

Public sector

Literature review



PSSRU

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The effectiveness and cost-effectiveness of support and services to informal carers of older people

A review of the literature prepared for the Audit Commission

by

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Introduction

This literature review of the effectiveness and cost-effectiveness of support and services to carers of older people is one of three literature reviews that were commissioned by the Audit Commission as part of its study of support for carers of older people in England. It was carried out in 2003 by Linda Pickard, Research Fellow at the Personal Social Services Research Unit at the London School of Economics.

Linda Pickard also carried out a second literature review which covered carers of older people and employment. This is produced as a separate publication.

Professor Caroline Glendinning of the National Primary Care Research and Development Centre at the University of Manchester carried out a third literature review which covered some intranational and international comparisons of support for older people.

The views expressed in these literature reviews are the authors. All three of them can be accessed at www.audit-commission.gov.uk/olderpeople. The review of the effectiveness and cost-effectiveness of support and services to carers of older people and the review of carers of older people and employment are also available as bound publications from the Audit Commission.

The report of the Audit Commission's study of support for carers of older people is one of five supporting reports to the Audit Commission's report *An Ageing Society*. The other supporting reports focus on:

- a changing approach;
- building a strategic approach;
- supporting frail older people; and
- assistive technology.

An Ageing Society, the report on the study of support for carers of older people and the other four supporting reports can all be accessed at www.audit-commission.gov.uk/olderpeople

David Browning
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Preface

This literature review is concerned with the effectiveness and cost-effectiveness of support and services to informal carers of older people in England and Wales. It has been undertaken by the Personal Social Services Research Unit at the request of the Audit Commission (the Commission).

In relation to the effectiveness of services to support carers, the Commission was particularly interested in the effectiveness of services in sustaining carers in their caring role and in delaying admissions of older people into residential and nursing home care. The Commission was also interested in the access of carers to effective services to support them. The researcher was asked to identify materials that addressed issues around what constitutes a service for carers and to interpret this broadly in terms of services aimed at both the carer and at the cared for person. In relation to cost-effectiveness, the Commission particularly asked the researcher to look at evidence from the United States (US) where it was felt that practices might be driven by considerations of cost-effectiveness. The Commission also asked the researcher to examine the hidden costs of unpaid caring, including both public and private expenditure costs. Within the constraints of the available literature, the review attempts to address these issues.

The review is divided into three parts. It begins with an introduction summarising key issues that need to be considered when looking at the effectiveness and cost-effectiveness of services for informal carers. This is followed by an examination of the literature on the effectiveness and cost-effectiveness of the different services that may be used, directly or indirectly, to support informal carers. Finally, the third part provides a summary and some conclusions.

At the outset it is important to define what is meant by informal carers in the present context. In the literature, carers of older people are located more generally within the context of people who provide unpaid care to “family, partners or friends in need of help because they are ill, frail or have a disability” (Carers UK 2002a). Use of the term informal carers here reflects usage in the literature and is not meant to imply that the care provided is of low intensity. Older people are defined as those aged either 60 or 65 and over.

Part 1

Issues in reviewing effectiveness and cost-effectiveness of services for informal carers

Informal care in England and Wales today

Informal care is the most important source of care for most older people living in this country today (Pickard *et al* 2000). It has been estimated that, for Great Britain as a whole, approximately 80 per cent of people aged 65 and over living in private households, who have help with domestic tasks, rely exclusively on unpaid informal help, that is, help from spouses, other household members, relatives outside the household, neighbours and friends (Pickard *et al* 2000).

Informal care of older people is particularly important at the present time because of the rising number of older people (aged 65 and over), especially very old people (aged 85 and over), in the population. There were 1.1 million people aged 85 and over in the United Kingdom in 2001, more than three times as many as in 1961 (ONS 2003a). The rise in the numbers of very old people is particularly important because it is these older people who have the greatest needs for care (Wittenberg *et al* 2001).

Informal carers are not a homogenous group. A distinction has been drawn in the social policy literature between 'informal helping' and 'heavily involved caring' (Parker 1992). It is the heavily involved carer who is most likely to need support. Heavily involved carers are usually defined in terms of long hours of caring (usually over 20 hours a week); sharing a household with the cared-for person (co-residence); or carrying out personal and/or physical tasks. The numbers of heavily involved carers can be estimated using General Household Survey (GHS) data on the provision of informal care. The most recent survey, carried out in 2000, estimated that there was a total of 6.8 million informal carers with around 27 per cent (approximately 1.8 million) spending 20 hours or more a week on caring tasks (Maher and Green 2002).

Approximately three-quarters of all carers are looking after older people. A distinction can be drawn among carers of older people between carers of parents or parents-in-law and spouse carers. Their characteristics and needs are rather different (Parker 1993a). Spouse carers are often elderly and in poor health themselves. Carers of parents and parents-in-law are usually of working age, raising issues to do with the relationship between caring and paid work. The most recent estimates of the numbers of people caring for an older person in Great Britain, using the 2000 GHS data,

suggest that there are over a third of a million spouse carers and nearly half a million children caring for an older parent/parent-in-law for 20 hours a week or more (Pickard 2002, updated using 2000 GHS).

The provision of intensive, informal care to frail older people can have profound consequences for the carer, particularly where the older person has a cognitive impairment. The responsibilities of caring often constrain social participation and necessitate withdrawal from the work force (Parker and Lawton 1994, Evandrou 1995, Joshi 1995). Intensive caring has profound adverse effects on the psychological health of carers, with consistent research evidence showing that carers are more at risk of mental health problems, particularly stress and depression, than other adults of the same age (Bauld *et al* 2000). One of the aims in providing services to carers is to reduce these negative effects of carer stress and burden by supporting carers **(Appendix 1)**.

The policy context of informal care provision

There have been a number of developments in policy relating to informal carers in the last decade or so. These include the community care reforms, associated with the *NHS and Community Care Act 1990*; the *Carers (Recognition and Services) Act 1995*; the *National Strategy for Carers* (1999a); the *Carers and Disabled Children Act 2000*; and the *National Service Frameworks for Mental Health* (Standard Six of which is concerned with *Caring about Carers*) and for *Older People* (DoH 1999b, 2001a). These developments are important in the present context because they shape the provision of services to carers and older people today.

The community care reforms of the early 1990s, which were preceded by the White Paper *Caring for People* (Secretaries of State 1989), broke new ground in policy terms by moving carers from a position in which they were virtually ignored in health and social care policy, to one where they were almost centre-stage (Baldwin and Parker 1989). A key objective set by the White Paper for service delivery was that “service providers make practical support for carers a high priority” (Secretaries of State 1989: 1.11).

The community care reforms introduced a number of changes to the structure of service provision to older people that have affected informal carers. First, a central aim of the reforms was to shift services away from institutional towards community services (Wistow *et al* 1996: 161). This emphasis on community care brought a new recognition to the care given by family members. Indeed, as one analyst has put it, “Carers have become recognised as one of the building blocks of community care” (Twigg 1998: 133). Second, the reforms introduced case management, termed under the legislation care management, one of the aims of which was to improve the targeting of community care so that services were more focused on the most disabled

people in the community (Wistow *et al* 1996: 161). Importantly, in the present context, the introduction of case management was also intended to improve the effectiveness of community care services (Davies *et al* 2000).

Subsequently, the *Carers (Recognition and Services) Act (1995)* and the *Carers and Disabled Children Act (2000)* respectively established, and then strengthened, carers' rights to an assessment of their own ability to provide care (Arksey *et al* 2002). The *Carers (Recognition and Services) Act (1995)* was important because it was "the first piece of legislation to recognize fully the role of carers within community care law" (Tinker *et al* 1999). The Act afforded carers, providing (or intending to provide) substantial care on a regular basis, the right to an assessment of their needs separate from that of the person they were supporting. The Act, however, conferred no duties on local authorities to provide services to carers following an assessment of their needs. This deficiency was addressed in the *Carers and Disabled Children Act (2000)* which enables local authorities to supply services direct to carers. The Act enables carers to ask for an assessment and receive services, even if the older or disabled person they support refuses to be assessed. These services can be delivered directly to the carer or to the older or disabled person. The only exception to this latter part of the arrangements is that 'intimate' services cannot, except in exceptional circumstances, be delivered to the older or disabled person without him or her having received a personal assessment of need (Parker and Clarke 2002).

