



BROTHERHOOD
of St LAURENCE

*It's the simple things that
matter*

An evaluation of the Banksia
host-home respite program

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Foreword

Given the choice, most of us would prefer, both for ourselves and our loved ones, the opportunity to stay for as long as possible living in our own home and local community. For people with dementia or other cognitive impairments, to remain living at home within a familiar neighbourhood is not always possible, unless relatives or friends are able to take on the demanding role of carer. Respite programs funded by the three levels of government and provided by a network of service providers play a crucial part in supporting families and others in their caring role.

Since the move from a focus on institutional care for people with dementia to provision of community-based care, it has become evident that there is no single respite service that fits the diverse requirements of different care-givers and people with dementia. Hence there is a need for innovative programs and for staff constantly to seek feedback from service users regarding their satisfaction with the services provided, and how the services could be enhanced to better meet both carers' needs and those of the person receiving care.

The Brotherhood of St Laurence has a long history of involvement in aged care and of developing new ways to cater for disadvantaged groups. The Brotherhood received funding from the Commonwealth Department of Health and Aged Care in early 2000 for the establishment of a pilot host-home respite program operating through the Banksia Centre. *It's the simple things that matter* is the result of the evaluation that was undertaken in 2001 by Sonya Holm and Stephen Ziguras, social researchers with the Brotherhood of St Laurence.

In recent times the concept of 'continuous improvement' has become a recurrent theme in the provision of aged care and community services. This report seeks to document a distinctive program and identify learnings from it, so that the Brotherhood and other service providers can develop and adapt respite programs which respond to diverse and changing needs.

Carers, care-recipients and staff are among the many people who have been most generous in contributing their time and perspectives to this evaluation.

The report identifies a number of key findings that will assist the Brotherhood of St Laurence in further meeting the needs of carers and care-recipients. It is also hoped it will assist all levels of Government to review and revise their policies relating to the provision of respite care.

Our special thanks go to all those who contributed to the completion of this report. We hope *It's the simple things that matter* will both inspire and encourage you.

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Thanks also to the members of the project's Advisory Committee who provided feedback and guidance. Members of the Committee were:

- Ila Howard, Manager of the Banksia Centre Respite Program
- Pamela Forster, Department of Health and Aged Care
- Jill Thompson, Council on the Ageing (Victoria)
- Elizabeth Ozanne, School of Social Work, University of Melbourne
- Philippa Angley, Alzheimer's Association Victoria

Thanks to the Brotherhood's accounts department for providing budget information in the form of hourly cost comparisons.

Other people consulted during the evaluation process were Jason Burton, Senior Respite Coordinator of the Alzheimer's Association of Western Australia, and Sally Cooper, Executive Officer of Family Day Care Victoria. We are grateful for their time and advice.

Glossary and abbreviations

Glossary of terms

Carer

‘A person of any age who provides informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or persons who are elderly, i.e., aged 60 years or over’ (Australian Bureau of Statistics 1998). In this report, we use the term to refer to family carers.

Care-recipient

The person with dementia who receives assistance from the agency by attending respite programs. This is the term used by the Department of Health and Aged Care.

Care-worker

A staff member who works in a respite centre or provides in-home or host-home care.

Dementia

Dementia is a term that covers a range of degenerative diseases that affect memory and thinking, the most common being Alzheimer’s disease. The various dementias ‘cause brain cells to die at a faster rate than normal and this may drastically change the way a person thinks and behaves’ (Alzheimer’s Association Australia 2001).

Abbreviations

BSL

Brotherhood of St Laurence.

HACC

Home and Community Care programs funded by the Commonwealth Government and the State Governments)

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Summary

This report describes an evaluation of an innovative host-home respite program for elderly people with dementia and their carers. The program is run by the Brotherhood of St Laurence as part of the respite services provided through the Banksia Centre in Carrum Downs. It was initiated to provide another respite option, especially for groups of people who might not be able to use or participate in existing respite programs.

One of the key differences of this program is that respite is provided in small groups in a care-worker's home. The result is that respite is provided in a relaxed and friendly atmosphere, like a group of friends meeting for the day. The host-home program is based on the Family Day Care model and a similar service that is operated in Western Australia by the Alzheimer's Association. It is currently the only example of this model of respite operating in Victoria.

Respite care and dementia

There has been a shift over the last 20 years away from institutional-based care, towards care provided in the community. Respite is acknowledged as being crucial for carers to remain in their role and for the care-recipient to stay in the community for longer. For those caring for a family member with dementia, the caring role is particularly complex and demanding, so access to appropriate respite can be even more important.

Need for innovative programs

Respite services for people with dementia need to take into account the constantly changing needs of both the carer and care-recipient in order to be effective. This means an integrated, coordinated and flexible approach to service delivery. Centre-based respite programs can be unsuitable for some elderly people, especially for people experiencing communication and language difficulties.

There is an increasing number of people in Australia who fulfil the caring role. As the population ages, this number is likely to increase. Therefore, it is likely that the demand for flexible respite options covering a range of needs will also continue to grow.

Method

Several sources of data were used for this evaluation. Relevant documentation, including funding submissions and program forms, was collected. Information was also provided by management regarding the number and demographics of care-recipients. The hourly costs of the host-home respite model compared with other models run by Banksia were provided by the Brotherhood's accounts department.

Semi-structured interviews were conducted with the two host-home care-workers and the Banksia Centre manager. Telephone interviews were conducted with seven carers whose relatives had attended the program. To gain a first-hand view of the service, participant observation was carried out during two respite sessions at care-workers' homes.

Key findings

The evaluation found the program is enjoyed by the care-recipients and valued by the carers and that the smaller-group format of the host-home program enabled care-workers to choose activities which suited the care-recipients' interests and skills. The informal atmosphere encouraged people to take part in conversation and to feel 'at home'. As one carer observed in relation to her mother's needs, 'It's the simple things that matter'. The personal qualities and training of the staff were important in its effectiveness, as was the provision of transport to and from the care-recipients' homes. Carers noted that their relatives were happy to attend the group, and consequently the carers themselves felt more at ease.

Recommendations

The learnings gained from this new and innovative program operating at Banksia suggest some critical issues if the model is to be implemented elsewhere. These include the issues relating to staff skills, the necessity of the program operating from a bigger centre rather than in isolation, and ensuring that cost shifting onto staff does not occur.

The host-home model of respite care appears to offer potential advantages for people from a non-English speaking background and Indigenous Australians. This report recommends further trials with such groups.

A strong recommendation of the research is that the Federal government establish standards for host-home programs. This will avoid potential problems relating to inadequate supervision or exploitation of staff. The establishment of standards would also encourage high quality care, helping to ensure that the success of the program operated by the Banksia Centre could be replicated elsewhere.

I. Introduction

This report describes an evaluation of an innovative host-home respite program for elderly people with dementia and their carers. The program is conducted by the Brotherhood of St Laurence through the Banksia Centre, which is one of several aged care services run by the BSL in inner-city Melbourne and the Mornington Peninsula.

Host-home respite is quite different from previous models of respite programs because care is provided in the home of a care-worker, not in a centre or in carer (or care-recipient's) home. In this way it is based on the Family Day Care model. There are also two other factors that make the host-home program different from other respite options currently offered at Banksia: the extended hours of respite (six hours instead of the four offered for in-home respite); and the routine provision of transport to and from the host-home.

The key objectives of this evaluation were to:

1. Explore the following questions:

- Why was the program established? What specific or unmet needs was it intended to meet?
- How did the program attempt to meet these needs? What was the program model and how did it differ from previous models?
- To what extent did the program overcome limitations identified in existing services?
- How effective was the program in meeting the needs of the participants?

2. Identify key recommendations if the host-home program is to be replicated in other centres.

The Brotherhood of St Laurence received funding from the Commonwealth Department of Health and Aged Care in early 2000 to run a pilot small group respite (host-home) program for carers of people with dementia and challenging behaviour, as part of the Banksia respite service.

The host-home program currently consists of two groups, one operating on Mondays and the other on Wednesdays. These groups are run by two different care-workers in two different suburbs. Each care-recipient attends one group only.

The evaluation was undertaken by two researchers from the Brotherhood of St Laurence Social Action and Research Unit.

In this report, Chapter 2 provides an overview of respite services in community care for elderly people and particular issues for caring for people with dementia. Chapter 3 provides the background to the host-home program, with a description of the Banksia Centre, the Family Day Care program, and a host-family program run in Western Australia. Chapter 4 outlines the methodology for the evaluation. Chapter 5 describes the host-home program in more detail, and compares the relative costs of the various respite services provided by the Banksia Centre. Chapter 6 consists of the views and experiences of carers and care-recipients of the program. The final chapter summarises the key findings and recommendations, including implications for the establishment of similar programs elsewhere.

