

AUSTRALIAN INSTITUTE FOR SOCIAL RESEARCH

EVALUATION OF THE DEMONSTRATION DAY RESPITE PILOT IN RESIDENTIAL AGED CARE FACILITIES INITIATIVE

ACCOMPANYING REPORT 1: RESPITE CARE: LESSONS LEARNED FROM THE RESEARCH

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FOREWORD

The review of the *Demonstration Sites for Day Respite in Residential Aged Care Facilities* initiative is being undertaken by a team led by the Australian Institute for Social Research (AISR) at The University of Adelaide. The team members are:

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This Discussion Paper is based on a review of Australian and international research relating to day respite, and is designed to elucidate the lessons learned from this knowledge base.

In researching the literature we have interrogated the following databases – Google Scholar, Web of Science, Pub Med, and Science Direct. From the research identified through these sources we have then ‘snowballed’ by exploring relevant references provided in that research. We have focused on studies with sound methodology, including several literature reviews that analysed both findings and the methods employed for individual studies.

The timeframe for the review is the past decade, with earlier studies included when they have been part of a comprehensive literature review undertaken by other researchers, or when the research has made a substantial contribution to the evidence base.

The Discussion Paper updates an earlier version provided in April 2009, including more recent research as well as an overview of recent policy and legislation pertaining to carers.

1 THE RESPITE CONCEPT

1.1 CONCEPTUALISING RESPITE CARE

The term 'respite' is widely accepted, and reflected in Australian policy and program guidelines, as involving a time-limited break from the responsibilities associated with informal caregiving. For some carers, this definition brings negative connotations because it implies the need to escape from the person in their care. Equally the widely used term 'burden of care' brings an extremely negative dimension to the relationship associated with the caregiving role, despite the fact that many carers' health and well-being are damaged by this role. This concept of respite perhaps has most relevance for those designing and developing services.

In order to make the concept of respite more meaningful to its target group – caregivers – it is more useful to contextualise respite within the caregiving relationship, delineating its primary purpose as being one of a range of means to support, sustain and enhance the caring relationship (Enduring Solutions, 2003: 5, 23).

Caring takes place within a human relationship and this is an extension of that relationship, not something separate, special or different. The relationship, as much as the caring task to be performed, is what shapes the experience of caring and which should influence the kind and amount of support that people need (Baldwin, 1999: 2).

The earlier and still important work of Julia Twigg explored the concept of caregiving in the context of familial and other close relationships, noting that it is best understood as an extension of existing personal or family bonds.

... many carers do not recognise themselves as such; the term is unfamiliar to them and, some would argue, at odds with how they perceive their actions, which they would regard as an extension of family or personal relations rather than in terms of being a carer, with its formal, quasi-employment overtones. ...

Conceptually, the term centres on the performance of tasks of a supportive character, but it also encapsulates elements of social and familial relationships.... It is ... often difficult to distinguish such carer relations from the ordinary patterns of care and dependency characteristic of family and gender relations; this is particularly the case with spouse carers (Twigg et al, 1990: 3).

Twigg makes a very important point, from the perspective of the carer. However, it is also important to note that from the perspective of the service provider, and the service system as a whole, carers fulfil a role that requires a formal definition that resonates in service terms. The formal and informal provision of care constitutes a partnership, and carers deserve recognition for the contribution they make to the service system as a whole.

Consequently, the research literature increasingly recognises that caregiving is located within an existing relationship, and positions respite services as having a dual focus – on meeting the needs of care recipients while providing a break for their caregivers (Mason *et al*, 2007: 2, Twigg: 1992; Eliot Stanford & Associates: 1999; Radoslovich: 1997).

Unlike most other services in the aged care system, the carer : care recipient dyad can bring significant challenges to the provision of respite care due to the potential for conflict of interest between the needs of both parties. This is particularly evident when the care recipient does not want to participate in the service that would offer their carer a break, when at the same time, the carer is seeking and needing this respite. Carers' willingness to accept respite services is likely to depend on their perceptions of the quality of those services and their impact on the care recipient. Many carers will not benefit from respite, or participate in respite services, if they believe the person in their care is resistant to or unlikely to benefit from day respite services (Eliot Stanford & Associates: 1999; Carers Australia: 2007).

As well as being a service and form of support, respite is also understood as representing an **outcome** for carers, which encourages a fundamental shift in the way it is designed and evaluated (Torjman: 2003; Eliot Stanford & Associates: 1999).

Respite is not a stand-alone service – its effectiveness is shaped by other services and supports being accessed by care recipients and by carers. From an evaluator's perspective, this interdependence makes it difficult to isolate and assess its impact (see *Section 2* for further discussion of this issue). The national policy position of Aged and Community Services Australia (2004: 2) describes respite as:

... only one aspect of a package of support required to effectively assist carers and care recipients. For respite to be successful carers' other support needs must also be met. It should be provided as part of a flexible and coordinated integrated service system.

Another central policy goal identified by the literature review is that of 'person-centred care' (Mason *et al*: 2007; Arksey & Bamford: 2007). Essentially this means that respite care must provide a positive experience that arises from –

- a) tailoring of the service to address individual preferences, interests and experiences;
- b) balancing the provision of care and risks with a promotion of independence;
- c) involvement of the care recipient in decision making relating to the activities they can pursue and more broadly in service development (Arksey & Bamford, 2007: 38).

Lesson 1: Good practice in respite care requires services tailored to individual need, interest and preference, involving care recipients in the planning of their activities and more broadly, in overall service development

Lesson 2: The perceived quality and purpose of respite significantly influences its acceptability to carers and care recipients.