The approach of the national strategy for carers, *Caring about Carers*, consists of three elements: information, support and care (DoH 1999a). The most important of these in the strategy is "care for carers". The emphasis is on the provision of short-term breaks from caring. The strategy announced a new Carers Special Grant, providing ring-fenced funding of £140 million for England over a three-year period to enable carers to take short-term breaks from caring (DoH 1999a: 6-7). The grant has since been renewed on a regular basis and has recently been extended to 2006, with funding increased to £185 million.

It has been argued elsewhere by the present author that the developments in policy relating to informal carers over the past decade or so embody a particular approach to carers (Pickard 2001). Drawing on Twigg's four-fold classification of carers in the service system (Twigg 1992), it is argued that current policies for carers are essentially concerned with ensuring the continuation of caring and with sustaining the well-being of carers (Pickard 2001). Current policies therefore combine an instrumental concern with ensuring that care-giving continues to be provided and a concern with the interests of the carer *per se*. This means that, to the extent that the research reviewed here reflects the approach adopted in current policies, it is likely to stress the importance, not just of enabling the carer to continue caring, but also of enhancing the sense of well-being of the carer.

The ‘disability rights’ perspective

The increasing public recognition of carers in policy over the last decade or so has not been uncontested. One source of challenge has been the disability rights perspective (Morris 1992) whose arguments have had an extensive impact on the academic and research communities (Oliver 1990, Morris 1991, Wood 1991, Keith 1992, Morris 1992, Campbell and Oliver 1996, Morris 1997).

The disability rights perspective has developed “a substantial critique of community care policy and the ways in which carers are relied on to deliver that policy” (Parker and Clarke 2002: 350). Those writing from a disability rights perspective have argued that policy should not endorse dependence through an emphasis on supporting carers but should underwrite the independence of the disabled and older people they care for. The emphasis on the needs of carers, in this view, diverts attention and resources from the real issue: the support of disabled and older people (Morris 1991, Keith 1992, Morris 1993, Morris 1997). The disability rights perspective has mainly been put forward by younger, physically disabled people, but it has been seen as relevant to older people as well (Morris 1997).

Recently, there has been criticism of the national strategy for carers from the disability rights perspective (Lloyd 2000, Parker and Clarke 2002). Lloyd (2000), for example, has argued that “there is little evidence in the strategy of the perspectives of people who are cared for and in this respect it can be seen as divisive. Indeed it runs the risk of putting the interests of carers above those of the people who are on the receiving end of care” (Lloyd 2000 148-9).

The ‘dual focus of caring’

The emphasis on specific services for carers in recent government policy does not reflect the approach adopted in the academic social policy literature more widely. Within social policy more generally, there is recognition of what has been described as the *dual focus of caring* (Twigg 1996). Ideas around the dual focus of caring have been particularly well expressed by Julia Twigg (1992, 1996, 1998). However, they are also found more widely in the social policy literature (for example, Parker 1993b, Baldwin 1995, Parker and Clarke 2002).

An emphasis on the dual focus of caring has a number of important implications. First, in research terms, it means that a focus on caring needs to be matched by a focus on the cared-for person. It is regarded as good practice in research on informal care to explore the effects of interventions not just on the carer but on the cared-for person. In the US, the carer and cared-for person are often referred to as a ‘dyad’ and this language is also found in research in Britain (for example, Davies *et al* 2000). The importance of the carer/cared-for dyad is explained as follows by a senior US researcher and colleague, specialising in research on caregivers of people with dementia:

“...we believe that it is critical that interventions evaluate the anticipated outcomes for both the caregiver and the person with Alzheimer’s disease. While most programs are targeted for one member of the dyad, both are impacted. Failure to examine the possible ramifications of the program on both members of the dyad and, indeed, on the larger social context, can lead to unanticipated outcomes as well as impeding the realization of benefits.”

(Zarit and Leitsch 2001 S84)

One implication of this for the present review is that it is important to examine the effectiveness of support and services not just for carers, but also the effects on the older person who is being cared for.

Second, the dual focus of caring also has importance in policy terms. As Twigg said, “the fact that caring takes place in a relationship imposes on policy an inescapable duality of focus” (Twigg 1996: 85). This duality of focus is important for two main reasons. First, although carers and the people they care for often have the same interests, their interests can also diverge. This is particularly clear in relation to services. Respite, for example, is often urgently needed by the carer, but the cared-for person may not wish to go into respite or be regarded as a burden from whom relief is needed (Twigg 1996). Second, the tensions around the dual focus have implications for the issue of who is properly to be considered the subject of welfare intervention, the disabled/older person or the carer (Twigg 1996). This in turn affects the definition of services for carers.

The definition of services for carers

In the context of the dual focus of caring, it has been suggested that there are two main forms of service for carers (Twigg, 1992). First, there are *specific carer services*. These are services that are unambiguously provided to carers, such as carer support groups and breaks from caring. Second, there are *carer allocations*. Carers also receive help from services aimed primarily at the person they look after. Sometimes the allocation is explicit, as for example, when a daycare place is provided for the cared-for person with the intention of relieving the carer. Sometimes it happens less overtly, as a by-product of assistance to the cared-for person (Twigg 1992: 60-61).

In social policy, it is generally accepted that what counts as a service for carers needs to be envisaged widely. Twigg for example has argued that,

“...the majority of help that comes to them [carers] does so from services aimed primarily at the person they look after. Because of the close interrelationship between the carer and cared-for person, there is a sense in which all help to the cared-for person is relevant to the carer also.”

(Twigg 1992: 60)

Most research studies looking at services and support for carers use a wide definition of services for carers, looking at services aimed not just at the carer but also at the cared-for person. For example, the recent review of the research literature, *Services to Support Carers of People with Mental Health Problems* (Arksey *et al* 2002) included both breaks from caring and domiciliary care services, as well as a large number of other types of intervention. The study of the community care reforms by Davies and Fernandez (2000), in its evaluation of the impact of the reforms on informal carers, looked at the effects of, among other services, home care, home-delivered meals, daycare, respite care and social work.

The implication for the present review is that it is important to take a wide definition of services for carers, and include both specific services for carers and services aimed primarily at the older person.

Services for carers or for the cared-for person?

Partly in response to the disability rights critique, there is an increasing body of opinion within the social policy literature in Britain supporting the view that the *primary* focus of policy should be on support for the disabled or older person. A widely-held academic view is that “while family care is an important resource that should be nurtured, the primary goal of policy must be to secure the dignity and quality of life of older citizens, and to ensure that they receive the support they need in the place, and manner, they prefer” (Baldwin 1995: 138). Support to the older person is seen as a way of relieving the burden on the carer, as well as being significant in its own right. Baldwin observes that this type of view has been expressed widely, citing Sinclair *et al.* (1990), Arber and Ginn (1991), Baldwin and Twigg (1991) and Baldwin (1994).

Indeed, it has been argued in the social policy literature that the most effective way of supporting carers is to provide support and services to the older or disabled person who is being cared-for (Parker 1999, Parker and Clarke 2002). Parker, for example, has argued that:

“As all the research literature shows the thing that makes the most difference to carers is the services and support that are provided to the person they care for.”

(Parker 1999: 61)

Recently, Parker and a colleague have reiterated this view, arguing that it is “core services which, all the evidence shows, support carers best”, specifying core services as “those which, generally speaking, go to disabled or older people themselves – personal care services, domestic services...and so on” (Parker and Clarke 2002: 349). In Parker’s view, good quality core services, along with other measures aimed at older

and disabled people, reduce the need for anyone to provide informal care, although it is also recognised that there is a need for recognition of unpaid carers and support for them, as well as for the person they help (Parker and Clarke 2002).