2. Respite care and dementia

This chapter covers three areas. The first section reviews respite care in the context of de-institutionalisation and community-based care. The second discusses dementia and particular issues in providing respite care to people with dementia. The third area outlines principles of service provision for people with dementia, which include service type, staff qualifications and experience, quality and management.

Community care

The need for respite care reflects the context of aged care since the mid-1980s: elderly people are remaining longer in their own homes with the provision of community support which can prevent, or at least delay, admission to institutional care (Rossiter 1993; Department of Health and Family Services 1996a). This shift towards community-based care has been accompanied and reinforced by government policy:

Policies aimed at limiting the growth of residential care have shifted the burden of care to the community and have encouraged the development of strategies to support those being cared for at home. (Clarke & Finucane 1995, p.183)

According to an evaluation of respite services carried out by the Aged and Community Care Division of the Commonwealth Department of Health and Family Services, the provision of respite care has two policy goals. It aims firstly to provide support for carers, and secondly, to prevent or delay admission to residential care (Department of Health and Family Services 1996a).

The Home and Community Care program (HACC) was established in 1985 and is financed by both the Commonwealth Government and the State Governments (Reynolds et al 1993). The central aim of HACC services is to help older people to remain as independent as possible and to continue living in their own homes (Department of Health and Aged Care 2001).

HACC programs are provided through local government, charitable and community organisations and some State Government agencies. As well as providing respite, HACC programs also assist with home help, transport, food services, personal care, community nursing and home maintenance (Department of Health and Aged Care 2001).

In 1997 funding was allocated to establish Carer Respite Centres in 58 regions around Australia. The Centres provide information for carers, assist in organising respite, and aim to ensure that respite care is responsive to carers' needs. Commonwealth Carelink Centres were announced in the 1999-2000 Budget; they will operate as regionally located information points, linked nationally, and will provide comprehensive information on a range of health and community services (Gray 2001). They are expected to be implemented during 2001.

The importance of respite

Respite is the provision of alternative care, where needed, to allow the carer some time away from their caring role. Such a break can allow the carer to catch up with the tasks of running a household (such as cleaning and shopping), to undertake paid work, to have some free-time, or catch up on sleep (Alzheimer's Association WA 2001; Rossiter 1993).

The provision of respite is widely acknowledged as being vital for carers (Rossiter 1993; Clarke & Finucane 1995). Rossiter notes that respite care is generally the most frequently requested service among carers (Rossiter 1993).

Respite has been shown to reduce stress levels, and may prevent the carers themselves from becoming too sick to continue in the caring role (Rossiter 1993; Alzheimer's Association WA 2001). The Commonwealth Government Respite Review found that:

Carers and their advocates have consistently raised the importance of being able to have a break from their caring role as crucial to their capacity to continue to care. (Department of Health and Family Services 1996a, p.ii)

Research by Reynolds and others, for instance, has showed that 'support of the carer enables them to continue to provide support and care to the care-recipient' (Reynolds et al 1993). For carers looking after elderly people with dementia, respite is even more critical (Rossiter 1993).

Carers now make up a significant section of the Australian community. In 1998, there were an estimated 2.3 million carers (caring for people with a range of conditions or disabilities), constituting 12 per cent of the population (ABS 1998). In 1993, the Commonwealth government estimated that over 184,000 people in Australia had dementia and resided in the community (Rossiter 1993, p.8). Given the ageing of the Australian population, it is likely that this number will grow considerably in the future.

Respite care is therefore a growing part of community care for elderly people, but until recently, relatively little work had been done in examining different models of respite care.

Models of respite care

The provision of respite can take different forms, including overnight (short-term overnight and planned blocks of up to six weeks), centre-based, in-home and host-home (sometimes called host-family). A brief summary of the different types of respite service follows:

Centre-based care

Regular or occasional day care may be provided in a community care facility. Care is provided in larger groups. For example, the Banksia Centre caters for up to 20 people at a time, with an average of between 15 and 18. Activities such as games or craft are often provided, and the hours are 10.00 a.m. to 4.00 p.m.

Overnight care

Overnight care generally refers to respite provided in a community facility. The stay is usually for one or two nights in a community house. Banksia offers Tuesday, Friday or Saturday overnight care from 9.00 p.m. to 9.00 a.m. Because care-recipients often attend the Centre-based program during the day beforehand, Banksia also provides 'afternoon care' from 4.00 p.m. to 9.00 p.m. when overnight care begins.

In-home care

Regular or occasional day care may be provided in the carer's (or care-recipient's) own home by a single staff member. This form of respite developed as an alternative to centre-based respite, where the person requiring care was unable to attend the centre. This is usually offered during the day for four hours, at a time suitable to care-recipients and carers.

Host-home or host-family care

The host-home respite model is comparatively new, and consists of regular or occasional day care for a small group of people (around four) provided in a care-worker's home. It is similar in some ways to the Family Day Care model of childcare, which is described in chapter 3.

Who is the client in respite care?

The notion of a 'client' is somewhat different when applied to respite services, compared with other human service programs. Respite is at one level a service provided to a carer to allow them a break. Rossiter (1993) suggests that there are three crucial considerations for carers of people with dementia: that they have access to respite when needed; that the care is provided by people who understand dementia; and that the individual care needs of the person are understood. However, respite is also very important for the care-recipient:

Respite care has the dual purpose of assisting two individuals at the same time. Although the name respite indicates that it is principally aimed at providing relief to carers, it is important that respite care is also beneficial to the person with dementia. (Rossiter 1993,p.46)

Similarly Sandlant, detailing a 'creative' respite program, states that:

When we provide respite, we are not just offering a 'sitting' service. Where possible, we link the person with dementia back into the community. We find out what the person is interested in. (Sandlant 1994, p.44)

Respite can offer the care-recipient an opportunity to interact with others, and to participate in community and recreation activities. This is often extremely important due to the isolation, loneliness and depression which many people with dementia experience (Askham & Thompson 1994). Isolation and loneliness may be a result of the loss of a spouse or the loss of social networks and friendships after the onset of dementia.

Moreover, Reynolds et al. (1993), in an evaluation of community care for people with dementia, found that strict definitions of who the client is, can lead to problems for the group (in this instance, carers) not deemed to have 'client' status (Reynolds et al 1993). Rossiter likewise observes that defining the client as *either* the carer or the care-recipient can create problems (Rossiter 1993).

It is important to acknowledge that both carers and those receiving care are 'clients' and that different aspects of respite may be beneficial to each. Home and Community Care policy about respite echoes this approach (Department of Health and Aged Care 2000). Hence programs should pay attention to the needs of both groups.

Caring and respite issues for people with dementia

Caring for an elderly family member is often demanding, but caring for someone with dementia is an even more difficult role. The particular behavioural manifestations of the condition, such as short-term memory loss, can make it very difficult for individual carers, and for services providing respite. This section provides an overview of the issues involved in caring for someone with dementia.

Dementia

Dementia is a term that covers a range of degenerative diseases that affect memory and thinking, the most common being Alzheimer's (Alzheimer's Association Australia 2001). Dementia progresses at different rates and affects people in different ways, but the condition is often described as mild, moderate or severe.

Mild dementia describes the condition where people begin experiencing memory problems. For example, they may start repeating themselves, forget details of recent events, or have difficulty in handling money.

With moderate dementia, the problems become more pronounced. People may forget the names of family or friends; confuse one person with another; forget how to use pots, pans and cooking facilities (e.g., may leave the gas on); get lost or become confused in unfamiliar surroundings; start to wander the streets; or become confused about time of day (e.g., may try to go shopping in the middle of the night). They may also become distressed, angry or upset because of feelings of frustration.

Severe dementia means the condition has progressed to the point where the person needs significant help with personal care. People may be unable to remember what happened a few minutes previously; may repeat sounds or phrases constantly; may be unable to recognise family and friends; or may display inappropriate behaviour (e.g. take their clothes off at inappropriate times). They may also be incontinent or have difficulty walking. (Alzheimer's Association WA 2001; Reynolds et al. 1993).

Issues for caring

Carers of people with dementia have a particularly complex role as they are increasingly required to become the 'substitute mind' of the person they are caring for as well as undertaking practical care tasks. These carers need to be constantly alert (Rossiter 1993:8).

Askham and Thompson argue that:

Dementia sufferers ... need people to help them with personal and house care; to safeguard them (and others who may be affected) from risks such as gas or road traffic, from harming themselves or others or from being harmed by others (for they may become vulnerable to attack, theft, etc.); and to provide them with companionship and emotional support in their frequent loneliness and depression. (Askham & Thompson 1994:11)

Difficulties in providing care also stem from varying and often more complex needs. These needs are often unpredictable and change over time (Rossiter 1993:). This applies primarily to people with dementia, but the caring role also changes. Specific areas of care for people with dementia may include supervision, help with eating or remembering to eat, assistance with medication or other forms of treatment, help with personal safety (such as negotiating steps) and hygiene standards. Help with transport is another major area of need (Rossiter 1993).