1.2 MODELS OF RESPITE CARE

A critical review of the literature (Pollock *et al.*: 2007) analysed the wide range of respite service models, finding variation across these four dimensions – purpose, duration, setting, and provider. Each of these dimensions brings a ‘continuum of options’ as well as a range of outcomes.

- Services can have a primary or secondary respite *purpose*, with primary services being designed specifically to provide carers with a break from caregiving, while secondary services provide the outcome of respite by involving care recipients in a range of formally provided activities that may or may not be designed to provide respite for their carers.
- Respite programs also vary in *duration* from a few hours to several weeks, providing different outcomes in the process.
- Respite can be provided in a range of *settings*, with the most common being in-home, in day centres or in residential facilities.
- Respite *providers* can include professional carers, family support groups, relatives and friends (Pollock *et al.*, 2007: 1).

An earlier statewide review of day centres in South Australia (Radoslovich: 1997) also identified a diversity of models and elucidated the lesson that needs can be met in a variety of ways and in a variety of settings - beyond the day centre itself, for example, via the use of a range of community facilities (Radoslovich, 1997: 51). A ‘one-size-fits-all’ approach is neither desirable, nor able to address diversity of need and circumstances.

Lesson 3: The needs of carers and care recipients are diverse and should be addressed using a variety of activities, settings and strategies, avoiding a ‘one-size-fits-all’ approach.

Reporting on the first stage of a two year national study of respite care and short breaks for people with dementia and their carers, Arksey and Bamford (2007: 38) identified nine service models that are summarised in the following chart.

Model of Respite Care	Defining features	Typical Setting	Usual availability
Day care	Provision of a range of activities in a stimulating environment	Typical settings are community buildings, hospital, residential aged care facilities	Weekdays
Host family day care	Small groups of care recipients spend the day with a host family.	Paid or volunteer carer's home	Weekdays
Social events or outings	Clubs or similar activities	Range of community settings	Monthly for up to 2 hours
Clubs, interest or activity groups	Focused on a particular activity (eg art), or a particular client group (eg younger people with dementia)	According to activity	Fixed times, usually once a week or less
Home-based support	One to one support	Person's home, primarily	Fixed number of hours, weekdays
Adult placement scheme	Care recipient stays overnight, or longer, with a paid or volunteer carer	Paid or volunteer carer's home	Not commonly available
Specialist respite facility	Overnight respite, sometimes in conjunction with day care	Building based eg residential facility	Regular, rolling respite, or as required
Respite beds	Dedicated respite beds within a setting whose primary function is not respite care provision	Hospital, residential aged care facility	Regular or emergency basis
Short breaks or holidays	Traditional holiday or opportunities to try new experiences	Hotels, bed and breakfast facilities, specialist holiday centres with staff to provide support	Weekend or week long breaks

Source: Arksey & Bamford (2007)

Adult day care fulfils the role of providing respite for carers but has a number of different models. The two most common can be described as 'rehabilitative' and 'multipurpose' (Baumgarten *et al*, 2002: 238). The first is clinical in focus, emphasising physical and functional restoration while the second is essentially social in orientation, enabling enhanced interpersonal and social development. These are not mutually exclusive roles, and are more usefully understood as part of a continuum of services that can be provided by day respite centres.

These purposes lead to a number of roles for day respite centres, including –

- Maintenance of care recipients' social contact and skills.
- Continued involvement of care recipients in the community and reduced isolation.
- Supporting care recipients' self esteem.
- Maintenance of informal carers' role by providing access to respite, information and other supports.
- Provision of access to therapeutic, rehabilitative or medical services.

- Monitoring of health and well-being.
- Cost-effective service provision through group model delivery (Radoslovich, 1997: 48-49).

In evaluating day respite programs, it is important to take into account which part of the continuum is addressed. For example, if a service is not designed to address therapeutic need, there is little point in assessing its impact on participants' health. However, if the focus is on social interaction, it will be important to measure changes in social skills and degree of interpersonal contact.

Lesson 4: Day respite centres can span a continuum involving services that address social and recreational needs to those providing therapeutic and rehabilitative care. This focus should be reflected in the design of evaluation studies.

Highlighting the importance of innovative responses to individual differences, an Australian service provider developed a 'host home' model of respite for older people with dementia who were unable to benefit from day centre respite due to communication difficulties. This provided care for up to six people in the home of a care worker, with structured activities, transport and outings being part of the care provided. Evaluation of the program found that care recipients, their carers and the care workers were extremely positive in their feedback about the model and its effectiveness (Holm & Ziguras: 2003).

Despite the range of models now available for providing respite care services, the research literature does not shed light on the specific types of respite care that carers and care recipients prefer, their current availability and the relative effectiveness of different models in meeting both sets of need and preventing the breakdown of informal care provision (Mason *et al*, 2007: 3). This may be due to the model being less relevant than the flexibility with which it is applied to individual clients. However, there are consistent themes in the preferences of carers identified by researchers, and these can be categorised into four requirements sought from respite services (regardless of type or model) –

- Choice and flexibility in choosing services to match their needs.
- Quality services that enable the carer to entrust the person in their care to those services.
- Access to information about available services to enable them to make effective choices.
- A coordinated network of services that enable ease of access (Pollock *et al*: 2007).

Lesson 5: Research has consistently identified that carers seek four key features of respite services – choice and flexibility so that services are tailored to their needs, quality of provision to achieve trust in the service provided, access to information to underpin their choices, and ease of access through a coordinated network of services.

2 IMPACT AND EFFECTIVENESS OF RESPITE CARE

There are few empirical studies that examine the impact or outcomes of respite and a number of researchers overviewing the literature conclude that there is a need for rigorous evaluation of the effectiveness of respite services (Pollock *et al*: 2007; Mason *et al*: 2007; Arksey *et al*: 2004). Other researchers, reviewing all English language studies published between 1989 and 2003 concluded that a comprehensive body of research on the impact of respite care is lacking (Chesson & Westwood: 2004).