The emphasis on supporting informal carers by providing services to older people was endorsed by the Royal Commission on Long Term Care (1999). The Royal Commission recommended that “Better services should be offered to those people who currently have a carer” (Royal Commission on Long Term Care 1999: xxi). Specifically, the Royal Commission recommended that the Government should “ensure that services become increasingly “*carer blind*”...”, meaning that “the existence of a carer will not lead to the failure to offer services” (90). In the approach adopted by the Royal Commission, the focus of intervention is not the carer but the cared-for person (Pickard 2001). The Chairman of the Royal Commission, in his introduction to the report, summarised the approach as one in which there is “support for carers by the provision of better services to those they care for” (Royal Commission on Long Term Care 1999: xiii). The report itself focuses on the neglect of services for “older people being cared for by informal carers” and on the need for “extra services to individuals who were being looked after by a carer” (90).

The approach advocated by the Royal Commission and, more widely, in academic social policy is clearly different from that adopted in current government policies (Pickard 2001). The national strategy, for example, emphasises that “helping carers is one of the best ways of helping the people they care for” (DoH 1999: 12). In contrast, critics of government policies argue that the best way to support carers is by helping the people they care for. These different approaches imply different views on the effectiveness of different types of services and raises questions for the literature review. What are the implications of different methods of supporting carers for the older people they care for? Are services provided to the older person more effective than specific carer services? Is there any evidence of improvements in access to services for carers, whether directed at themselves or at the person they care for, as a result of policy developments over the past decade or so?

Cost-effectiveness

The current review is concerned not just with the effectiveness of services to support carers of older people but also with their cost-effectiveness.

The current review has been fortunate in being able to draw upon a recent literature review of the effectiveness and cost-effectiveness of services to support carers of people with mental health problems, carried out by researchers at the Social Policy Research Unit (SPRU) (Arksey *et al* 2002).¹ This report defines cost-effectiveness in the following way:

¹ Building on this review, Arksey and colleagues have recently produced a new study, entitled ‘*Review of Respite Services and Short-Term Breaks for Carers of People with Dementia*’ (Arksey *et al* 2003a), and two separate reports on access to health care for carers (Arksey 2003, Arksey *et al* 2003b). These reports are currently in the process of being finalised.

“In many ways, the term ‘cost-effectiveness’ is self-explanatory. It involves the identification and measurement of inputs (costs) and outputs (outcomes) and their synthesis. Cost-effectiveness may be expressed as a ratio, such as the cost per unit of outcome. For example, we may estimate the costs of providing a counselling service for carers of patients with Alzheimer’s Disease and measure the effectiveness of that intervention in terms of the reduction of carer burden or improvement in carer’s mental health. By linking the cost with the effectiveness, we have a summary index of cost-effectiveness, such as the cost of reducing carer burden by one point on a particular scale.”

(Arksey et al 2002: 80)

As Arksey *et al* go on to point out, to determine cost-effectiveness, the costs and outcomes associated with an alternative or comparator intervention must be made. The question is whether the intervention under investigation can either yield a better outcome than the comparator at the same cost or an equivalent outcome at lower cost.

The interest in cost-effectiveness arises in part from the desire to achieve better outcomes through the use of limited resources. As the respected US researcher, S H Zarit and a colleague have recently argued:

“The possibility of cost savings has been a frequent interest in community long-term care studies, where the cost of providing one type of service (e.g. respite) may be offset by savings in another area (e.g. delayed institutionalization).”

(Zarit and Leitsch 2001: S94)

Reducing or delaying institutionalisation is often identified as a major source of potential savings and a key question addressed in many studies with a cost component is whether the intervention does in fact reduce or delay admission to institutional care.

A key issue in whether there are cost savings associated with a particular intervention to support carers is the perspective that is adopted. As Arksey *et al* have argued,

“Alternative patterns of care may change the way costs are distributed across patients and carers, health and social services and other agencies, such as charities. Consequently it is appropriate to assume a societal perspective when analysing costs of interventions for carers...Failure to do so may lead to unintended and undesirable cost-shifting, with adverse affects upon patient outcomes.”

(Arksey et al 2002: 81)

As Arksey *et al* go on to point out, the viewpoint that is chosen for an economic evaluation may determine the results of the analysis. If carer time, for example, is not evaluated, then an intervention that maintains the carer in a principal role may look more cost-effective than one in which carer time is given a market value (Arksey *et al* 2002).

An important factor in estimating the costs of interventions to support carers is the treatment of the hidden costs of unpaid caring (**Appendix 2**). These hidden costs relate to both public expenditure and private or individual expenditure. Hidden public expenditure costs of caring include, for example, costs to the NHS incurred by carers; costs to the Department for Work and Pensions (DWP) arising from increased social security benefits and pensions paid to carers; and lost income to the Inland Revenue arising from the lower employment rates of carers. Hidden individual costs of caring include the opportunity costs of caring, that is, the alternatives forgone by the carer as a result of taking on a caring role, such as employment opportunities and leisure (Arksey *et al* 2002). In addition, carers can also incur direct costs of caring and costs arising from the caregiving role (Glendinning 1992).

A key question in looking at the literature on the cost-effectiveness of interventions to support carers is whether or not these hidden costs of caring are taken into account.

Summary of definitions/questions relating to effectiveness and cost-effectiveness of services to support carers

Drawing on the discussion above, the literature review will use the following definitions and focus on the following questions.

Definition of services

A wide definition of services to support informal carers will be used, including both specific carer services (such as breaks from caring, carer support groups and social work/counselling for carers) and services primarily aimed at the older person (such as the home help/care service). The focus will be on mainstream services, that is, on services that are likely to be found in all or most localities, although some reference will also be made to innovative schemes¹. A full list of the services included in the review is given in Box A below.

¹ The review focuses on mainstream services partly because of the difficulties of transferring innovative schemes into mainstream practice. A review of innovative schemes was carried out by Leat (1992). More recently, the reviews by Arksey *et al* (2002, 2003a) also cover innovative schemes. The latest review by Arksey *et al* includes reference to innovative use of the Carers Special Grant in England (Arksey 2003a).

Box A

Services included in the review

- Breaks from caring or respite care
 - Mixed respite care services
 - Daycare services
 - In-home respite care
 - Institutional respite care;
- Carer support groups;
- Social work and counselling;
- The home help/care services; and
- Multi-dimensional approaches.

Key Questions

Within the time and resource constraints, the literature review aims to address the following key questions:

Effectiveness

- Which services/forms of support to informal carers of older people have positive outcomes for carers?
- Under what conditions do different forms of services and support for carers have positive outcomes for carers?
- What are the implications of different methods of supporting carers for the older people they care for?
- Are services provided to the older person more effective than specific carer services?

Cost-effectiveness

- Which services/forms of support to carers of older people are cost-effective or result in cost savings?
- Under what conditions are different forms of services and support for carers cost-effective or result in cost savings?

Access

- To what extent do informal carers of older people have access to effective forms of services and support?

- Is there any evidence of improvements in access to services for carers, whether directed at themselves or the person they care for, as a result of policy developments over the past decade or so?

Definition of outcome measures

Outcome measures for carers include measures of carer burden and carer well-being, as well as more general measures of carers' physical and emotional health (**Appendix 1**). Outcomes for the older person include, for example, measures of the older person's physical and emotional health and satisfaction with services, as well as rates of admission to institutional care or hospital and other service utilisation rates.

Definition of effectiveness

A service or form of support for informal carers of older people is effective if it yields positive outcomes for carers. Positive outcomes for carers potentially include:

- **reducing carer burden;**
- reducing carers' mortality;
- reducing carers' unmet needs for support;
- **increasing carers' physical or emotional health;**
- increasing carer well-being;
- increasing carers' social interaction;
- increasing carers' satisfaction with services; and
- increasing carers' employment

Most of the literature included here refers to the highlighted outcomes. From the perspective of the older person, a service or form of support is effective if it yields positive outcomes for the older person. Positive outcomes include: increasing physical or emotional health; increasing satisfaction with services received; reducing rates of admission to institutional care or hospital; and reducing the older person's mortality.