Principles of respite service delivery

In this section we discuss the principles involved in the provision of high-quality respite services which include the type of service provided; the quality of respite care; and management issues and the needs of care-workers

Type of service

The type of respite service provided for elderly people with dementia is critically important. The key aspects are a flexible approach to service delivery, including careful monitoring of needs; the qualities and qualifications of staff; the activities chosen; and the targeting of services.

Flexibility of approach

The degenerative nature of dementia means that needs change frequently. To be effective, therefore, respite services have to offer an integrated, coordinated and flexible approach. Flexibility seems particularly important, as it is necessary for services to be able to respond to rapidly changing or emerging needs (Rossiter 1995; Alzheimer's Association WA 2001).

Building rapport between the care-worker and all parties involved is also essential:

Working directly with people with dementia requires special sensitivity as to how services are delivered. Establishing rapport and trust is facilitated when a familiar service provider fits in with the accepted routine of the care-recipient. (Reynolds et al 1993, p.xviii)

Sandlant, commenting on Magill Community Options, a dementia respite program offered in South Australia, highlights the need to build rapport (Sandlant 1994). At the Magill program this was done by meeting with the carer and person with dementia, often several times, before attendance at the program commenced. A good relationship between the care-worker and both the carer and care-recipient assists communication and ongoing monitoring.

Qualities and qualifications of staff

The skills and competencies of care-workers when providing respite services to people with dementia are crucial. Understanding the emerging and changing needs of both carers and care-recipients requires knowledge about dementia and ageing (Reynolds et al 1993), and experience of working with people with dementia, as does developing appropriate activities for people with dementia to undertake during respite.

...[A]dequate education of staff is necessary to ensure that they understand the nature of dementia and ways of communicating and working with people with dementia and their carers ... In many cases, attitudes are as fundamental as technical skills in working effectively with people with dementia. (Rossiter 1993, p.27)

Activities

The role of activities in respite is vital:

Workers in day respite should know about suitable programs for people with dementia and understand the devastating impact of large groups of people, tasks that are 'too hard', or noisy unfamiliar environments. (Rossiter 1993, p.28)

In a similar vein, the Alzheimer's Association of Western Australia aims to provide respite that offers 'companionship and stimulation through a variety of meaningful and familiar activities' (Clay, Hedley & Pieloor 1999, p.4).

Planning activities for people who may not remember what they did last week, or what they had for breakfast, can be a real challenge. In their policy paper on community care for people with dementia, the Alzheimer's Association recommend that activities should be chosen that are 'familiar and meaningful to the individual' (Rossiter 1993, p.28). There should also be no expectation of learning new skills, but a strong emphasis on reinforcing old ones.

The importance of appropriate activities for people with dementia is summarised by Sandlant, reflecting on the respite service offered in South Australia.

Like all of us they [people with dementia] need to do things that make them feel good, worthwhile, useful, important and needed. (Sandlant 1994, p. 45)

Targeting services

There is some debate about the degree of specialisation or targeting of services. On the one hand, some argue that people with dementia should not be treated differently from other elderly people. The creative respite program provided in South Australia had an approach of integrating people with dementia into broader groups, with the aid of an assistant. This 'mainstreaming' approach was based on the idea that staff might have lower expectations of people in 'dementia-specific groups' and that their skills might not be maintained to the level they could be (Sandlant 1994, p.44).

On the other hand, some argue for dementia-specific services on the basis that: 'carers need community services appropriate to their own needs and those of the person with dementia' (Rossiter 1993, p.27).

These approaches are not necessarily mutually exclusive. Reynolds et al argue, for instance, that 'rather than build a totally separate system of services ... we recommend a balance of approaches' (1993, p.xiii).

Quality of respite care

This section consists of quality of service identified for the Alzheimer's Association in an issues and policy paper by Rossiter (1993). It also notes key elements of best practice highlighted in *The Respite Review* (1996).

Key components of quality as identified by Rossiter (1993, p.44) include:

- appropriate design of facilities;
- a program that is suited to the individual needs of the people attending;
- staff with formal qualifications, including adequate knowledge of dementia;
- sensitive staff attitudes and an aptitude for working with care-recipients with dementia;
- continuity of workers; and
- the overall philosophy of the auspice body.

Care-recipients also benefit from:

- a warm, friendly, homelike, reassuring environment; and
- visual and auditory cues appropriate to the participants' age and cultural background;
- a service which enhances abilities and feelings of usefulness amongst participants .

The overall objective of *The Respite Review* (1996) was to examine current models of respite care provided by the HACC and Commonwealth Respite for Carers (CRC) programs, and 'determine the extent to which these services met the needs of carers and the people they care for in the community' (Department of Health and Family Services 1996a, Appendix 8). The terms of reference for the review included identifying the key elements of providing respite care. Consumer consultation was undertaken in order to develop the models for best practice. One of the main findings was that:

Community consultation indicated that best practice required that respite services be individually tailored to meet the needs of the carer and the recipient, in range, scope, quantity and timing. (Department of Health and Family Services 1996b, p.3)

Management issues and the needs of care-workers

Crucial areas for managing programs and addressing staff needs include:

- collection and documentation of information about the needs and requirements of both care-recipients and carers;
- clearly defined roles and responsibilities for the care-workers;
- support for care-workers (e.g., opportunities to de-brief and share ideas).

Increasing dementia-capable practice requires staff development and training with emphasis on attitudes and skills in working directly with care-recipients and carers...Educational material...[and] face-to-face sharing of knowledge among practitioners can focus on critical case reviews and discussion of failures as well as successes. Group support can limit the stresses of continually working with people in difficulty. (Reynolds et al 1993, p. xviii)

The first two items above could be achieved in part by having clearly documented policies and procedures. The Western Australia host-home program, as recorded by Clay, Hedley and Pieloor (1999) demonstrates this. This program involves the systematic collection of data and a system of monitoring and appraising staff. Staff have designed policies, procedures and forms including policy and guidelines for host family care-workers, a care-workers' code of conduct, guidelines for legal and financial matters, statements of rights and responsibilities, guidelines for administering medication and for taking care-recipients out, and lists of people to contact in emergencies. They also have a home club resource kit of activities (Clay, Hedley and Pieloor 1999).

The Senior Respite Coordinator of the Alzheimer's Association of Western Australia, Jason Burton, confirmed that the guidelines and documentation are still being used, but are being continually improved. The Western Australia host-home program is discussed further in the following chapter.

3. Background to the host-home program

Banksia Centre

The Banksia Centre provides a range of respite services on Victoria's outer-metropolitan Mornington Peninsula, including centre-based respite offered at two centres (one in Carrum Downs and one in Frankston), overnight respite offered three nights per week, in-home respite, and the host-home program (operating at Seaford and Pearcedale).

Banksia has been operating since the early 1990s, and aims to provide activities and day care for older people who may be socially isolated, and respite and support for people who are looking after a relative or friend. The various respite programs offer practical support and care in an environment that aims to enhance the quality of life of both care recipients and carers.

Other services offered through Banksia include day activities and outings, social gatherings, cooked meals, information about and assistance to access other services, and transport to and from the Banksia Centre for care-recipients and carers if required. Carers have access to carer support groups, a resource room, information, social events, and audiovisual equipment.

The target groups for the service are:

- older, frail people;
- people with dementia and challenging behaviour;
- people with acquired brain injury;
- people with psychiatric disorders; and
- vulnerable people residing in the community.

Funding for centre-based and overnight respite is from HACC as part of the Adult Day Activity and Support Services program (ADASS). The host-home and in-home programs are funded by the Commonwealth Department of Health and Aged Care, as part of the 'National respite for carers program: Carers of people with dementia and challenging behaviour'. Additional funding was provided in 2000 for new services for people with dementia and challenging behaviour. Twenty-five programs were funded in Victoria, with 82 projects across Australia (Bishop 2000). The Banksia host-home program for carers of people with dementia is currently the only one operating in Victoria.

The Banksia pilot program was proposed in order to provide respite care for a small group of elderly people with dementia and disordered behaviour in a person's home, a model similar to family day care. It was argued that this model would embrace people who found it hard to attend centre-based respite because of communication and language difficulties, such as those who lacked confidence in a large group, whose behaviour made large group respite unsuitable, or who were from Koori or non-English-speaking backgrounds.

Two different models of service provision have influenced the Banksia host-home project: the Family Day Care program and the Host-family respite program operating in Western Australia. A brief description of each is provided below.

Family Day Care

Family day care is child-care provided in a care-worker's own home. It began in 1971 as a pilot project run by the Brotherhood of St Laurence, and was inspired by innovative child-care programs operating overseas (D'Mello & Bugueno 1989; Quagliana unpub.). Thirty years after its inception, there are 74 schemes operating across Victoria, encompassing approximately 4,500 individual homes providing child-care (Family Day Care Victoria 2001).