In reviewing the literature, it is evident that a degree of inconsistency applies to the findings made by different researchers and some of this variance is likely to arise from the methodologies employed. Consequently, the findings presented in this section are based on these cautions.

As discussed in *Section 1*, respite is one of a package of services needed by carers and care recipients, and its effectiveness to a degree, is influenced by the impact of those other services (Carers Australia, 2007: 19). Two tiers of services can be distinguished, involving a base tier of supportive general practitioners, accessible information, and supportive informal networks. The second tier involves the respite service itself (Arksey *et al*: 2004).

Many evaluations of respite services are confounded by the existence of other services being provided at the same time as respite, making it difficult to isolate the specific effect of respite care on delayed entry to residential aged care (Keefe & Manning, 2005: 10). At the same time, the presence of those other services has been found to affect the impact of respite in a positive way (Davies and Fernandez, 2000: 128-134). The planning, delivery and evaluation of respite services needs to be situated in the context of other support services, as these will impact on take-up rates and effectiveness (Arksey *et al*, 2004: 123).

There are a number of factors that respite services need to address to maximise accessibility, and research findings on these are discussed in the following section

2.1 RESPITE BARRIERS AND FACILITATORS

Australian research has identified four major factors that act as **barriers** to carers' use of respite services.

- ⇒ Insufficient or inadequate **information** about respite services. Ideally, carers' use of respite services should be based on informed choice. Not knowing about services, or being misinformed, or having them promoted in a way which fails to address cross-cultural factors impedes access. It has also been found that carers often receive information in a fragmented way, which they must piece together – often without understanding the service system as a whole (Lara & Gowan-McKenna, 2005: 6-7).
- ⇒ **Resource limitations** have been identified as a key barrier, with rigid eligibility criteria (such as those set by formal assessment) excluding some or leading to significant unmet need. Similarly lack of flexibility that precludes tailoring to individual need acts as a barrier, and is often driven by inadequate program funding.

- ⇒ Carers may not use respite services for **emotional** reasons which may arise from negative initial experience of respite, resistance by the person in their care which in turn generates carer guilt, and anxiety about the perceived quality of the respite service.
- ⇒ The final factor identified by researchers involves **perceived need**, with carers choosing not to access respite services because they did not need see them as relevant to their current circumstances (but without precluding possible future need), or did not regard it as relevant to their caring situation. Others do not use respite care as they have sufficient informal support to continue in their caregiving role (Carers Australia, 2007: 11-12).

Lesson 6: Ideally, carers' use of respite services should reflect informed choice, hence the way in which services are promoted to them needs to ensure that information is accurate, accessible, culturally inclusive and presented in a coordinated way.

Lesson 7: Carers' access to respite service may be inhibited by a range of emotional factors including anxiety about the perceived quality of service, resistance from the person in their care and guilt about accepting their need for respite. Information and promotion strategies need to address emotion, and its impact on perceptions, as a critical access issue.

In order to support those carers having, or likely to have, significant difficulties in accessing residential respite, the Commonwealth Carer Respite Centre in Victoria's Western Metropolitan Region has developed the role of *Residential Respite Carer Support Worker*. This was developed in response to the identified needs of reluctant respite users and carers caring for people with complex needs, and utilises a flexible brokerage strategy to assist carers, care recipients and service providers (Lara & Gowan-McKenna, 2005: 14).

However, research has identified that the most effective respite outcomes are achieved when there is informed preparation for respite care (Lara & Gowan-McKenna, 2005: 9). An Australian evaluation of an emergency respite care service that prepared a plan of action to be implemented when an emergency arose (for example, the caregiver needing to go into hospital) found that this was extremely effective. Preparation of the emergency plan involved a significant transfer of information to carers from respite providers, and tailoring of a planned response in the face of a crisis situation, removing from carers the anxiety associated with 'What if? ...' situations (Kate Barnett & Associates: 2002).

In determining features of good practice in respite care, it is important to consider the continuum from assessment and entry to exit from the service. The preparatory phase for respite, beginning with assessment of need, is critical to its future impact on carers and care recipients.

Lesson 8: Respite services are more likely to have a positive impact on carers when consideration is given to designing the preparatory phase to support informed choice and accurate assessment of need.

With regard to the assessment process, research undertaken by two Victorian Commonwealth Carer Respite Centres (CCRCs) on behalf of a local carer respite network (Lara & Gowan-McKenna, 2005: 4-5) found that successful respite begins with a holistic and comprehensive assessment of a range of factors affecting the carer and the care recipient. These require input from a range of people, utilise a number of assessment tools, and require good rapport between service providers and the carer and care recipient. Based on their first hand experience, they recommend that respite facilities not rely solely on the Aged Care Client Record administered by aged care assessment services to access a Commonwealth funded aged care facility because it cannot capture changing levels of functioning and the care recipient's response to the respite environment. The researchers have found a customisation of a range of tools is most effective. The two regions involved (CCRC Barwon and CCRC Eastern Metropolitan) have designed a single assessment tool, developed in consultation with all facilities providing respite and reflecting their information requirements. In addition, a Carer Profile has been developed for use by all Victorian CCRCs when making and receiving referrals.

2.2 IMPACT ON CARERS

In an extensive review of the literature on the impact of respite care on carers (Mason *et al*: 2007), conclusions drawn related mainly to randomised or well-controlled studies, and these found only modest benefits for carers, with not all carers having benefited. Similarly, other literature reviews (Keefe & Manning, 2005: 6; Arksey *et al*, 2004: 9) found little reliable evidence demonstrating an enduring positive impact on carer wellbeing, while another (McNally, Ben-Schlomo & Newman: 1999) concluded that the evidence of impact on carers is not known. More recent research by Bamford, Arksey and others (2009: 16) has reiterated the lack of evidence regarding the effectiveness of respite care services and the need for evaluative tools that can be used across different respite models to compare the impacts of service for carers and care recipients.