Definition of cost-effectiveness

An intervention is cost-effective if it yields either a better outcome than a comparator at the same cost, or an equivalent outcome at a lower cost. Improved use of resources may occur when the costs of providing one type of service (for example, respite) are offset by savings in another area (for example, delayed institutionalisation). The concept of cost-effectiveness needs to be examined in the light of the 'hidden' public expenditure costs of unpaid caring (for example, costs to the NHS, lost taxation, increased benefits) and the hidden costs of caring for private individuals.

Scope/countries to be included

The study will focus on relatively recent (post-community care reform) literature relating to England and Wales, and will also include some international literature, particularly from the US.

Part 2

Review of individual services and their effects

Introduction

This part of the review focuses on the effectiveness and cost-effectiveness of individual services that may, directly or indirectly, support informal carers. For each service there is a description of the service in England and Wales, followed by an evaluation of the national and international literature relating to the effectiveness and cost-effectiveness of the service. Subject to the availability of literature, services are evaluated according to a number of criteria: outcomes for carers, including the conditions associated with positive outcomes for carers; effects on older people's admission to institutional care; other effects on the person being cared for; cost-effectiveness/cost savings associated with the service; and access to the service by carers in England and Wales. *At the end of the section on each service, there is a succinct summary of key points.*

Approach to the literature review

In looking at the effectiveness of services, it needs to be borne in mind that this is likely to be contextual. The recent community care reforms in the UK, associated with the *NHS and Community Care Act 1990*, aimed to change the effectiveness of services, primarily through the introduction of targeting and care management. To the extent that they have been successful, the effectiveness of services may have increased in the last decade. Studies relating to the period before 1993, when the community care legislation was fully implemented, may show less effectiveness than studies relating to the period after 1993. Therefore the timing of studies carried out in the UK is important.

The review has tried to focus in particular on recent studies of the effectiveness of services in the UK, in order to reflect current community care policies. The review has drawn on the programme of research commissioned by the Department of Health which was designed to monitor the effects of the community care reforms. The programme included studies of care management (Challis *et al* 2001, Weiner *et al* 2002), community care for older people with dementia (Moriarty and Webb 2000), the experiences of social work practitioners and managers (Levin and Webb 1997) and an evaluation of community care for elderly people (ECCEP) (Bauld *et al* 2000, Davies and Fernandez 2000). In terms of evaluating the effectiveness of services under current community care arrangements, the most relevant study is the ECCEP study. The ECCEP study has produced two volumes, *Equity and Efficiency Policy in Community Care* (Davies and Fernandez 2000) and *Caring for Older People* (Bauld *et al* 2000). Both volumes have been useful in the present review but, given its subject matter, the volume by Davies and Fernandez has been particularly valuable.

In addition to the ECCEP study of equity and efficiency, three other key studies are drawn upon extensively in this literature review. Two of these were studies carried out by the (then) National Institute for Social Work (NISW), *Families, Services and Confusion in Old Age* (Levin *et al* 1989) and *Better for the Break* (Levin *et al* 1994), both of which relate to the period before the community care reforms were introduced. The third study is the companion to the ECCEP study, the Domiciliary Care Project (DCP), whose results were published in *Resources, Needs and Outcomes in Community-Based Care* (Davies *et al* 1990) and which also pre-dates the community care reforms. The literature review draws on these three studies, together with *Equity and Efficiency Policy in Community Care*, for information on the effectiveness of a number of different services in England and Wales. Some key features of these four studies are summarised in Box B at the end of this section.

The review has also drawn on a number of existing literature reviews relating to England and Wales, including the reviews carried out by Twigg (1992), Pickard (1999) and Arksey *et al* (2002). In addition, key journals have been searched for recent, relevant articles, including *Ageing and Society*, *British Journal of Social Work*, *Health & Social Care in the Community* and *Social Policy and Administration*.

The review primarily refers to England and Wales. However, it has also drawn on relevant research from the US. A key US journal, *The Gerontologist*, and a key international journal, *The International Journal of Geriatric Psychiatry*, were searched for recent relevant articles on the effectiveness and cost-effectiveness of interventions to support informal carers.

Methodology: approach to the literature review

The review has adopted a focused, rather than a systematic, approach to the selection of literature. The resources available did not allow for a fully comprehensive, systematic literature review to be undertaken. The approach adopted was, therefore, to build on the work of others, through using existing literature reviews, especially the recent review by Arksey and colleagues (Arksey *et al* 2002). To ensure that the present review was up-to-date, recent issues of key journals (as indicated above) were trawled for relevant material, key websites were searched and other researchers in the field contacted. Bibliographies of studies were checked to identify relevant material. Material was selected for inclusion in the literature review primarily on the basis of its relevance to the subject matter. The quality of the material was primarily screened through using material that had either been produced by authors working in established research centres or that had appeared in peer-reviewed journals. Any issues around the quality of the material cited here, for example small sample sizes, are discussed in the review itself.

Box B

Key studies relating to services for carers of older people in England and Wales

Families, Services and Confusion in Old Age (Levin *et al* 1989)

The study aimed to identify the specific problems faced by the families of older people with dementia and to explore the effectiveness of services in alleviating them. It was carried out in three geographical areas in England and had a sample of 150 elderly persons and their supporters. Follow-up interviews were conducted with 137 supporters about one year after their initial interviews. Outcome measures for carers included the General Health Questionnaire (GHQ) and the Social Behavioural Assessment Schedule (SBAS).

Better for the Break (Levin *et al* 1994)

The study was concerned with the characteristics and problems of confused elderly people and their carers using different respite services. A key aim was to examine the effectiveness of different types of and mixes of respite services in terms of their acceptability, their impact on the carers' psychological health, their impact on the elderly people and their effects upon the admission of the elderly people to permanent residential care. The study was carried out in three geographical areas in England with a sample of 287 carers between 1989 and 1991. Follow-up interviews were conducted with 243 carers about one year after their initial interviews. Outcome measures for carers included the General Health Questionnaire (GHQ) and the SELFCARE (D).

Resources, Needs and Outcomes in Community-Based Care. A Comparative Study of the Production of Welfare for Elderly People in Ten Local Authorities in England and Wales (Davies *et al* 1990)

The study was concerned with how resources used in community social services affect the well-being of elderly consumers and their informal carers. It estimated the relations between inputs and outputs and explained variations, using the production of welfare approach. The study, which was entitled the Domiciliary Care Project (DCP), was undertaken in 1984/85 in ten local authorities in England and Wales, with a sample of 589 consumers of community services. Follow-up interviews were conducted with 443 consumers about six months after their initial interviews, and with 210 principal carers.

Equity and Efficiency Policy in Community Care Needs, Service Productivities, Efficiencies and their Implications (Davies and Fernandez 2000)

The study was concerned with the effects of the community care reforms on productivity of services for outputs. It was entitled *Evaluating Community Care for Elderly People* (ECCEP). The study was undertaken in 1994/95 in ten local authorities in England and Wales, with a sample of 419 users of community services, their 238 principal informal caregivers and 425 care managers. Follow-up interviews were conducted with 299 users surviving in the community, their 186 principal informal caregivers and 418 care managers six months after the first interviews. The study focused on the general population of frail older people using community services, rather than any particular subgroup. One set of outcomes examined in the study related to the subjective burden experienced by carers, measured by the Kosberg Carer Burden Scale.

Breaks from caring or respite care

Introduction

There are three main forms of breaks from caring that are considered in the literature: daycare services, in-home respite and institutional respite (Arksey *et al* 2002). Although many studies explore the impact of each of these separately, or are concerned with only one type of respite, there are a number of important studies evaluating large-scale respite demonstration programmes in the US that have included mixed respite care services. These studies do not analyse the effects of the use of different types of respite service separately. It is, however, useful to start with these studies because they provide a context for the more detailed consideration of each type of service that follows later in this section.