This service is open to any family, with individual fee structures determined by each family day care scheme (Family Day Care Victoria 2001). A care provider can look after up to four pre-school children at one time (Dixon 1990), but up to seven children may be present in the home, providing only four of them are under pre-school age (DFaCS 2000).

The family day care program seeks to provide a flexible service operating seven days a week, 24 hours a day, and offers respite, casual care, weekend care and overnight stays. Programs are operated by local government and community organisations, with funding provided by the Commonwealth Government (Family Day Care Victoria 2001). Individual schemes coordinate the registration process, but the minimum requirement to become a Registered Care Provider involves a police check, having a safe clean home, and also a current First Aid Certificate.

In spite of the growth of family day care, there is no national regulatory body. There are also no set standards of care provider status in terms of whether workers are considered employees in a full or partial capacity, or whether they are contractors. This has led to complications relating to wages and conditions (Dixon 1990) as well as to expectations of employees and the parameters of responsibility — for example, whether picking up individual children from school is part of the service. Another issue is that family day care may be used to avoid the capital costs of centre-based facilities, or to transfer the recurrent cost of these facilities to the staff (Dixon 1990). Some of these issues are also relevant to the host-home model of respite care.

Host-family respite care in Western Australia

The host-family respite program described here was provided by the Alzheimer's Association of Western Australia, and partially funded through HACC (Alzheimer's Association WA 2001). The program began with two years of pilot funding in 1997 (Clay, Hedley & Pieloor 1999).

The host-family respite program was developed to provide a service catering to the needs of people with dementia who might be unsuitable for main centre respite, or reluctant to attend. The approach was to fill the gap in service provision, and create more options for carers to ensure they receive a break from their role (Clay, Hedley & Pieloor 1999). Respite is provided in the home of a care-worker, with a maximum of four people per home. The aim of the service is to provide a limited break for the carer; and also to provide quality care for the person with dementia, which includes:

- to maintain and enhancing the person's skills;
- to provide something meaningful to do;
- to retain and/or return the person's social roles/place in the community; and
- to improve/maintain the person's quality of life. (Clay, Hedley & Pieloor 1999, p.31)

The program was based on a 'home from home' program operating in Scotland, and also the family day care model. Although a host-home arrangement had been used in Australia for providing a service to people with disabilities, it had not previously been extended to include people with dementia (Clay, Hedley & Pieloor 1999).

The program is open to people:

- with a medically diagnosed, irreversible dementia;
- who are reluctant to attend centre-based respite;
- who do not live in an area where suitable centre-based respite care is available; and
- whose Family Carer has a preference for respite being provided outside their home setting. (Clay, Hedley & Pieloor 1999, p.4)

The service is considered to be more suitable for those in the early to middle stages of dementia. The fee is \$6.00 per day, which covers lunch and beverages. An additional charge of \$1.00 is made if transport is provided to and from the host-family program. (Alzheimer's Association of WA 2001).

The program currently consists of five different groups (offered in five different suburbs). Four groups run twice a week, and one group runs three days a week. The last group offers care on one day to younger people with dementia (Alzheimer's Association of WA 2001; Jason Burton, Senior Respite Coordinator, Host Family Program, personal communication).

In 1999 the Alzheimer's Association of WA produced a kit for other services wishing to provide a host-family program. The kit provides information on:

Recruiting and orientating staff and recruiting care-recipients... systems to monitor and appraise staff, review and monitor care-recipients, and integrate the service into the overall respite service [also] includes a list of some of the items in the activity resource box from which staff can borrow. (Clay, Hedley & Pieloor 1999, p.4)

The Alzheimer's Association of Western Australia is also in the early stages of developing a new program of host-home overnight stays. It currently operates by linking a volunteer with a family, who then takes the person with dementia to stay overnight at their home. One family is currently using this service.

4. Method

Because the Banksia host-home program is relatively new, the main aim of this evaluation was to describe key elements of the program, how it operates and how it attempts to meet the needs of carers and people with dementia. We also aimed to gather the views of carers and people with dementia about the program, and to compare the hourly cost of the host-home model of respite with other models run by Banksia.

Data collection

Several sources of data were used. Relevant literature such as funding submissions, program forms, leaflets for carers was collected, and some data on care-recipient demographics, number of care-recipients, and costs of each program was provided by management.

Semistructured interviews (either face to face or by telephone) were conducted with the two host-home care-workers and the Banksia manager to establish some of the details of, and their views about, the operation of the service. To gain a first-hand view of the service, we each attended a morning during a respite session at a care-worker's home, and talked with the care-recipients who attended that day.

Telephone interviews were conducted with seven carers whose relatives have attended the program. We had originally planned to conduct focus groups with carers but this turned out to be difficult as most had little time to attend groups, or faced difficulty in travelling. However, seven of the eight carers contacted were happy to be involved in telephone interviews. The experience of one family was written up as a case study as it highlighted some important aspects of the host-home program.

Relative cost analysis

Although we did not aim to conduct a cost-benefit analysis of the various types of respite service, we thought it would be useful to calculate the relative cost of the different respite options offered by Banksia. This was partly because the host-homes program was considered to be a more efficient model than the in-home program, where there was one care-recipient per staff member.

To examine the relative costs, the total costs of each of the services were calculated, including all staff, administration, property and provisions. One hour of service delivery represents a client accessing a service for one hour. Data used was based on the 2001-2002 budget.

Ethical issues

Carers' participation in the study was voluntary. Verbal consent was gained from carers to speak to them about their views and experiences of the program. Written and verbal consent was gained from the carers in order to speak to their relative (the care-recipient). We thought this was necessary since there was some doubt about the competence of some care-recipients to give informed consent due to their dementia; and since some carers had been appointed as guardians or administrators under the Guardianship and Administration Act.

We have complied with confidentiality and privacy requirements by not revealing any names, or comments connected to names (or other identifying information) in the formal report. (Names used in the case study are fictitious.) We also do not disclose information such as comments made to the service provider or staff in such a manner that the care-recipients would be easily identifiable.

The Brotherhood of St Laurence attempts to value and promote consumer participation in research. In this project we attempted to involve consumers by conducting interviews with carers, and

informal discussions with some of the care-recipients. Our policy is to pay people who participate in research. In this situation, to ensure that all contributors shared the benefits of the payment, a contribution of \$200 was made to the host-home programs (via the Banksia Centre) to go towards group activities which they could not otherwise afford.

5. Program description

This chapter consists of information about program rationale and target group, program description, management and policy issues, and staff perspectives about the program and their work. We also provide a comparison of the costs of the main types of respite offered at Banksia.

Program rationale and target group

The host-home program was established to fill a perceived gap in the provision of respite services. Management and staff at Banksia felt that there were carers who wished to access respite services, but could not for the reasons listed below.

From discussions with the manager and staff, the target group seemed quite diverse. They thought the program suited a range of care-recipients and carers for whom other respite options were inappropriate, including:

- people with severe dementia who found the centre too confusing;
- people with hearing problems who could not hear well in large groups;
- people who found it difficult to establish relationships;
- people with mobility problems who would remain socially isolated with in-home respite; and
- those who saw the centres as too institutional or formal.

Reasons for not accessing respite also included individual problems for the carers, such as transport, and whether they were living near a respite centre.

Care-recipient characteristics

Demographic data was available for 18 care-recipients who had been through the program, and time in the program was available for 17 care-recipients. The manager believed that around 25 care-recipients had used the program since the groups started. No information was available about some care-recipients as it took some time for systematic data collection procedures to be implemented.

Of the 18 care-recipients for whom data was available, 15 (or 83.3%) were female. Six were born in the United Kingdom, one in India and the other eleven were born in Australia. Nine were married when they used the service, and the rest were widowed or never married. Half listed their spouse as their closest living relative, six their daughter, one a son, and one person listed a friend as she had no family in Australia. The average age of all those who had participated in the program was 81.5 years, while the average age of those currently in the program was 80.5 years.

Overview and demographic profile of carers

Out of the seven carers interviewed, six were female and one was male. Three were born in Australia, three born overseas in countries where English was the main language, and one was from a non-English speaking background.

For two people, their relative attending the host-home program was their husband, for five it was their mother. Five lived in the same house as their relative at the time they attended the program (four continue to do so). The two other care-recipients who attend the program lived alone in retirement villages.