By contrast, a well constructed study that involved an assessment of the short and long term impact of respite on both carers and those in their care (Zank & Schacke: 2002: 355) found that carers reported a reduction in 'carer burden' that improved over time. This is consistent with previous literature reviews which have found some evidence of a small positive effect in terms of reduced 'burden of care' and improved mental or physical health (Mason *et al*, 2007: 25).

Given the responsibility of caring for a frail older person or a person with dementia usually involves increasing levels of care, it is not surprising that the impact on carer health and well being is not large. It is perhaps unreasonable to expect that respite care could achieve such an outcome, as it is designed to provide a break from caregiving, not to change the underlying causes of carer stress or responsibility.

An innovative day respite service, funded under the *Demonstration Sites in Day Respite Care in Residential Aged Care Facilities Initiative*, is designed to promote the health and well-being of carers and care recipients, and this is reflected in its program of activities and infrastructure design. An independent evaluation of the Centre for Healthy Ageing (Elton Associates, November 2009 unpublished) identified a number of positive impacts for carers accessing the Centre, based on interviews as well as quantitative analysis. Key outcomes identified were increased -

- Happiness, relaxation and reduced stress
- Social interactions and improved personal relationships
- Mobility and physical activity, improved health and fitness
- Confidence and enjoyment of life
- Choice and freedom
- Capacity to choose to keep care recipients at home rather than access residential care for them.

The evaluation included measurement of carer well being using the *Personal Wellbeing Index (PWI)*, a quantitative tool¹ that measures quality of life and subjective wellbeing. It provides an overall score out of 100, with the normal range being between 70 and 80. This tool has been applied in a series of national surveys, the 17th of which identified the low average PWI for carers in Australia. In response to this finding, an additional special survey of carers was undertaken in partnership with Carers Australia in 2007. This returned an average PWI score of 58.5 for carers, and carers emerged as the group with the lowest average PWI. Carers accessing the Centre had an average PWI of 76.4, which is much higher than that of carers nationally, and this score increased with length of time using the Centre's services.

Carer feedback about what they valued most about the Centre followed these 6 themes –

- An environment they trust to provide quality care to the person in their care
- Feeling valued and respected as individuals
- Feeling understood and supported as carers
- Recognition of the needs of both carer and care recipient
- Holistic and diverse program of activities
- A sense of control and autonomy.

The evaluation identified 7 dimensions of the care model which are integral to its success –

1. Client focus
2. Holistic integrated service
3. Wellness focus
4. Flexibility and being driven by client needs, promotion of carer autonomy and control
5. Physical setting and design – enabling flexible use of space to meet diverse needs and a friendly, welcoming environment
6. Staff – possessing appropriate skills as well as values
7. Resourcing that is sufficient to support the model.

There is a strong trend in the literature for studies to report **high levels of carer satisfaction** (Mason *et al*: 2007; Irigoyen *et al*, 2002; Zank: 2000; Pickard: 2004) with respite care services. However, different assessment tools have been employed across the different studies making comparability and the

¹ See www.deakin.edu.au/research/acqol/index_wellbeing/index.htm

identification of clear trends extremely difficult. Using multivariate analysis, one study found that carer satisfaction declines with three factors –

- ⇒ increasing years of providing informal care,
- ⇒ having to combine caregiving with paid work, and
- ⇒ having to spend respite time in unpaid work or other caregiving activities (Van Exel *et al*, 2006: 202).

Van Exel *et al* (op cit: 204) also found a clear relationship between carer and care recipient satisfaction with respite services, illustrating the importance of the caring relationship in defining the impact of services on either party.

2.2.1 FACTORS THAT CAN AFFECT THE IMPACT OF RESPITE SERVICES ON CARERS

There are multiple factors which shape the impact of respite services on carers, some of which are outside the sphere of influence of service providers, while others can be addressed by them.

Subgroup analyses of available research findings by Mason *et al* (2007) indicated that day respite had a more positive effect on carers who were **not caring for a spouse**, who had **not recently been hospitalised** and who were **satisfied with the amount of informal support** they were receiving (Mason *et al*, 2007: 25). Other carer characteristics that were found as *possibly* influencing the impact of respite were gender (with male carers possibly benefiting more than female carers), cultural background (cultural morés may inhibit carers' accessing formal respite services, and language may be a barrier) and the degree of guilt or other psychological barriers inhibiting the ability to accept support. However, there were no controlled studies identified that explored the impact of factors like ethnicity, socio-economic status, age or gender upon carer or care recipient outcomes (Mason *et al*, 2007: 74-75).

Earlier research found that different patterns of service usage were associated with **generational differences**, with younger carers being more familiar with formal services and more willing to use them, but also being more likely to be employed than older spouse carers. **Kin relationship** was also found to bring different expectations about the caregiving role and associated responsibilities (Zarit *et al*, 1998: 360).

It is often the case that a crisis acts as the trigger for accessing respite, with general practitioners or other service providers linking them to services when it was evident the carer was not coping well. Related factors include deteriorating health and well being of the carer, relationship breakdown – including within the caring relationship, the intensity of the caregiving role – especially where challenging behaviours or reduced health of the care recipient is involved, and inadequate informal support from family and friends (Carers Australia, 2007: 12-13).