Before doing so, it is important to mention briefly the issue of the language of ‘respite’ or ‘breaks from caring’. The US literature tends to refer to respite care. In the UK, however, the national carers’ strategy preferred the term ‘breaks from caring’. As the booklet accompanying the strategy, *A Real Break*, explained, this was on the grounds that that many people feel that respite is “too negative a term” (Weightman 1999: 5). In this review, to reflect the literature, both the terms respite and breaks from caring will be used.

Mixed respite care services: evidence from the USA

Respite demonstration Programmes in the USA

There have been at least three evaluations of large-scale respite demonstration programmes in different states in the USA that were concerned with carers of older people with Alzheimer’s disease and related conditions (Arksey *et al* 2002). The largest study was of the Philadelphia Respite Demonstration Program, in which some 632 carers of older people with Alzheimer’s disease, distributed between a treatment group and a control group, took part (Lawton *et al* 1989). The other two studies were on a slightly smaller scale. The evaluation of the respite programme established in the state of Maryland for carers of people with Alzheimer’s disease had a sample size of 228, comprising carers who were ‘users’, ‘stoppers’ and ‘non-users’ (Cox 1997).¹ The evaluation of the Michigan Model Projects Specialised Respite Care Programme had a sample size of 114 carers of older people with Alzheimer’s disease (Kosloski and Montgomery 1993a, 1993b). Generally speaking, these programmes offered one or more of the following three forms of respite: adult daycare, in-home respite care and/or short-stay institutional respite in a nursing or residential home.

In addition, there has been a large-scale study of the effects of different support programmes on families caring for impaired older people in Seattle (Montgomery and Borgatta 1989, Kosloski and Montgomery 1995). The study involved 541 family units

¹ Cox distinguished between ‘users’ (carers who used respite services), ‘stoppers’ (carers who initially used respite services but subsequently stopped doing so) and non-users (carers who did not use available respite services). The research focused in particular on understanding the under-utilisation of respite care (discussed in ‘Access to mixed respite care’).

of impaired older persons and caregivers, randomly assigned to one of five treatment programs or a control group. The study looked at educational services as well as all three forms of respite care.

Effectiveness of mixed respite care: outcomes for carers

Taken together, these studies have produced apparently contradictory results with respect to the impact of respite care on the psychological health of carers. The largest study found no impact of respite on carers' psychological health (Lawton *et al* 1989), whereas the other studies found that respite care improved carers' psychological health, by reducing carers' subjective burden, negative appraisals and depression, for example (Montgomery and Borgatta 1989, Kosloski and Montgomery 1993a, Cox 1997).

In seeking an explanation for these variations, it has been argued that a key factor has been the intensity of respite care provided (Zarit and Leitsch 2001). Looking at the studies of the impact of respite on carers of older people with dementia, it has been suggested that, where these identified improvements in carers' mental health, carers utilised greater amounts of respite care over longer periods of time, thus ensuring that they received a 'significant' dose of care (Gaugler *et al* 2002: 56). On the other hand, the same authors also point out that it has tended to be the smaller studies that have identified improvements in the psychological health of carers looking after older people with dementia. Many of these studies have been characterised by relatively small sample sizes and designs prone to attrition and selection bias, so that their conclusions may be less robust (Gaugler *et al* 2002: 56).

Although the largest study, the Philadelphia Respite Demonstration Program, found no impact of respite on carers' psychological health, it did find very high levels of carer satisfaction with respite services that they received (Lawton *et al* 1989). This study identifies a pattern found in a number of other studies in the US and elsewhere: that carers receiving respite services often report very high levels of satisfaction that are not reflected in improvements in their psychological health (Arksey *et al* 2002). As Arksey *et al* note, this may suggest that some carers may be benefiting from respite in ways that are not captured in existing research evidence (Arksey *et al* 2002).

Effectiveness of mixed respite care: effects on older people's admission to institutional care

The larger studies also examined the relationship between provision of respite care and subsequent institutionalisation of the older person (Lawton *et al* 1989, Montgomery and Borgatta 1989, Kosloski and Montgomery 1995). As the authors of one study point out, "The goal of relieving strain on family caregivers is usually linked to the program goal of avoiding or delaying nursing home admission, thereby reducing the economic costs of care" (Lawton *et al* 1989: 8).

The reported results again appear somewhat mixed. In the Philadelphia Respite Demonstration Program, it was found that families who received respite care maintained their impaired relative significantly longer (22 days) in the community than those without respite care (Lawton *et al* 1989). On the other hand, the Seattle study of support programmes for families of impaired elderly people initially found that nursing home placement was delayed for adult child caregivers, but increased for spouse caregivers (Montgomery and Borgatta 1989). The results showed that spouses in the treatment group receiving respite care spent significantly longer in nursing home placements than those in the control group did. The mean number of months spent by spouses in nursing home placements was 2.5, compared to 0.1 in the control group (Montgomery and Borgatta 1989). Subsequent reanalysis of the data from the Seattle study, using more sophisticated statistical techniques, however, found that as respite care increased, the probability of nursing home placement decreased (Kosloski and Montgomery 1995).¹ Taking the results of all these studies together, they suggest that respite care in general is associated with delayed admission to institutional care, though it may also be associated with increased admission for some groups. These results are consistent with findings reported more widely in the international literature (Arksey *et al* 2002).

Cost-effectiveness of mixed respite care

The respite care studies reported here did not report directly on economic aspects of the interventions. The issue of cost-effectiveness has, however, been addressed directly in other large-scale demonstration programmes in the US, such as the Medicare Alzheimer Disease Demonstration and Evaluation (MADDE) (Fox *et al* 2000). This demonstration evaluated a case management approach and included, not just respite care, but community care services more generally. It is considered later in this review, under 'multi-dimensional approaches' to supporting carers.

Access to mixed respite care

An important aspect of these studies of respite care demonstrations in the US is the identification of low utilisation rates of services in the presence of ostensibly high need, that is, the under-use of these services (Kosloski and Montgomery 1993b, Cox 1997). In the two largest studies, involving caregivers who participated in programmes where the availability of services was known to the caregivers and where these were provided free or at a greatly reduced cost, as many as 30 to 50 per cent of participating families failed to use available respite services at all (Lawton *et al* 1989, Montgomery and Borgatta 1989). In other words, many families who were eligible for services through the programmes did not use them. The under-utilisation of respite care services was specifically addressed in Cox's research on carers accepted into the Maryland Alzheimer's Demonstration Grant (Cox 1997). The research found that determinants of programme use included the poorer cognitive status of the relative and less anxiety and greater burden among the caregivers.

¹ The reanalysis of the data by Kosloski and Montgomery used a regression model with statistical covariates to control for spurious factors that might bias estimates of treatment effects. To evaluate the possibility that the relationship between the amount of respite use and the probability of nursing home placement had a non-linear component, a quadratic term for 'amount of respite use' was added to the model in place of the linear term. The quadratic variable did not add significantly to the model (Kosloski and Montgomery 1995).

Summary of results from US studies of mixed respite care services

- US studies have found contradictory results regarding the impact of respite care on the psychological health of carers, with studies reporting both positive effects and no noticeable effects on carers' psychological health.
- These variations may be due to methodological differences between the studies or to differences in the intensity of respite care received by participants.
- Carers often report very high levels of satisfaction with respite care that are not reflected in improvements in their mental health.
- Studies suggest that respite care in general is associated with delayed admission to institutional care, though it may also be associated with increased admission for some groups.
- Under-use of respite care by caregivers is widely reported in the US studies, and many families eligible for respite services through the demonstration programmes did not use them.