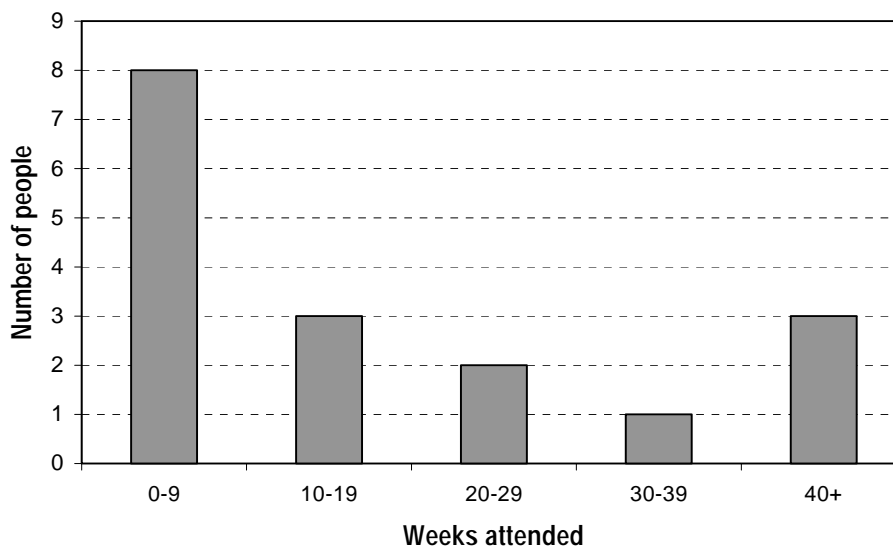
The carers who live with their relative all undertake domestic duties (such as cooking, cleaning, and shopping) and some bathe and dress their relative also. Of the carers not residing with their

relative, the care provided consists of meals, regular phone calls, regular visits, management of financial matters, and taking their relative out for shopping trips etc. At the time of involvement with the host-home program all lived in the south-eastern suburbs of Melbourne.

Attendance of care-recipients

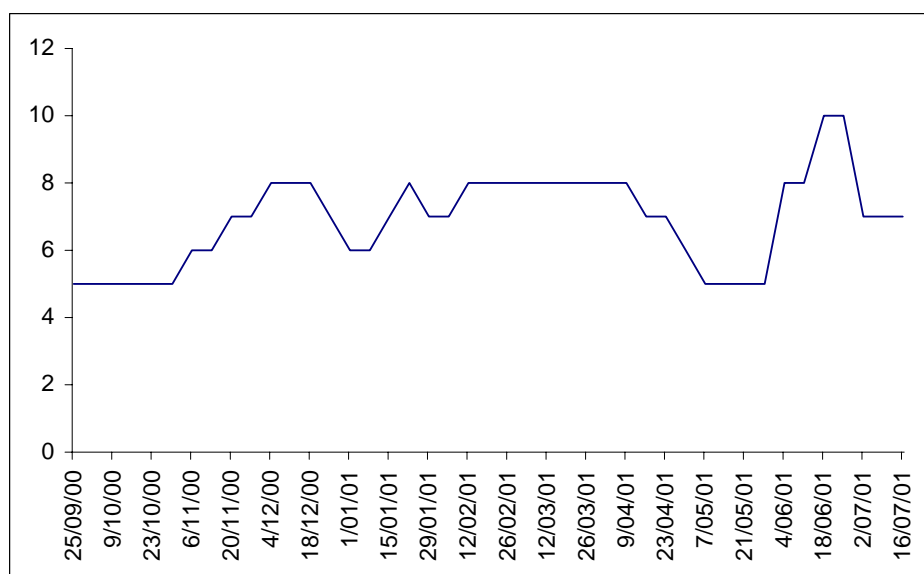
Care-recipients who had been through the program attended for an average of 17 weeks, with individuals attending from one to 45 weeks. Figure 1 shows the distribution of the number of weeks attended by each care-recipient.

Figure 1 Number of weeks attended by each care-recipient



Two care-recipients who joined a group when it began were still attending. According to staff, most of those who no longer attend have entered a residential aged care facility. Figure 2 shows the number of care-recipients attending each week from September 2000 until July 2001.

Figure 2 Number attending host-home groups each week



The manager and staff considered that the care-recipients in the program had a significant level of dependence and physical frailty. We did not attempt to assess the severity of care-recipients' dementia, but the relatively short period of time that care-recipients attended the program before going into residential care (17 weeks), suggest that the care-recipient group had moderate to severe dementia and a high level of disability.

According to the Banksia manager, the program is also sometimes used for 'occasional respite' for those people whose carers may need to suddenly take some time away from their caring role, but not on a regular basis. An example given was a man who wanted to attend a funeral and Banksia was able to place his wife in the host-home for one day. From the data provided, it seemed that only one or two care-recipients were in this situation.

Description of programs

The first group started in September 2000 and the second about a month later. Care is provided for up to six care-recipients in the home of a care-worker. As stated above, this is quite different from previous models of respite programs, in that it is based neither in a centre nor in the carer (or care-recipient's) own home. Other differences are the extended hours of respite (six hours instead of four for in-home respite), and the fact that the care-recipients are picked up and dropped off home again.

Two groups are currently running as part of the host-home program. One group is held on a Monday, and the other on a Wednesday. The Monday group has a maximum of four members, and the Wednesday group has up to six people. The two groups are run by two different care-workers whose homes are in different suburbs (Seaford and Pearcedale respectively). The groups meet from between 9.00 a.m. and 9.30 a.m. to between 3.00 p.m. and 3.30 p.m.

Two participant observation sessions were undertaken, one with each of the programs. The following was written after these sessions:

Monday group

Margaret and her daughter Meisha (who often volunteers to help with the program) live in a fairly new looking brick home in a suburban street in Pearcedale. On the day we visited two care-recipients were present. One lady who normally attended was sick (with a question mark over whether she would be able to attend in the future), the other regular participant of the host-home program was having visitors to her house so could not make it.

We spent most of our time in the kitchen and started off by having tea and cinnamon toast. The conversation was fairly general and friendly. One lady talked about the person who picks them up from their homes and drops them off at the program. She is an ex-school teacher who volunteers for Banksia, and evidently gets on very well with the participants. Both the ladies had brought along old photographs of themselves, as Margaret had asked them to the previous week, so we had a photograph session. Margaret brought out some of her photographs too and so we all had a chat about them. It was a very jovial bright session.

We played three games of alphabet bingo. A different category was chosen each time – we covered boys' names, girls' names and place names. It was a lot of fun and Margaret carefully arranged the game so that everyone got a chance to win. The prize for winning was a sugar-free lolly. One lady saved hers to take home to give to her grandchild who always asks for her Bingo lollies.

The next game we played was a memory/reminiscing one. Margaret had prepared a whole lot of cards on different subjects. All the cards were different colours, with a separate colour for each category. It was a bit like 'Trivial Pursuit' but with a personal orientation, with questions like 'Can you name a teacher you had at school?' or 'Did you collect anything as a child?'. Meisha played the game while Margaret began preparing the lunch, coming over to join in at every opportunity.

Both Margaret and Meisha were very engaging and everyone was included and treated with respect. The atmosphere was very friendly. The impression was that for participants, it was a lot of fun.

Wednesday group

The care-worker, Josie, lived in a modern new home on a small farm in Pearcedale, a semi-rural area about 10 km from the Banksia centre. Another Banksia worker, Maureen, was also working with Josie as there are sometimes too many people for just one staff member. Josie generally picks up care-recipients, and if there are more than three, Maureen or a volunteer picks up the others. Three care-recipients were there the day of the visit. The day began with morning tea, which consisted of pancakes cooked by Josie. Everyone sat around the kitchen table chatting about the weather, birds, dogs, and each person's favourite or most hated food.

Footy tipping was the next activity for the day. Josie went through the football results from the weekend, and worked out who had tipped the most winners. Tips for the following week were chosen, with quite a bit of discussion about form and well-known characteristics of each team ('so and so are all thugs – but I shouldn't say that'). This was followed by a 'thought of the day' read from a book and everyone discussed what it meant to them. The atmosphere was one of good humour and joviality, and much reminiscing about things that people did in their youth.

According to Josie, the group often plays a card game after lunch (their favourite is Uno). Josie also brings in a few magazines which people take in turns to borrow and return the following week. Later in the day, the group also does some gentle exercise and stretches.

The group has been on a few outings: these have included music concerts, attending the Older Women's Circus, fishing, a drive to the Dandenongs and a trip to the Garden Centre. These outings are enjoyable activities in themselves, but they also provide useful topics for discussion. They all seemed to really enjoy going out.

Josie said that when one of the men was there, he enjoyed taking part in the discussion but also liked to do craft activities such as making stick figures out of gumnuts, or small household chores. Sometimes he was encouraged to undertake minor repair jobs.

In summary we felt that the atmosphere was very relaxed and friendly, and the participants clearly enjoyed being there. The programs are provided in very informal settings and more like a group of friends meeting up for the day.