Research by Davies and Fernandez in the UK (2000: 132) found that **carers in paid employment** were one group likely to benefit from day respite, which in turn, was associated with reduced levels of carer stress. However, an Australian evaluation of an overnight community respite model, found that these and day centre models need to address issues of logistics, time and cost of transporting care recipients to and from respite in order to be effective. Employed carers indicated a preference for in-home respite when these issues were not addressed as part of overall program provision (Urbis, 2008: 131). For some carers, the time required to transport the person in their care to and from day respite may add to their burden and provide a disincentive to participate (Baumgarten *et al*, 2002: 255).

The amount of respite received has been identified as a factor determining its effectiveness for carers (Health Canada, date unknown, citing previous research findings). Respite services have been found to have a positive impact on carers when they are of **good quality** and used in **sufficient amounts** (Zarit: 2001). In one study that took into account the **amount of respite** provided, carers of people with dementia using day respite twice a week for at least 3 months, or more, were found to have lower levels of stress and depression compared with a control group (Zarit: 1998). Both groups of carers had positive attitudes towards day respite and neither had used this service during the 3 months before the study. A major study by Davies & Fernandez (2000: 128-134) also found that day respite had a positive impact on carers once it was provided for at least two days a week. However, length of usage can be associated with the **severity and complexity of care recipients' needs**, and these can lessen the positive impact of respite on caregivers (Zarit *et al*: 1999).

Lesson 9: There are multiple factors that affect the impact of respite services on caregivers. From a service provision perspective, these include the amount of respite provided (with the research indicating that at least two days a week is needed for a discernible impact), the provision of transport, quality of service, and length of usage.

Outside of the service provider's sphere of influence, factors affecting the impact of respite include the nature of the caring relationship (including whether this is kinship based or not), carer age and familiarity with formal services, whether or not the carer is in paid employment, the severity and complexity of the care recipient's needs (and whether they had been recently hospitalised) and the amount of informal support being received. Factors like carer gender and cultural background, and carer perceptions and attitudes may also be influential.

These differing factors underscore the importance of flexibility in delivery, taking into account as much as possible, individual circumstances and need.

2.3 IMPACT ON CARE RECIPIENTS

Extensive literature reviews (of research undertaken between 1985 and 2003) have found no reliable experimental evidence that respite care provides significant short or long term benefits to care recipients (Arksey *et al*, 2004: 9) or that it adversely affects them (Mason *et al*, 2007: 1), regardless of respite care model. Individual studies have drawn similar conclusions (Lee: 2004; McNally, Ben-Shlomo & Newman: 1999; Roberts *et al*: 2000; Baumgarten *et al*: 2002).

In a meta-analysis which used regression analysis to assess the impact of day respite, Sørensen, Pinquart & Duberstein (2002) found reduced 'carer burden' and self-rated carer depression and increased carer well-being, but no significant impact on care recipients. Similar findings about impact were made by Yin,

Zhou & Bashford (2002) when studies using poorly constructed methodologies were excluded from their meta-analysis.

The previously cited research by Zank & Schacke (2002), however, found that care recipients with dementia responded positively to day respite services, with a stabilisation or improvement in their symptoms and wellbeing. Symptoms of agitation had decreased (without medication) while those of the control group had increased. They also showed better overall health (2002: 355-356). These differences were attributed to the rehabilitative processes offered by the day program. The research undertaken by Baumgarten *et al* (2002: 253), while concurring with previous studies finding little discernible impact of day respite on care recipients or their carers, did identify that the majority of care recipients interviewed felt that their loneliness had reduced and about half felt less anxious and depressed.

One group of researchers, who found that care recipients and carers perceived day respite as beneficial to them, but were not able to measure this with a rigorous experimental design and standard research instruments, concluded that existing research tools may not be able to capture these perceptions adequately (Baumgarten *et al*, 2002: 256).

Another review of available research (Zarit: 2001) identified that the effectiveness of respite is highest when it is provided in association with other community support programs. In other words, respite cannot be considered to be a stand-alone service and has a more positive impact if other supports and services are being provided.

2.4 IMPACT ON ENTRY TO FULL TIME RESIDENTIAL CARE

In their comprehensive review of the literature, Mason *et al* (2007) found no widespread reliable evidence that respite can delay entry to residential care. This is due largely to the difficulty of separating the impact of other factors (DoHA: 2002), including the care recipient's own need for care and the carer's capacity to manage.

However, one study reviewed by them, which was focused on the cost effectiveness of day care compared with other community services, found that those receiving day care spent significantly more days in the community (172 days), with improvements noted for both carers and care recipients. This was found to compensate for the relatively higher costs associated with the day care service, which were three times those of usual community care. The study covered a twelve month timeframe and although not randomised, groups were matched (Donaldson & Gregson: 1989).

A major study in the UK (Davies & Fernandez, 2000: 60-61) found that day respite had a positive effect on length of time in the community, although the size of the effect was shaped by **client characteristics** and the **amount of day care** received. Day care provided to people with cognitive impairment demonstrated a more pronounced impact on duration remaining in the community compared with other service users. The researchers calculated that one day a week of day care increased the time spent in the community by some 200 days, while two days a week increased this time to approximately 270 days (2000: 60, Figure 4.1).

An earlier Scandinavian study (Engedal: 1989) examined 78 older people with dementia randomly allocated to either a day care group or a control group, examining them at six and twelve month intervals for activities of daily living and cognitive capacity, as well as for entry to acute health care or residential aged care. After 12 months, the day care group was found to have significantly shorter lengths of stay in

acute care and more frequent use of short term stays in residential aged care, making their overall service utilisation profile more cost effective than those of the control group. There was no statistically significant difference in cognitive functioning between both groups or in delay of entry to full time residential care.