Daycare services

Description of the service in England and Wales

A widely accepted definition of daycare in the UK is that it “offers communal care, with paid or voluntary caregivers present, in a setting outside the user’s own home. Individuals come or are brought to use the services, which are available for at least four hours during the day” (Tester 1989).

Most daycare falls into two broad categories (Burch and Borland 2001). One is day hospital care, provided by the NHS, which aims to offer assessment and active rehabilitation. A review of day hospital provision carried out in 1995 identified over 600 day hospitals in England, providing 16,000 weekday places at an estimated cost of £125 million a year (Committee of Public Accounts 1995, cited in Burch and Borland 2001). The other main category of daycare is that provided by local authority social services, the voluntary sector and the independent sector. Here the emphasis has been more firmly on providing social contact, although day centers are increasingly catering for a more vulnerable and frail client group as older people are encouraged to remain at home as long as possible (Burch and Borland 2001: 20).

There is wide variation in the amount, source and type of provision across the country (Levin *et al* 1994). Daycare may be located in premises such as purpose built free-standing centers, clubs or church halls. A development in recent years has been a substantial growth in daycare in residential or nursing homes (Tinker *et al* 1999). Such daycare is, however, often of poor quality, with the older person doing no more than joining others in the lounge (Twigg 1992).

Daycare has been described as the main community service for people with dementia (Levin *et al* 1994). Daycare for people with dementia is sometimes provided in specialist centres, although many day centres for older people accept attenders who have some degree of confusion. The majority of NHS day hospital attenders are reported to be dementia sufferers (Tinker *et al*, 1999).

More innovative daycare services are less widely available. These include schemes such as daycare in ordinary housing or Front Room Daycare (Tinker *et al*, 1999).

Effectiveness of daycare: outcomes for carers

There are a number of British studies preceding the community care reforms, which looked at the impact of daycare on the psychological health of informal carers. All were concerned with carers of older people with cognitive impairment or confusion. The results of the studies were mixed. Several studies found that daycare could enhance the objectively measured well-being of some carers (Gilleard *et al* 1984, Levin *et al* 1989) and reduce the emotional distress experienced by them (Gilleard 1987). However, the most important study of respite care, *Better for the Break* could find no evidence of a detectable effect of respite services, including daycare services, on the psychological health of carers (Levin *et al* 1994: 153-4). It suggested that this may have been because of the low intensity of services provided, arguing that “it may be unrealistic to expect that standard services could have a detectable impact on the carer’s psychological health” (Levin *et al* 1994: 155).

In spite of this ambiguity regarding the effectiveness of daycare on the psychological health of carers, very high levels of satisfaction with the service have been reported by carers. Indeed, the second NISW study reported that the vast majority of carers (92 per cent) considered that the daycare service had brought some improvement in their lives (Levin *et al* 1994). As Levin *et al* wrote:

“The carers in our study looked after a group of very dependent elderly people. Many relied on daycare as their only source of a break each week. They greatly appreciated the service for the help it gave both to them and to their elderly relatives. The theme which ran through the carers’ comments was that it made life a lot easier. This opinion should be taken seriously...In our view, the value of the service to the carers in our study strengthens an already strong case for the provision of daycare service for elderly people with dementia and their carers.”

(Levin *et al* 1994: 82)

The results of the NISW study therefore mirror the findings of some of the US research into mixed respite care, in that it found that carers reported very high levels of satisfaction with daycare that was not reflected in improvements in their psychological health.

The main study looking at the effects of services on outcomes for carers since the community care reforms were introduced is the ECCEP study (Davies and Fernandez 2000). One set of outcomes examined in the study related to the subjective burden experienced by carers, measured by the Kosberg Carer Burden Scale (Davies and Fernandez 2000: 128-34). The study estimated that, overall, there were reductions in subjective burden for about 85 per cent of the carers of users of daycare. It found that daycare had beneficial effects on carer stress when provided on its own and when provided together with other services, in particular, home care and meals on wheels. On its own, daycare had beneficial effects on the subjective burden experienced by two groups of carers in particular.

First, daycare was found to have a large effect on the burden experienced by carers of severely cognitively impaired older people, who made up around 30 per cent of the daycare users in the study. This was, however, only up to a certain point, which was reached when daycare was provided for approximately twice a week (with a value in 1996 prices of about £60 a week). Up to this point, increases in the provision of daycare were associated with reduced levels of carer stress. However, beyond this point, daycare was associated with negative marginal productivities, that is, higher levels of daycare were associated with smaller overall improvements in carer stress.¹ Davies and Fernandez suggest that the reason why levels of daycare provided beyond around two days a week brought no further improvements in outcomes may have been because the users had very severe cognitive impairment and imply that there is only so much a community package can do to reduce carer stress:

“It is not surprising that the degree and nature of the strains associated with the highest level of cognitive impairment are such that a community package can make no further impact on caregiver stress; and indeed higher levels of stress remove the gains possible at low levels.”

(Davies and Fernandez 2000: 130)

The second group of carers who benefited from daycare in the ECCEP study were carers in paid employment. Approximately 40 per cent of recipients of daycare in the study had principal informal caregivers who were in paid employment. For these carers, greater provision of daycare to the older person was associated with reduced levels of carer stress. The marginal impact did, however, decrease as the amount of day care increased (Davies and Fernandez 2000: 132).

In addition to the studies of mixed respite care carried out in the US reported earlier, there are a number of other international studies looking at the effectiveness of the provision of daycare on outcomes for carers. These international studies, which primarily focus on carers of older people with cognitive impairment, report somewhat mixed results. On the one hand, some studies from both the US and Australia have reported high levels of carer satisfaction associated with use of daycare, but little improvement in the psychological health of carers (Dziegielewski and Ricks 2000,

¹ The use of the terms productivity, service productivity and marginal productivity in this review largely reflects the language used in the ECCEP study. ‘Productivity’ and ‘service productivity’ refer in general to the beneficial effects of services on outcomes. The most frequently used measure in the ECCEP study is ‘marginal productivity’, which refers to the positive effect of the next unit of service on the outcome.

Johnson and Maguire 1989, Wells *et al* 1990, cited in Arskey *et al* 2002). On the other hand, other studies from the US have found that daycare is effective in reducing carers' psychological distress (Zarit *et al* 1998, Gaugler *et al* 2002).

In summary, taking the studies of daycare from both the UK and internationally together, and putting them in the context of the studies of mixed respite care reported earlier, the evidence suggests that the provision of day respite care is often associated with very high levels of satisfaction on behalf of carers, even if this is not always associated with changes in their psychological health. Evidence of the effectiveness of daycare on the psychological health of carers is mixed. In the UK, studies pre-dating the community care reforms found inconsistent results regarding the effectiveness of daycare in reducing carer stress, possibly due to the low intensity of services provided. Since the community care reforms were introduced in the UK, evidence has been found that daycare is effective in reducing carer burden in relation to two specific groups of carers: carers of users with severe cognitive impairment (receiving up to around two days a week of daycare) and carers in paid employment. The improved effectiveness of daycare services since the community care reforms were introduced may, in part, be due to the targeting of resources associated with the reforms.

Effectiveness of daycare: effects on older people's admission to institutional care

In the UK, the pre-community care reform studies of the impact of daycare on older people's admission to institutional care found mixed results. Some studies suggested that daycare services could delay the admission of some elderly people into residential care (Gilleard 1987, O'Connor *et al* 1991). Where reductions in carer stress had been found, it was sometimes suggested that this contributed to the delay in admission. As one of these early studies suggested "The significance of reduced levels of distress appears to be that it permits carers to continue caring, while the converse – a failure to reduce the supporter's distress – seems to predict the breakdown of care and resulting institutionalisation" (Gilleard 1987: 222). Other studies, however, found that daycare was not associated with delayed admission to institutional care (Levin *et al* 1989, 1994). The first NISW study found that, overall, older people with daycare were equally as likely to have entered residential care as those without it (Levin *et al* 1989). However, the results from the NISW studies were somewhat complex (Levin *et al* 1989, 1994). It was found that older people who had daycare or sitters, but did not have residential relief care, were more likely to have remained at home on follow-up (Levin *et al* 1994). However, older people who had residential relief care, which was almost always used in conjunction with daycare or sitting, were more likely to have entered residential care (Levin *et al* 1994).