Fees

Initially the care-recipients were charged \$5.00 for each session. The money was paid directly to the care-workers, who used it to cover their own expenses, such as food for morning tea, lunch and afternoon tea. This system of payment, however, was modified in order to strengthen accountability and consistency with other respite programs.

The fee for care-recipients was increased to \$8.00 for each session, which is the same amount that participants at the day centre pay each day. The money is paid directly to the Banksia Centre. The care-workers are provided with a float of \$100 for supplies, and are reimbursed by Banksia after providing receipts for expenses. The care-worker is expected to provide morning and afternoon tea and lunch with this budget.

Banksia also had a budget of \$5000 which was available for minor capital works (changes necessary at the workers' homes such as installation of rails), regular maintenance, renewable supplies (such as toilet paper, cleaning materials, rubber gloves), and a contribution to the insurance on the workers' houses.

Referral and needs assessment

Referral to the main Banksia Centre occurs in several ways. A formal written referral may be received from another agency or medical practitioner or an enquiry (either written or verbal) may be made directly by family and friends of the carer or care-recipient. About one-third of referrals come via an agency and two-thirds directly from the family. Once Banksia receives a referral, the intake worker conducts an assessment and suggests a specific respite program.

A relatively informal assessment is conducted. This includes firstly trying to establish the needs of the carers, in terms of what type of respite service they require (overnight, in-home etc). Priority of access to services is generally given to carers under significant stress.

Information regarding care-recipients is collected during a telephone conversation between the manager and the carer. Information sought usually includes the immediate of the care-recipient history (over the previous two years), and any major medical conditions.

Suitability of different respite options is considered by taking the needs of the care-recipient into account. For example, whether a smaller group setting rather than a larger group would be more appropriate or acceptable. If there is no carer, or the carer is not interested in being involved, then the decisions are based solely on the needs of the care-recipient.

The Banksia Centre does not undertake formal (e.g. medical or physical) assessments, but may suggest that the family contact the Aged Care Assessment Service (ACAS) or Psychogeriatric Assessment Teams (PGAT) for a specialised assessment if this seems necessary.

Staffing

Two care-workers are currently employed to run the groups. Both are female and both have extensive caring experience. One previously worked at the Centre as an overnight relief worker one night per week for three years, and the other has worked at the day program and also nursed an ageing relative.

The manager had expected to advertise for the positions after the program was funded. She was initially reluctant to offer these to existing Centre staff because she felt that they might have some difficulty in adapting to a very different service model. However the two care-workers expressed great enthusiasm for the program and wanted to be involved. In preparation, they went through several training sessions at the Centre. The second group's leader spent some time observing the first group in action before starting another group.

Up to six people attend the Wednesday group, although the average weekly attendance is about four. The care-worker for this group started off with a limit of four, but asked for more people to attend the program, in order to improve the group dynamics. Because of the nature of the service often some of the participants cannot attend, so even if there are a total of six people per group, often fewer will be at each session. It was also felt that more people provided for greater interaction and discussion.

However, if five or six people attended, two staff were needed. For the group with large numbers, two workers were allocated, but if fewer participants turned up then one worker would spend the day at the day program instead. For larger groups, two staff were needed because:

- people have to be picked up and two cars are needed;
- most care-recipients need help getting up and down steps, and others can't be left alone;
- some need help going to the toilet, and someone else needs to be there with the others; and
- some care-recipients can 'wander' and require closer attention, especially on trips or outings.

Management and policy

There were several management questions posed by the host-homes program; these relate to staff supervision and accountability, monitoring care-recipients' needs, care-recipient and staff safety, and insurance.

Provision of care outside a formal workplace raises some questions about how managers supervise staff. Because both staff had also worked at the Banksia Centre, and were well known to the manager before starting the host-home program, the manager had confidence in their abilities. She had been able to observe them working at the centre and they had received considerable 'on-the-job' training. Once the host-home program started, the care-workers would discuss issues relating to care-recipients with the manager or deputy manager when they were at the Centre, but they and the manager felt that they needed a more formal way of sharing information and discussing concerns.

At the time of writing, it was planned to have a regular meeting with the staff to allow this. This weekly contact would also be used to check care-recipients' progress, so that all staff were kept up-to-date.

Needs of care-recipients were monitored by care workers on an informal basis. They felt that the smaller group made it easier to observe a person's behaviour and any changes which might be due to a worsening of their dementia. It was also easier to discuss any of the care-recipients' concerns. When picking up or dropping off care-recipients at their homes, care-workers were able to communicate with carers.

Another potentially difficult issue was ensuring staff and care-recipient safety in a worker's home. Before the program started, the manager conducted a safety assessment with the care worker of the host-home. Some modifications to both workers' houses were undertaken. These included installing rails in toilets and altering steps. Staff are also expected to complete a written report for all incidents such as a fall (including minor ones).

Before they started the groups each worker informed their insurance company about the program, and had their home insurance increased, at an annual cost of around \$30 each. This cost was borne by the program budget, and staff were required to submit a copy of their insurance policy before the groups could begin.

Staff perspectives

This section consists of feedback from both care-workers about the aim of the program for both carers and care-recipients. It also covers the skills required from care-workers and the distinctive features of the program from the care-workers' perspective.

Staff felt that the aim of the program for carers was to 'give them free time', to allow them 'six hours to spend time alone'. They thought that it was important that carers received a break, and that the respite program could 'relieve them of responsibility, constant caring and pressure'. One commented that 'caring can be very difficult and carers need relief.' Both staff had had some experience in caring for their own elderly parents and this may have attuned them to the demands of caring.

Staff of the host-home programs felt that the aim for care-recipients was to provide 'a really lovely day, an outing for them, a marvellous morning tea, a social activity'. The benefits of the program for care-recipients included the chance 'to socialise, to form friendships, and to care for one another'.

It was clear both from interviews and attending the groups that staff felt strongly that the program should cater to the needs and desires of care-recipients as well as carers. Staff went to considerable lengths to include activities that people would enjoy, and to tailor these to the actual people present. For example, one care-worker made a deliberate effort to engage one man in her group by providing opportunities for him to fix things and make toys.

We asked staff what skills were required for this type of job:

Genuine liking of old people. Empathy, patience. A lot of patience – the sort of patience required for listening to anecdotes over and over while responding enthusiastically, not showing that you've heard them before. Sociability. You need a natural affinity to do this job.

Care-workers identified a number of distinctive and beneficial features of the host-home model:

This is a unique service. Informal, just like having a group of friends over to your home. Less institutional than bigger centres. They do a fantastic job here (Banksia Centre) but the formality of it, it's like going to school. This is absolutely necessary in larger groups, but the host-home program is a completely different program altogether.

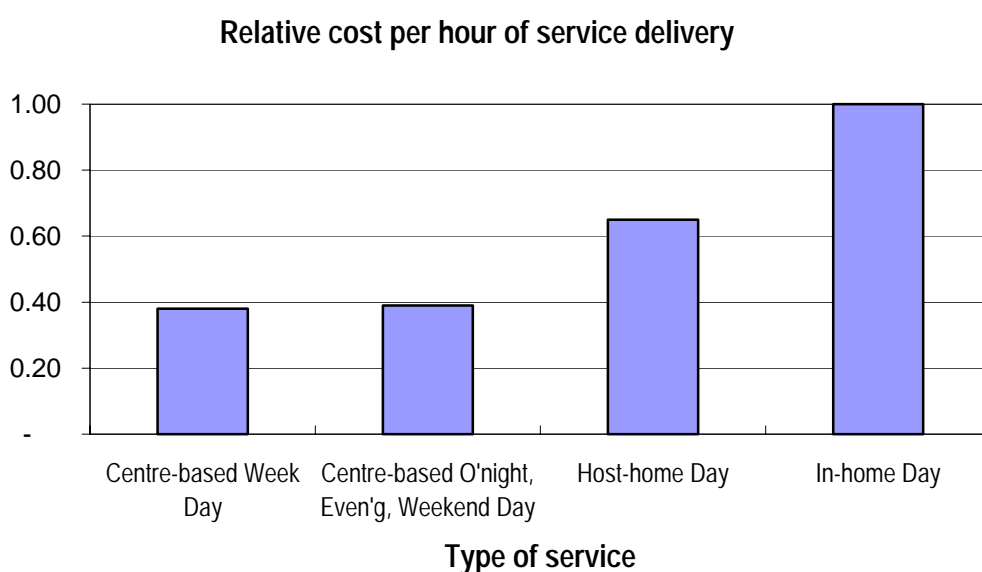
They emphasised the relaxed and informal atmosphere:

The participants can form friendships. Totally different: more personalised, more socialised, more stimulation, more interaction, great opportunities. They get to know each other on a more personal level. Huge benefits for the participants. The participants won't be able to tell you what they did last week during the program, but they will notice if one of the other people is missing.

