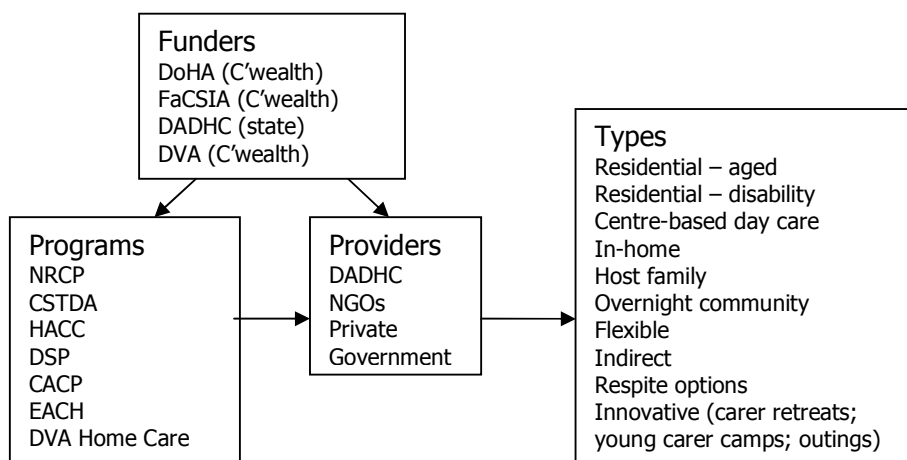
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<sup>1</sup> Most have been introduced by the DoHA. FaCS introduced respite for young carers.

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.

An overview of respite programs in NSW demonstrates that there are a number of respite service types delivered through several departments of the Australian and NSW governments (as shown in Figure 1).

FIGURE 1: RESPITE IN NSW



Direct respite services can be categorised as:

- Residential respite in aged care homes (nursing homes and hostels)
- Respite in disability group homes;
- Community respite (eg day centres, in-home respite, host family respite and overnight respite);
- Indirect respite (flexible funding delivered under CCRC guidelines, enabling them to purchase services on behalf of the carer that will assist them with their caring role)

Importantly the aims of respite services can be achieved through use of other services which are not specifically funded as respite but 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.

### 3. Respite statistics

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 Survey of Disability, Ageing and Carers 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>2</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 nationally (ABS 2004b)<sup>3</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 How many carers access respite services?

Given current data (shown 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 recorded as the person requiring assistance, not their carer. Many of the clients do not have carers. Furthermore many people access more than one type of respite and therefore are captured in multiple data sets.

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<sup>2</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>3</sup> No statistics are available for NSW however it can be assumed that the national statistics are reflected in NSW.

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/r emote	ATSI (%)	CALD (%)
DoHA DADHC	HACC <sup>4</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/respice homes <sup>5</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>6</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.

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.

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.

<sup>4</sup> Geographical distribution for all HACC services, not only respite.

<sup>5</sup> Includes group homes or 'residential' respite services for younger people with disability which are funded and operated by DADHC.

<sup>6</sup> Limited data available for NRCP program. National figures only.

## 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>7</sup>) and cultural diversity<sup>8</sup>.

The focus group questions and online survey questions mainly addressed questions relating to the use and non-use of respite by carers; and 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 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***

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.

Often carers received information in a fragmented way and they had to piece it together themselves. For some carers this was effective 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***

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 or that could not 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.
- 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

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<sup>7</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.

<sup>8</sup> Most of the carers that were consulted 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.

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**".

"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).

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

Emotional barriers to using respite included:

- Negative first experience of respite.
- 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, or that respite was a last resort.

"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; or
- 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.

## **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 that they were not coping.

A range of triggers that led carers to access respite 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

"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).

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

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

#### ***Outcomes of effective respite***

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, maintain a balance in their lives, or to have time to relax, catch up on sleep or 'recharge the batteries'. These were all important outcomes.

A positive experience and continuity of care for person requiring assistance was another good outcome, as was improved relationship between the carer and person they support. Others described respite as preventing family breakdown.

#### ***Factors of effective respite***

Factors contributing to a good respite experience included:

- 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 the service provider what activities both the carer and the care recipient would do in the respite time
- Knowing and having confidence in the support worker and the service provider

"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).

#### ***Barriers to effective respite***

"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...**Where is my break?**" (carer of two children with disabilities, Sydney) (emphasis added).

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

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.

## 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. The main gap in services identified was a lack of respite for carers of younger people with disabilities (both in and out of home).

Several types of service gaps were identified in this 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>9</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).

### 5.2 Challenges for service providers

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.
8. The use of respite beds for permanent accommodation, or 'blocked' respite beds;
9. OH&S issues diverting resources away from families needing 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. Reporting requirements. As one provider commented, "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".