A number of pre-reform studies expressed caution about the use of daycare to prolong the length of time spent by older people in the community. Fennell and colleagues (1981) questioned the use of daycare for clients who were on the margins of admission, arguing that that the relief it gave needed to be set against the costs to

the carers of maintaining a situation that was essentially at crisis point (Fennell *et al* 1981, cited in Twigg 1992). Levin *et al* (1994) argued that community respite services, like daycare, brought only modest relief to carers compared with residential care and that residential care needed to be an option that was available to carers (Levin *et al* 1994: 155).

The post-community care study by Davies and Fernandez (2000) found that provision of daycare had a large positive impact on length of time in the community for all recipients of the service, although the size of the effect varied with the characteristics of the users and the level of daycare received. In particular, daycare provided to users suffering from cognitive impairment showed a greater effect on the length of stay in the community than daycare provided to other users (Davies and Fernandez 2000: 61). For older people with cognitive impairment, one day a week of daycare (costing around £40 a week in 1996 prices) increased the time spent in the community by approximately 200 days, while two days a week of daycare increased the time spent in the community by approximately 270 days (Davies and Fernandez 2000: 60, Figure 4.1). The effect, therefore, showed significant decreasing returns to scale, a finding common to most of the services and outcomes in the study (Davies and Fernandez 2000: 59). The effects of daycare were lower for other older people using daycare. Daycare had an impact on length of time in the community for highly dependent users both with and without principal informal carers. The study also carried out an analysis of joint supply effects, which suggested that improvements in the users' length of stay in the community might be achieved through interventions aimed at reducing the burden on informal carers (Davies and Fernandez 2000: 164). Decreases in carer stress increased significantly the users' ability to stay in the community for extended periods of time.

In addition to the studies of mixed respite care carried out in the US, reported earlier, there are a number of studies that have been carried out outside the UK looking at the relationship between the provision of daycare to the older person, outcomes for carers and subsequent institutionalisation of the older person (Aneshensel *et al* 1995, Zarit and Zarit 1998). Studies carried out in the US have suggested the complexity of the effects of daycare on carer stress and its relationship to placement of the older person in institutional care. Zarit and Zarit (1998), for example, in their study of adult daycare for older people with mental disorders, found improvements on two of three measures of care-related stressors, overload and strain. A third measure, role captivity did not change. Role captivity, however, has been found to be a strong predictor of placement in nursing homes (Aneshensel *et al* 1995). Thus Zarit and Zarit's study found benefits for caregivers, but these did not address a dimension of the stress process that is directly related to placement in nursing homes.

Like the UK studies, US studies have pointed out that the use of daycare (and other respite services) to delay the institutionalisation of the older person may not always be in the best interests of the carer. Zarit and Leitsch have recently argued that the timing of institutional placement illustrates in the most striking way the discrepancy of interest between caregivers and older people:

“...placing a relative with Alzheimer’s disease [in a nursing home] relieves much (though not all) of care-related stress from the primary caregiver. But placement is also associated with increased mortality for the person with dementia. Thus, a program that seeks to delay placement may differentially benefit the person with dementia, while one that facilitates an easier placement decision provides greater help to the family.”

(Zarit and Leitsch 2001: S85-86)

In summary, taking the UK and international studies of daycare together, and putting them in the context of the US studies of mixed respite care reported earlier, the evidence is somewhat mixed with regard to the effectiveness of the provision of day respite on the older person’s subsequent admission to institutional care. Some studies carried out in the UK prior to the community care reforms found that daycare services could delay the admission of some elderly people into residential care, but others found that daycare made little difference to this outcome. The main post-community care reform study found that provision of daycare had a positive impact on length of time in the community. US studies suggest that there is a complex relationship between the effects of daycare on carer stress and subsequent placement of the older person in institutional care. Studies in the UK and internationally stress that the older person may have a greater interest in delaying institutional care than the carer.

Effectiveness of daycare: impact on the user

Studies in the UK have stressed that, although older people may have an interest in remaining in the community, they are not always willing to go to a day centre. Daycare, itself, may therefore raise dilemmas for some carers. While they may need the break, the person they care for may be unwilling to go to daycare (Twigg 1992). As McLaughlin & Glendinning put it, “For all disabled people, the very language of daycare and respite care may be experienced as insulting. Such care-oriented/substitute care services portray disabled people as a burden from which their carer needs or ‘deserves’ to be rescued” (McLaughlin & Glendinning 1994: 56).

The potential conflicts between older people and carers over the use of daycare were illustrated in the ECCEP study of community care in England and Wales since the reforms of the early 1990s (Davies and Fernandez 2000). Davies and Fernandez found that there was a strong productivity effect for user satisfaction with daycare up to around £55 a week (around 2 attendances a week) but that, from that level, the impact on satisfaction diminished with increases in the service (Davies and Fernandez 2000: 67). For users allocated over four attendances a week, the overall daycare effect

became negative, and was therefore associated with a reduction in user satisfaction. As Davies and Fernandez put it “This may reflect the users’ frustration when ‘stuck’ in daycare facilities” (Davies and Fernandez 2000: 68). The authors suggest that, when users are given very high levels of daycare, this may be to relieve the carer and illustrates the conflict of interest that may arise over use of daycare services:

“Indeed, for cases where the levels of daycare consumed are large, the main beneficiary may not be the user but the caregiver. The interests of caregivers and users were considered by care managers to conflict for a substantial proportion of cases... So, the care plan may deliberately be aiming at, what in the view of the user is an excessive consumption of daycare in order to relieve stress on the caregiver, or otherwise to benefit her.”

(Davies and Fernandez 2000: 68)

When cared-for people do not want to go to daycare, carers themselves may be understandably reluctant to use it and this may reduce its value as a service for them. It has been reported that carers of older people with physical disabilities and spouse carers are particularly unlikely to use daycare (Twigg 1992). One US study of carers of dementia patients, cited by Arksey *et al* (2002), reported that spouses are particularly concerned about the quality of respite and prefer in-home care to adult daycare (Cotrell 1996). It also reported that spouses are more likely to seek respite that provides benefits to the care recipient (Cotrell 1996). This is partly an issue about the attractiveness of the service for the attender and the type of services that are on offer. Twigg has argued for the need to improve the experience of daycare for disabled and older people if it is to be of use and be used by carers (Twigg, 1992: 81).

Cost-effectiveness of daycare

It is often assumed that community-based respite care services, such as daycare, are likely to be cost-effective if they lead to reduced expenditure due to lower admissions to residential care.¹ This hypothesis was tested in one UK study preceding the community care reforms. This small-scale study by Donaldson and Gregson (1989) looked at the cost-effectiveness of tailored psychogeriatric day and respite care provided by a Family Service Unit (FSU) in the north-east of England. The care was aimed at helping carers to enable confused elderly people to remain at home for as long as possible. The study found that the recipients of the FSU service were institutionalised almost six months later than a control group. The difference in the rate of institutionalisation meant that the intervention was cost-effective, compared to admission to a long-term care hospital bed. The authors pointed out, however, that the cost savings would not have accrued to the local authority that was jointly responsible for funding the FSU (Donaldson and Gregson 2002).

With regard to the post community care reform period, the study by Davies and Fernandez (2000) has implications for cost-effectiveness. The authors carried out an ‘optimisation analysis’. One set of assumptions under this analysis, was that the number of days in the community would be optimised, while the overall budget

¹ This is not the only form that cost-effectiveness of daycare may take. As the ECCEP work, reported below shows, daycare can also be cost-effective if it leads to better outcomes for users and/or carers at equivalent costs to alternative services.

remained fixed (Davies and Fernandez 2000). This scenario allowed for a redistribution of resources both across users and services, assuming constant service prices. In essence, the approach involved maximising days in the community, and hence minimising days in residential care, by reallocating a fixed budget between users and services. The input mix efficiency,^I optimising length of stay in the community meant that, among other changes to services inputs, there would be more daycare utilized. The biggest increase would be for users with cognitive impairment or behavioural disturbances. This analysis suggests that it would be cost-effective to increase use of daycare for these client groups, if users' length of stay in the community is to be maximised.