Relative cost of Banksia respite services

Figure 3 shows the relative cost per hour of respite services provided through the Banksia Centre, based on data from the 2000-2001 budget. The calculations aim to capture the total costs of the service, including all staff, administration, property and provisions. One 'hour of service delivery' means one client accessing a respite service for one hour. The hourly cost of in-home care has been set at 1.00, and the cost of other respite services expressed as a proportion of in-home care.

Figure 3 Relative cost of Banksia respite services



The graph shows that for the Banksia Centre, providing host-home respite is almost 40 per cent cheaper than in-home care, but that both services cost more than centre-based care (both day and overnight). The data used is based on a particular service model adopted by the Brotherhood of St Laurence. It is possible that other providers may have varying models resulting in different cost profiles.

The higher cost of providing staff at penalty rates for centre-based overnight, evening and weekend day respite is offset by cleaners and catering staff predominantly being employed during weekdays. The higher cost per hour for non-centre based service delivery is largely due to the higher staffing ratios required.

6. Views and experiences of participants

This chapter consists of the experiences and views of both the care-recipients and the carers who are involved in the Banksia host-home program. The methodology consisted of telephone interviews with carers, attendance at two of the groups by the researchers and informal discussions with some care-recipients. This chapter ends with a case study to illustrate some of the aspects of the program.

Carers' perspectives

Interviews were conducted with seven carers of people who have attended the host-home program, five of whom continued to do so at the time of writing. The care-recipients who no longer attended the program had moved to residential facilities (both high-care and low-care). To ensure confidentiality, references to specific staff by name have all been substituted with 'care-worker'.

Ways of finding out about the host-home respite care varied. Two of the care-recipients had been in the main centre and their carers had the smaller host-home program recommended to them. One carer contacted the council and was referred to the Banksia Centre as the council service was full. One carer was completing her student placement at the Centre, and was informed about the new program by other staff.

They found me. It was fantastic. I didn't know the service was there. [partner]

Four of the carers had no previous experience with a respite service, so could not offer any direct comparison, but were pleased with the way the host-home care had suited their relative. Three who could make comparisons felt that the smaller group setting was different, and beneficial:

It's smaller, more intimate. It's better for people with dementia having three or four people to each staff member instead of twenty. [daughter]

Two carers also emphasised the homelike location.

The group is a smaller size, which is very important. It's a homelike environment, which is a help. There is no clinical, hospital-like or institutional feel to it. [daughter]

Another person commented:

It is wonderful for my mother. It is a brilliant, wonderful service. I appreciate it very much. It's given her a new lease on life. She got lonely when she lived in Queensland. I see my mum and she's got such a smile on her face. It is nice to know people care and give time to the elderly. When I'm not working full time I'd like to be involved in a service like this. [daughter]

Comments were made about the care-workers, the benefits for themselves and the benefits of the program for their relative. The comments about the service and staff were overwhelmingly positive. Two themes were the attitudes of care-workers and the activities chosen.

Mum and the care-worker have a great rapport happening. [daughter]

Wonderful, doing a great service... I would go barmy without it. At first he was a bit afraid to go, but the care-worker was really good at finding things to do that he liked. The care-worker was wonderful. It was wonderful, so helpful. I have nothing but praise. [person whose partner is no longer able to attend the group, but now receives in-home care once a week].

The carers spoke about the benefits of respite for themselves in terms of getting a break and being confident that their relative was being well cared for and safe in their absence.

They also mentioned the benefits for their relative:

It's so wonderful, the time and devotion given. The people they give care to are not the easiest to handle. Jack is quite cheerful when he comes home. It gives me a day's break. [partner]

From Mum's feedback, I know she loves it. She's doing things that she looks forward to. Keep it up. [son]

Loves it. Just loves the people. So happy to be involved. I can't believe how kind people are, to pick her up and take her there. She really missed it last week when she was sick. She loves going, it's just brilliant. [daughter]

The best thing that could have happened... Mum feels part of the community. If it wasn't for the program on a Monday — Mum can't see that well, can't hear that well, and can no longer knit — she would just sit at home and vegetate. The personalised picking up is good, as transport was a problem: Mum can't cope with taxis anymore, it worries her. It is useful for me because I know Mum is somewhere enjoying herself and is well looked after. I can't fault it. [daughter]

It seems that two aspects of the program made it easier for carers to seek or accept respite for their relative. The first was that they felt that their relatives were enjoying themselves and getting some benefit from the program as well. This may help avoid the guilt or anxiety involved in being a carer and needing to time for yourself, yet still feeling the responsibility for a relative in respite. It may be easier to accept respite if it obviously meets needs of carers and care-recipients. Second, most carers spoke favourably of the 'homelike' atmosphere in contrast to institutional care. Nursing homes and institutions still have very negative associations for many people.

Care-recipients' perspectives

We discussed care-recipients' views during attendance at one of the groups. Attending the respite program seemed to be an important part of everyone's week, providing a good opportunity to spend time with others.

We are all happy together. We all join in and we get along.

Good to get out of the house, it can get quite lonely.

Playing Uno is good fun.

The benefits of attending the smaller host-home program were highlighted by one of the participants:

This is better than the Centre, because here you see the same people each week and get to be friends. At the Centre, you start a conversation with one person and when you turn around they've gone and someone else is there.

Generally, the aspects that people liked were the chance to socialise and to form friendships, and the activities. For one group, outings were particularly popular and there was a lot of discussion about previous trips — where the group went, what shows they saw, and afternoon tea. From observation of both groups, and from care-recipients' comments, we got the impression that care-recipients found the program enjoyable and entertaining. The activities helped to provide structure, but, overall, most people seemed really happy being able to talk to each other in a casual friendly setting.

A case study – Charlotte's story

Charlotte is aged 54. Her mother, Joyce, is 83. Joyce lived with Charlotte for a year before moving into a nursing home. During her stay with Charlotte, Joyce took part in the host-home program. Charlotte is studying social work and community development. As part of her course placement she spent some time at the Banksia Centre.

Charlotte said that from her experience as a care-worker, big group settings for respite seemed to work for some people. She said that there is usually a good mix of men and women and lots of good activities. But Charlotte said she felt a homelike environment is much better for others. Charlotte said in a large group her mother normally 'goes quite quiet and won't say too much, she gets into her own little shell' and that 'she can be a bit of an introvert'.

Charlotte's mother Joyce was born in India and spent most of her time there. She does speak English but it is not her first language. She attended the host-home group for about eight weeks, just after the program started.

Other staff at the Banksia centre suggested to Charlotte that her mother attend the new program being established. So she decided to take her mother along.

I thought I'd sit through the first one with her, but we got to lunchtime and she told me to leave! My husband was picking her up, and she said to tell him 'Don't pick me up too early!'

She liked the activities there, she liked playing bingo. In a big group she would get lost. She can't see properly and she can't hear properly. But in the host-home program she would sit down and tell all her life stories. I think it was therapy for her too. It changed Mum so much.

Charlotte said that small groups give quieter people a chance to talk. If things are worrying them, then they have a chance to talk about that too. The care worker who was running the host-home program that Joyce attended had spent most of her childhood in India, so they had plenty to talk about!

Charlotte said that the respite program was useful for her too, in her role as primary carer for her mother:

When she was cared for during the day I could go to school without being worried. It was good to know she was being cared for, and that she would have a really good meal.

Charlotte said that her mother had spent years as a housewife, cooking, washing and cleaning. Joyce was quite at home sitting around a kitchen table, sipping tea and chatting. In Charlotte's words, 'It's the simple things that matter'.

7. Discussion, conclusion and recommendations

Discussion

The host-home program was initiated to provide a greater range of respite options, especially for groups of people who might not be able to use or participate in other respite programs.

The target group was fairly broad, but people participating were generally those who had, or would have had, difficulty in using the Centre-based respite service. They included people with more advanced dementia who found the Centre too confusing and busy, people with hearing problems, those who simply preferred being in a smaller group, people who lived near the host-home but found that the Centre was too far away to travel to regularly.

Meeting the needs of the carers and care-participants

The program appeared to meet the needs of the carers in several ways. It provided another respite option, in terms both of geography and acceptability to care-recipients. The ability of staff to transport care-recipients to and from the program was positive for both carers and care-recipients. Overall, the care-recipients seemed to enjoy the program and their carers were happy with the service.

Two aspects may have helped by making respite a more acceptable option for carers. These were the homely feel of the program which several carers contrasted with the more formal atmosphere of an institutional setting, and the fact that their relatives obviously enjoyed going, so carers may have felt more comfortable in using a respite service at all.

Care-recipients appeared to enjoy the program immensely, and cited the caring staff, the social contact and friendships, and the activities as things they enjoyed most. Staff also believed the smaller group enabled people to form closer relationships than in the centre. The greater emotional connection is reflected in the fact that due to their level of dementia care-recipients participating in the program might not be able to remember activities of the previous week, but they would often notice if someone who had been there previously did not make it the next time.