However, it should also be remembered that the needs of carers and care recipients are not always in harmony, and prolonged stay in the community may not be beneficial for the caregiver (Pickard, 2004: 31). There are several studies which have found that some older people are not willing to use day care services, while their carers may need the respite these provide (Pickard, 2004: 32).

When cared-for people do not want to go into day care, carers themselves may be understandably reluctant to use it and this may reduce its value as a service for them (Pickard, 2004: 32).

Critical to entry to permanent residential care is the ability of the caregiver to continue in their role, and respite services are designed to enable them to do this. One Canadian study (Herbert *et al*: 2001) identified the following variables as being significantly associated with institutional placement of people with dementia (albeit with a sample of 32) – caregiver burden, caregiver depression, type of dementia, severity of disability, behavioural disturbances, caregiver age, and the caregiver not being a spouse or child. These variables relate to both carer and care recipient characteristics. Another study that investigated data over a three year period associated with 4,000 people with dementia in the USA (Gaugler *et al*: 2003a) concluded that these factors (most of which focus on carer capacity to continue in the caregiving role) were associated with ‘expedited placement’ in long term care –

- Carer burden
- Carer self-rated health
- Existing use of community services
- Changes in carers’ functional abilities.

Residential respite service use may also be a factor associated with entry to permanent residential care. A small number of studies that have found provision of respite in a residential facility (in the form of overnight or extended residential respite) may encourage entry to residential aged care because of familiarisation with the setting or because carers were seeking this form of care and using the respite as a stop-gap (Keefe & Manning: 2005; Pickard: 2004). In such cases, respite was found to enable a planned rather than crisis admission to residential aged care, acting as a bridge.

Linking administrative data for the residential aged care and CACP programs, and HACC minimum data set information, recent pathway analysis by the Australian Institute of Health and Welfare (2006) has found that although 40% of people who completed a period of respite care in one quarter were admitted to permanent residential care by the end of the following quarter, the use of the residential respite was not a ‘necessary precursor’ for entry into permanent residential care.

A substantial proportion of the people who use residential respite care in one quarter are admitted into permanent residential care by the end of the next quarter. However, looking at transitions from the perspective of permanent RAC, use of residential respite care is by no means a necessary precursor to entry into permanent residential care (AIHW, 2006: 12).

The AIHW research found that the use of community care services by residential care clients appears to delay entry into permanent residential care. Some 46% of people who used residential respite without also using HACC or CACP services in one quarter were admitted to permanent residential care by the end of the next quarter, compared with 35% of those who also access these community care services (2006: 4).

Among users of residential respite care, use of community care services appears to delay entry into permanent residential aged care: around 46% of people who use residential respite but neither HACC nor CACP services in one quarter are admitted to permanent RAC by the end of the next quarter, compared with 35% of those who also access these community care services (AIHW, 2006: 1).

2.5 DAY RESPITE DELIVERED IN THE RESIDENTIAL CARE SETTING

The **setting** in which respite care is provided can also be a determining factor on impact and effectiveness, but the research holds contradictory findings on this issue. There is very little information in the research literature about the impact of the residential care setting for respite on entry to residential aged care.

Earlier studies, when day care was first provided in residential aged care settings, found this form of care to be of poor quality in most instances, with participants having no structured program of activities and simply joining others in the recreation room (Twigg: 1992; Pickard: 2004). One such study identified that many older people do not want to receive care in a residential aged care facility, including respite that is a temporary activity, because of ambivalence about residential care that may have been due in part to stigmatisation and lack of understanding of this environment (Twigg, 1992: 85-86). Whether or not this negative view extends to participating in day respite in a residential environment, and so acts as a barrier, is not known from the existing research.

Researchers from the Australian Institute of Health and Welfare examined the use of respite care in residential aged care facilities and the destinations of care recipients on completion of their respite stay. Analysing data on admissions and separations for low and high care facilities and on client characteristics for the period 1991 to 1995, they found that 57% of low care respite and 39% of high care respite residents returned to the community within twelve months, and that high care respite residents were more likely than those using low care respite to become permanent residents. The likelihood of permanent entry to residential care increased with age and was more likely for women than for men (Choi & Lui, 1998: 78). One of the factors influencing this trend could have been the use by families of residential respite as a transition from home to institutional care. The impact of residential respite on attitudes (detering or discouraging) to residential care was not able to be determined but the authors identified the need for research on this issue (Choi & Lui, 1998: 79).

A few studies have found that provision of respite in a residential facility (in the form of overnight or extended residential respite) may encourage entry to residential aged care because of familiarisation with the setting or because carers were seeking this form of care and using the respite as a stop-gap (Keefe & Manning: 2005; Pickard: 2004). In such cases, respite enables a planned rather than crisis admission to residential aged care, acting as a bridge.

Scandinavian research (Engedal: 1989) found that day centre programs for older people with dementia had reduced the frequency of admissions to acute hospital care, but had not delayed permanent admission to residential aged care. Another early study of the impact of respite care provided in a residential care setting on carer capacity to provide long term care (Scharlach & Frenzel, 1986: 79-81) found that caregivers' health had improved as a result of the respite service, and most felt that this facilitated the continuation of their role. However, this did not equate to reducing the likelihood of placing the person in their care into a residential facility for full time care. Carers were divided into the 33% who saw permanent placement as less likely due to the respite service and the 30% who saw this outcome as being more likely. The researchers discussed the impact made by familiarity with a residential

setting on these carers' perceptions of this form of care – and because the care was seen by those carers as being of a high quality.

... exposure to a nursing home setting on a temporary basis had shown them that institutions are much better than they had previously imagined and might offer beneficial services that they themselves were unable to provide. In addition, some caregivers reported that the temporary experience of relief made them more aware of what they were sacrificing by giving up so much in their own lives to care for their loved ones. As one caregiver stated, 'I finally realized that he can exist without my constant care'....