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<sup>9</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.

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).

Another 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 including liaison 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.

**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>10</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.

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<sup>10</sup> Commonwealth Carer Respite Centres are funded through the NRCP to provide respite for young carers.

## 6. Analysis and Policy Implications

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?

A key finding of this research is that many carers who need respite do not use it, despite the positive effects that it can have on individuals and caring relationships. Many carers have a need for breaks from caring regardless of whether they access respite services.

A number of explanations have emerged from this 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. These include:

- 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 Effective respite

In order to achieve effective respite there must be a shared understanding of its purpose, aims and intended outcomes. Carers NSW recommends the following:

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.

Respite must be effective on two levels: individual outcomes; and systemic and cost effectiveness.

Two components of improving individual outcomes for carers using respite are:

1. Positioning respite in a package or continuum of support for carers; and
2. Developing measurable outcomes for carers using a respite service.

Holistic support for carers 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.

### **6.3 Measuring and reporting on effectiveness of respite**

Recommended measurable outcomes for carers and those they support (to be used in carer assessment) include:

#### ***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

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.

Effective respite must involve the following, based on consensus from the literature (Kilner 2002; StollzNow 2005; Coopers and Lybrand 1996; Arksey et al 2004) and carers who were consulted for this paper must include:

- ✓ 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
- ✓ Responsiveness to identified needs of the carer and the person they support

**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.

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. There is a degree of respite system ineffectiveness in NSW demonstrated by 'blocked' respite beds, for example. 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.

The literature on the effectiveness (including cost effectiveness) of respite to date is inconclusive (Arksey et al 2004; Jeon et al 2005) partly because there is little consensus on the measurable variables. 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. 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.

**6.4 Defining Respite**

'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.

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.

Other services that should be available to people when needed (and are often substituted by respite when unavailable) 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); and ongoing accommodation for people requiring support.

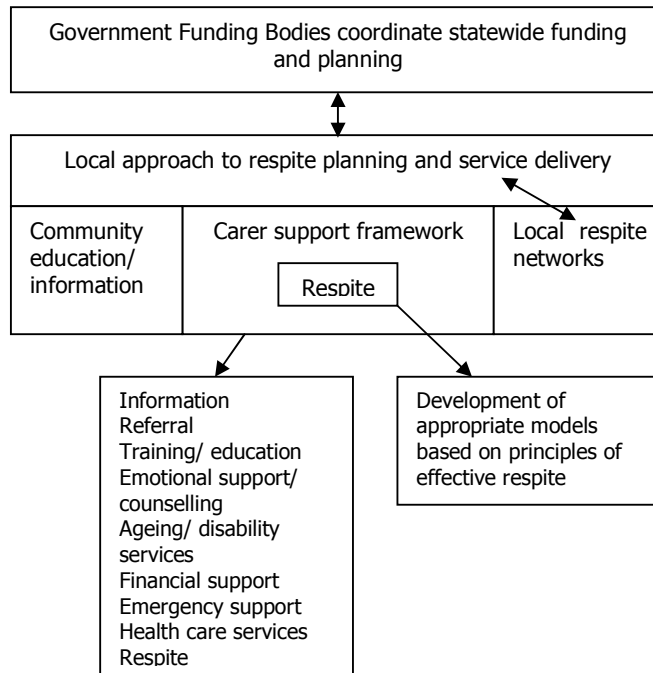
### **6.5 Planning, coordination and delivery of respite**

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 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.

Based on consultation and research the approaches recommended by Carers NSW to improve planning coordination and delivery of respite are:

1. Support and resource local networks for of respite providers using existing models (eg RAPID; TAB2).
2. Adopt a localised approach to planning and coordination (Figure 2).
3. Employ local networks (which include government providers) assist with data collection to report on unmet need.
4. Incorporate the elements of effective respite (outlined above).
5. Ensure respite is located in a comprehensive system of carer support.
6. Ensure mechanisms for carer and consumer input into planning and quality control.
7. Develop a tool for assessing and recording respite outcomes and make these reports publicly available.

FIGURE 2: LOCAL RESPITE FRAMEWORK



In terms of developing innovative models of respite, Carers NSW recommends that:

- Models should be developed in consultation with families and local service providers to address specific needs of the community;
- A commitment should be made provide ongoing funding for successful respite pilot programs
- Flexible funding should be made available to enable service providers to respond to existing need

In order to address low take up of respite community education and information about respite and what to expect when accessing it should be made available. 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.

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.

There are important benefits to be gained from investment in the respite system. The potential benefits to carers and the people they support have been identified in this paper. 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 the need for respite is 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 and those they support in the community.

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