Staff also felt that they were able to pay greater attention to care-recipients than they could in the Centre-based program and could also develop activities which were more relevant to participants requests and needs. The host-home program represents an approach that is able to respond better to individual needs, and potentially to monitor and respond to changes in a person's health or behaviour.

Conclusion

A feature of the Banksia program was the emphasis placed on meeting care-recipients' needs and ensuring that the respite experience was positive and enjoyable. This occurred through carefully tailored activities, promoting socialisation, and greater attention from staff than would be possible in Centre-based services designed for a more diverse client group. This type of program provides extra, flexible respite, and is useful for a range of care-recipients for whom current community respite options are unsuitable.

Specific groups

The host-homes model seems to have great potential for providing a community respite option not only for individuals with particular needs, but also for some groups who are poorly served by the current system. Although not addressed in the Banksia model as implemented, it may be

particularly suitable for people of non-English-speaking background and for Aboriginal groups because it may allow more culturally sensitive options such as care-workers from the same background, appropriate activities and culturally specific food. It is easier to provide this type of program on a small scale rather than in a respite centre because ethnic and Aboriginal communities are often geographically spread and consequently populations in specific areas are too small to sustain entire centres.

However, such models would need support from a larger organisation, perhaps an existing respite service, for staff support and training, financial management, central monitoring and accountability. There is also the potential for partnership between ethno-specific or Aboriginal agencies and respite services.

Needs of staff are an important consideration. This is in terms not only of the potential for cost-shifting as detailed below, but also of the level of imposition—for example, the number of times per week the service could be provided in their home without disrupting their home life.

Because the service takes place in a worker's home, there are also several issues involved in monitoring the workers' performance and ensuring quality. As with its in-home respite program, Banksia took care to employ experienced staff whom management could trust to run the program in their own homes.

This type of program should probably be run by an agency that has the capacity to provide staff and or volunteers flexibly from week to week depending on how many are in the group. Staff need to be experienced in providing care to the elderly as well having as dementia-specific experience and they also need an awareness of associated problems such as incontinence.

Potential for cost shifting

The Banksia program made a point of assessing costs incurred by care-workers — both initial capital costs and recurrent program costs — and made an effort ensure these were covered by the program.

There is however, considerable potential in this model for cost shifting, both in terms of direct costs borne by worker, and the amount of time spent by staff. It is important that all recurrent costs are met — for example, heating, electricity, cleaning, petrol, house and car maintenance costs. For some activities such as cleaning, cooking and shopping, however, it is difficult to disentangle work responsibilities from private roles and therefore problematic for assessing reimbursement.

Entry point to respite and residential care

The host-home model may allow carers to feel more comfortable in using respite services because it avoids an institutional 'feel' and includes a strong focus on the particular needs of care-recipients.

The recent review of reforms in aged care (Gray 2001) suggested that residential respite options were being under-utilised because of organisational tensions between long-term residential care and overnight respite care. It was suggested that carer respite centres such as the Banksia Centre have a greater role (as Banksia does already) and that 'the ease with which people can access respite care is relatively more important than allocation or utilisation' (Gray 2001, p.3). The host-home program may allow this to happen by acting as a transition point between living at home, different forms of respite, and residential care.

Desirable staff to care-recipient ratio

For the host-home respite model to be effective, the number of care-recipients attending each host-home program needs to be sufficient for social interaction and group activities. If programs only have three or four 'registered' care-recipients, and expect that often one or more will be missing due to ill-health or other factors, then numbers may drop to ineffective levels (i.e., only one or two care-recipients present). On the other hand, with a core group of five or six, if a couple are away then the group is still sustainable, but if all attend then there really needs to be another staff member present for care-recipient safety. This is an awkward dilemma if host-homes operate in isolation. However, an organisation which runs centre respite and therefore has access to a number of staff is better placed to offer some flexibility, by assigning to larger groups a second staff member who can undertake other duties at the main centre when host-home attendance is small.

Recommendations

A number of principles emerge from this evaluation, for the wider implementation of the host-home model of respite care.

1. Costs of the host-home program should be fully funded, including:
 - Insurance
 - Minor capital works (such as ramps, hand rails)
 - Recurrent maintenance
 - Food
 - Cleaning
 - Contribution to electricity, gas and water costs
 - Renewable supplies such as protective gloves, incontinence pads, materials for activities
2. The host-home model should be run by or in conjunction with an established respite service.
3. Staff need to be experienced in working with people with dementia.
4. Staff should be consulted concerning the number of times per week the service could be provided in their home, without disrupting their home life.
5. Since no guidelines currently exist, the federal government needs to establish guidelines and standards appropriate to host-home programs, to avoid potential problems such as inadequate supervision or exploitation of staff, and to promote quality care.
6. It would be useful to fund a larger group of trials, especially of programs targeting people of non-English-speaking backgrounds and Indigenous groups.

8. References

Alzheimer's Association Australia, [Electronic]. Available at <http://www.alzheimers.org.au> [Accessed October 2001]

Alzheimer's Association WA, 'Respite' [Electronic]. Available at http://www.alzheimers.asn.au/alzheimers.nsf/LinkDocuments/Frame_Home_IE [Accessed 23 October 2001]

Askham, J & Thompson, C 1994, *Dementia and home care: A research report on a home support scheme for dementia sufferers*, Age Concern Institute of Gerontology Research Paper No.4, Age Concern England, Surrey.

Australian Bureau of Statistics (ABS) 2000, *Population projections Australia 1999-2051*, Cat. no. 3222.0, ABS, Canberra.

Australian Bureau of Statistics 1998, *Disability, ageing and carers: Summary of findings*, Cat. no. 4330.0, Reissue, page 44, table 29 ABS, Canberra.

Bishop, B 2000, Department of Health and Aged Care, *Media Release* '\$13.4m for services for carers of people with dementia in Victoria', 24 May 2000, [Electronic]. Available at <http://www.health.gov.au/mediarel/yr2000/bb/bb20049.htm> [Accessed 25 October 2001]

Clarke, R & Finucane, P 1995, 'Care-receivers' and care-givers' experience and perceptions of respite care: implications for service provision', *Australian Journal on Ageing*, vol.13, no.4, November 1995, pp. 183-187.

Clay, C; Hedley, L & Pieloor, J 1999 *Host family respite*, Alzheimer's Association WA, Shenton Park.

D'Mello, A & Bugueno, R 1989 *Ethnic response to family day care: A report on the study of usage/non-usage of family day care by immigrants and refugees from Non-English speaking backgrounds*, Victorian Co-operative on Children's Services for Ethnic Groups (VICSEG), Melbourne.

Department of Family and Community Services (DFaCS) Commonwealth Child Care Program 2000, *Family Day Care Handbook July 2000, Appendix F National Standards*, DFaCS, [Electronic]. Available at http://www.facs.gov.au/internet/facsinternet.nsf/childcare/handbooks-handbook_fdc.htm. [Accessed 25 October 2001]

Department of Health and Aged Care 2001, *Staying at home: Care and support for older Australians*, Consumer publication, [Electronic]. Available at <http://www.health.gov.au/hfs/acc/publicat/brochures/stayhome.htm> [Accessed 25 October 2001]

Department of Health and Aged Care 2000, *Guidelines to the HACC MDS Version 1.5 June 2001: A companion to the HACC Data Dictionary v 1.0 May 1998* [Electronic]. Available at <http://www.health.gov.au/acc/hacc/download/guide2001v15.pdf> [Accessed 9 November 2001]

Department of Health and Family Services 1996a, *The Respite Review Report*, Australian Government Publishing Service, Canberra.

Department of Health and Family Services 1996b, *Review of respite care services provided in the community*, Respite Review Supporting Paper no.2, Australian Government Publishing Service, Canberra.

Department of Human Services 2000, *Dementia-Care and Support in Victoria 2000 and Beyond*, Department of Human Services, Melbourne.

Dixon, D 1990 *Family day care strategy*, Municipal Association of Victoria, Melbourne.

Family Day Care Victoria Inc, homepage [Electronic]. Available at <http://www.familydaycare.org.au> [Accessed 25 October 2001]

Gray, L 2001 *Two year review of aged care reforms*, Department of Health and Aged Care, Canberra.

Quagliana, J (c.1990, unpublished) *Family day care: More than twenty years on*, Brotherhood of St Laurence, Fitzroy.

Reynolds, A et al 1993, *Community care for people with dementia: An evaluation*, Department of Health, Housing and Local Government & Community Services, Canberra.

Rossiter, C 1993, *Community care for people with dementia and their carers: Issues and policy paper*, Alzheimer's Association Australia, North Ryde.

Sandlant, V 1994, 'Creative respite', *Australian Journal on Ageing*, vol.13, no.1, February 1994, pp. 44-45.