Through their experiences with the high quality ... nursing home facilities, they became increasingly aware that good patient care did not have to be provided at the expense of their own personal physical and emotional well-being.... For them, respite care may have served as an acceptable introduction to institutional long-term care solutions that they had previously avoided ... (Scharlach & Frenzel, 1986: 80-81).

The importance of carer attitudes and perceptions and the impact of the experience of good quality care in a residential setting is an important factor, but unfortunately, one that has had insufficient research – especially in recent years – to assist in evaluating the impact of day respite provided in this setting. Scharlach and Frenzel (1986: 81) also make the important point that this form of respite care can be seen as a link in the continuum of long term care, and in the difficult transition from care in the community to care in a residential facility.

3 COST EFFECTIVENESS OF RESPITE CARE

Cost-effectiveness has numerous definitions but essentially examines the balance between inputs and outputs (including outcomes) to determine if the intervention studied represents value for money. It also compares the intervention with others that can be implemented using the same resources (Keefe & Manning, 2005: 6).

There is little consensus in the research literature about the variables required to measure the cost-effectiveness of respite care services (Carers Australia, 2007: 20). Determining the range of variables that can be taken into account when determining the costs of respite is an inexact science, and setting the boundaries for inclusion and exclusion is difficult. Should it, for example, include the costs to government of medical care for carer stress or ill health arising from their caregiving role? Should it include the taxes lost when carers must leave the paid workforce in order to provide care? (Keefe & Manning, 2005: 8).

Most of the available literature examines cost-effectiveness from the perspective of carers and care recipients, rather than from the perspective of service providers or funders (Arksey *et al*, 2004: 47). They are, therefore, actually 'cost-consequences'² rather than 'cost effectiveness' analyses, but in this paper we will use the latter term to reflect the original language of the studies reviewed.

Two of the most comprehensive studies of cost effectiveness in respite care involved a systematic review of research. Both were undertaken by teams from the University of York's Social Policy Research Centre (Mason *et al*: 2007a and Arksey *et al*: 2004). The review by the second team concluded that there was a '*... lack of robust cost-effectiveness to support the use of particular types of respite care ...*' (Arksey *et al*, 2004: 123).

The work by Mason *et al* was designed to appraise and synthesise evidence for the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. The analysis extended to the research methods employed and the subsequent reliability of their findings. Only five economic evaluations of respite care were identified, all of which compared day care with 'usual care'³, and most assessed health and social service usage and cost. Across these evaluations, different outcome measures were applied, making it difficult to compare outcomes across the studies or to aggregate the data (Mason *et al*, 2007a: 63).

Day respite was the only form of respite for which economic effects could be identified. The total cost of day respite care needs to take into account whether institutionalisation has been delayed and the reviewers found no reliable evidence about the impact of respite on extending care recipients' capacity to remain in the community (and by implication for carers to be able to continue in their role). However, the lack of reliable evidence about the effectiveness of respite services does not necessarily mean that they are ineffective or without benefit (Arksey *et al*: 2004).

... a lack of good evidence ... is not a conclusion that respite services are not of benefit to caregivers or of cost benefit to the taxpayer (Keefe & Manning, 2005: 9).

² *Cost-consequence* analysis combines information about costs and outcomes (including clinical) in the form of a balance sheet, and is particularly useful when evaluating human services programs

³ Defined by Mason *et al* as involving '*use of care in the community, including home visits*' (2007a: 63).

The cost of respite has been found to vary with the **type of respite**, the **provider** and the **needs of care recipients** – for example, older people with dementia require more input from staff and so costs associated with their respite care are higher than for other client groups (Mason *et al*, 2007a: 4). In-home respite costs have been found to be considerably higher than those of community day care, and costs for out of hours provision, not surprisingly, to be higher than those for normal business hours (Mason *et al*, 2007: 4).

A study by Irigoyen *et al* (2002) that compared two groups of Spanish care recipients – one in a psychogeriatric day centre and the other receiving other community care services - found higher costs for the day centre model, mainly due to the cognitive and functional needs of the client group. Carers of this group recorded higher levels of satisfaction than those in the control group. A similar study in Canada compared two groups – one receiving day care that provided a range of group based activities, and the other receiving usual community care services (Baumgarten *et al*: 2002). Impact on carers and care recipients was measured as well as cost of services. Day care was associated with higher costs (not statistically significant) but also with more benefits (again, not statistically significant).

A cost-effectiveness study of community day respite care in the USA compared with usual community care over a twelve month period (Gaugler *et al*: 2003) concluded that day respite was both more costly and more effective (in terms of reducing carer overload and depression). Daily costs were also found to have fallen over the twelve month timeframe.

While most of the studies reviewed have attempted to evaluate the costs of day respite against the outcomes achieved for clients, there are few models for determining cost-effectiveness that combine both sets of data, and Mason *et al* (2007a: 71) recommend that this occur in order to address a significant gap in the current evidence base.

An overview of research undertaken in the UK (Arksey *et al*, 2004) has identified a range of indicators, both quantitative and qualitative, against which the effectiveness of respite services should be measured. It was concluded that qualitative measures should be identified by carers themselves through consultation and assessment, and that they should also be measured by carers. The key measure should be the outcome (s) sought by the carer, not the functions carried out by the respite service. Outcomes need to encompass health and social benefits and broader quality of life. The following specific qualitative measures were proposed:

- *The appropriateness, timeliness and availability* of the service to the identified need (s).
- *The degree of readiness* with which care recipients and carers accepted the service.
- *The degree of enjoyment and stimulation* the care recipients gained from the service.
- *The degree of confidence* felt by carers about the service.
- *The outcomes achieved for carers* – including, reduction of ‘burden of care’, increased feeling of being supported.
- *The outcomes achieved for the care recipients* – including, attention to safety needs, having a positive experience, support for quality of life.

- More quantifiable measures include *measures of care recipient and carer health* on commencement of the service, and at later intervals, including exit from the service, together with an *assessment of the impact of day respite activities* on care recipients' behaviour, sleep patterns, and activities of daily living.
- Evaluation of the above in the context of the range or package of services being provided to carers and care recipients, rather than assessing respite services in isolation from the rest of the service system, and from other supports provided (Arksey *et al*, 2004: 93-94).

Lesson 10: There is little guidance provided in the existing research literature about measuring the cost-effectiveness of respite services, largely because of the range of variables that can affect this. Determining the boundaries within which this analysis is also fraught. However, it is possible to undertake 'cost-consequence' analysis by comparing input costs with outcomes achieved for care recipients and their carers.

4 GOOD PRACTICE IN RESPITE CARE

4.1 SUMMARISING THE INDICATORS OF GOOD PRACTICE IN DAY RESPITE

A number of indicators of good practice in respite care, including day respite, can be distilled from available research findings. These are summarised in the table which follows. This separates inputs from outcomes, and levels of impact. Taken together, these indicators can be applied in service monitoring and evaluation.

LEVEL	INPUTS
Service provision - Preparation	
	Effective initial information and preparation for respite care.
	Timely, coordinated, and culturally appropriate information and referral.
	Emotional support and assistance with access.
	Planned and developed in consultation with the carer.
	Designed with a dual focus on the needs of carers and care recipients.
Service provision - delivery	
	Flexible service delivery that is tailored to the individual cultural and lifestyle needs.
	Responsiveness to the identified needs of the carer and care recipient.
	Provision of a choice of options for the carer and care recipient.
	A sound activities program that reflects individual need and interests.
	Consistency of staff for people with dementia.
	Maintenance of individual daily routines for people with dementia.
	Appropriate length of time (eg 2+ days per week)
	Affordable care.
Service provision - quality	
	Appropriately trained staff for the needs of the care recipient.
	High quality, reliable care and support.
	Well supported, qualified and experienced staff.
	Staffing ratios that support individualised care.
LEVEL	OUTPUTS AND IMPACT
Carer and care recipient	
	Maintenance or improvement of carer and care recipient health, well-being and quality of life.
	Improvement in the ability to continue in the caring role.
	Reduction of carer stress in both the short and longer term.
	Improvement in the caring relationship, and with other relationships.
	Maintenance of cultural beliefs and practices.
	A positive experience for the care recipient.
	Positive social participation achieved for the care recipient.
	Ability of the carer to balance caregiving with other parts of their life.
	Linkage to other required services and supports.
Service system	
	Prevention of inappropriate or premature admission to residential facilities.
	Reduced pressure on other services including acute care and emergency services, resulting in cost savings to government.

(Lara & Gowan-McKenna: 2005; Carers Australia: 2007; Arksey *et al*: 2004; Mason *et al*: 2007).

4.2 SUMMARISING THE LESSONS ARISING FROM RESEARCH FINDINGS

This review of research has distilled ten lessons that are of relevance in designing, delivering and evaluating respite care services.

- 1) Good practice in respite care requires services tailored to individual need, interest and preference, involving care recipients in the planning of their activities and more broadly, in overall service development (page 3).
- 2) The perceived quality and purpose of respite significantly influences its acceptability to carers and care recipients (page 3).
- 3) The needs of carers and care recipients are diverse and should be addressed using a variety of activities, settings and strategies, avoiding a 'one-size-fits-all' approach (page 4).
- 4) Day respite centres can span a continuum involving services that address social and recreational needs to those providing therapeutic and rehabilitative care. This focus should be reflected in the design of evaluation studies (page 6).
- 5) Research has consistently identified that carers seek four key features of respite services – choice and flexibility so that services are tailored to their needs, quality of provision to achieve trust in the service provided, access to information to underpin their choices, and ease of access through a coordinated network of services (page 6).
- 6) Ideally, carers' use of respite services should reflect informed choice, hence the way in which services are promoted to them needs to ensure that information is accurate, accessible, culturally inclusive and presented in a coordinated way (page 8).
- 7) Carers' access to respite service may be inhibited by a range of emotional factors including anxiety about the perceived quality of service, resistance from the person in their care and guilt about accepting their need for respite. Information and promotion strategies need to address emotion, and its impact on perceptions, as a critical access issue (page 8).
- 8) Respite services are more likely to have a positive impact on carers when consideration is given to designing the preparatory phase to support informed choice and accurate assessment of need (page 9).
- 9) There are multiple factors that affect the impact of respite services on caregivers. From a service provision perspective, these include the amount of respite provided (with the research indicating that at least two days a week is needed for a discernible impact), the provision of transport, quality of service, and length of usage.

Outside of the service provider's sphere of influence, factors affecting the impact of respite include the nature of the caring relationship (including whether this is kinship based or not), carer age and familiarity with formal services, whether or not the carer is in paid employment, the severity and complexity of the care recipient's needs (and whether they had been recently hospitalised) and the amount of informal support being received. Factors like carer gender and cultural background, and carer perceptions and attitudes may also be influential.

These differing factors underscore the importance of flexibility in delivery, taking into account as much as possible, individual circumstances and need (page 11).

- 10) There is little guidance provided in the existing research literature about measuring the cost-effectiveness of respite services, largely because of the range of variables that can affect this. Determining the boundaries within which this analysis is also fraught. However, it is possible to undertake 'cost-consequence' analysis by comparing input costs with outcomes achieved for care recipients and their carers (page 17).

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