The authors also carried out a similar optimization analysis, but this time optimizing a reduction in subjective carer burden. The input mix efficiency optimising a reduction in subjective carer burden also meant that, among other changes to services inputs, there would be more daycare utilized (Davies and Fernandez 2000: 299). It should be noted, however, that optimising a reduction in carer burden would result in a decline in the length of time spent by the user in the community, although this is due to the effects of inputs other than daycare.^{II}

Access to daycare in the UK

Prior to the community care reforms, daycare was identified as being a poorly targeted service, which was directed away from older people with the greatest disabilities (Davies *et al* 1990). Certain clients were considered 'too bad for daycare' and returned to the sole care of their families (Lewis and Meredith 1988, Twigg 1992).

The community care reforms aimed to change this and to target services on people with greater disabilities. The ECCEP study suggests that they may have had some success, in that daycare services are now targeted more on those with the greatest level of disability (Bauld *et al* 2000). In addition, services are now targeted on users with carers. Users with a carer are now receiving a higher level of daycare than users without carers across all levels of need (Bauld *et al* 2000). However, at the same time, the overall level of daycare received has declined. As Bauld *et al* write: "In relation to daycare however, the picture is one of *reduction in service levels* between DCP (1980s) and ECCEP (1990s)" (Bauld *et al* 2000: 256, emphasis added). Thus, the DCP study, carried out in the mid-1980s, found that the most dependent users (those with critical interval needs) without a carer received on average approximately 0.8 days per week of daycare, whereas the ECCEP mean was 0.34 days per week. Similarly, the DCP study found that the most dependent users with a carer received on average approximately 1.1 days a week of daycare, whereas the ECCEP mean was 0.96 days a week (Davies *et al* 1990, Bauld *et al* 2000).

National data suggest that, consistent with targeting, access to daycare by older people has declined in Great Britain since the 1980s. The most recent General Household Survey (GHS) data for people aged 65 and over found that the proportion of all older people attending day centres declined from 5 per cent in 1985 to 3 per cent

^I Input mix efficiency refers to the most cost-effective mix of inputs. It refers to the mixture of services that maximises the desired outcome from a particular expenditure. For example, input mix efficiency refers to the mix of services that, given a particular expenditure, maximises days in the community.

^{II} The comprehensive review of respite services for carers by Arksey and colleagues (Arksey *et al* 2003a), which is currently being finalised, identified four economic evaluations of daycare internationally. None were UK-based. They comprised evaluations from Norway (Engedal 1989), the US (Gaugler *et al* 2003) and Sweden (Wimo *et al* 1990, 1994). Two of the evaluations suggested that daycare might be cost-saving and two suggested that daycare might provide greater benefits but at a higher cost as compared to standard care.

in 2001 (ONS 2003b). Department of Health data for England also suggest that the number of local authority funded daycare recipients aged 65 and over may be falling. In 1998, there were 121,700 older local authority funded daycare recipients, compared to 115,000 in 2002, although a change to the form used to collect the data means that these figures need to be interpreted with some caution.

National survey data also suggest that the intensity of daycare provision remains low. The 1998 GHS data for people aged 65 and over suggests that older people in Britain with dependency needs who used daycare attended on average for 1.8 days per week (Pickard *et al* 2001). This had increased slightly since 1994, when dependent older people who used daycare attended on average for 1.5 days per week (Pickard *et al* 2001). Unlike the ECCEP data, the GHS data therefore show a slight increase in intensity of daycare use during the mid/late 1990s. Greater reliance, however, should be placed on the ECCEP findings, however, because the GHS asks quite broad questions on daycare attendance, from which it is difficult to derive precise intensity data.

Summary of results from studies of day respite care

- The evidence regarding the effectiveness of daycare in improving the psychological health of carers is mixed, with some studies reporting that daycare can reduce the psychological distress of carers and other studies reporting no effects.
- The provision of day respite care is often associated with very high levels of satisfaction on behalf of carers, even if this is not always associated with changes in their psychological health.
- The evidence is somewhat mixed with regard to the effectiveness of the provision of day respite on the older person's subsequent admission to institutional care.
- US studies suggest that there is a complex relationship between the effects of daycare on carer stress and subsequent placement of the older person in institutional care.
- The ECCEP study in England and Wales, carried out since the community care reforms were introduced, found that daycare reduced stress for about 85 per cent of the carers of users of daycare. On its own, daycare had beneficial effects on the subjective burden experienced by carers of users with severe cognitive impairment (receiving up to around two days a week of daycare) and carers in paid employment.
- The same study also found that decreases in carer stress increased significantly the older person's ability to stay in the community for extended periods of time.
- There can be conflicts of interest between older people and carers regarding the use of daycare. Daycare that is provided to benefit the carer may not be what the user wants, especially when this involves large amounts of daycare.

- The ECCEP study suggests that it may be cost-effective to increase daycare, particularly for older people with cognitive impairment or behavioural disturbances, in order to maximise either users' length of time in the community or reductions in carer burden.
- Access to daycare by older people has declined in Great Britain since the 1980s. This is consistent with targeting resources on people with greatest disabilities.
- There is evidence from the ECCEP study that daycare is now targeted more on frail older people with carers, but that the intensity of daycare provision has declined since the 1980s.

In-home respite care

Description of in-home respite care in England and Wales

In England and Wales, in-home respite care takes the form of sitter and other types of home care relief services, which provide alternative care for the older person at home and enable the carer to take a break (Twigg *et al* 1990, Hills 1991, Leat 1992, Tinker *et al* 1999). Some sitter services are limited to providing companionship and limited assistance. Other schemes provide somebody to substitute for the carer, undertaking care tasks for the disabled person and replicating what the carer would be doing at that time of day. In some areas, night sitting services exist, although the majority of schemes only provide relief during the day (Tinker *et al* 1999). Many sitter and other types of home care relief schemes are provided from within the voluntary sector, although they may be funded by the statutory sector.

In-home respite care cannot be described as a mainstream service in England and Wales. In the ECCEP study of community care in the 1990s, only 5 per cent of the older people in the sample received sitting services, compared to 24 per cent who received daycare and 18 per cent who received respite care (Bauld *et al* 2000). The numbers in the sample were so small that no analysis of the effectiveness of the service was carried out (Davies and Fernandez 2000). Sitting services, therefore, still tend to be more of an innovatory than a mainstream service.

Effectiveness of in-home respite care

The effectiveness of sitting and other home relief services on carers of older people is not clear. The review of sitting services carried out by Leat in 1992 found that few evaluations of sitting services had been carried out (Leat 1992). Little seems to have changed in the intervening decade. Arksey *et al* (2002) identified only four studies internationally focusing on in-home respite care for carers of older people with mental health problems (Gwyther 1989, Milne *et al* 1993, Jansson *et al* 1998, Wishart *et al* 2000). Of these, only one study was carried out in the UK. This was a study by Milne *et al* of a scheme provided by Age Concern in which care attendants undertook in-home respite care with people looking after elderly, physically handicapped and sick people

(Milne *et al* 1993). Arksey *et al* concluded that: “The small number of studies and small sample sizes of these is indicative of the relative paucity of evidence regarding the effectiveness of in-home respite services” (Arksey *et al* 2002: 38).

There is, however, evidence that sitting services are popular with carers, especially co-resident carers (Twigg *et al* 1990, Leat 1992, Tinker *et al* 1999). The Social Services Inspection (SSI) of services for carers in the London Borough of Merton, carried out in 1998, found that many of the carers they talked to were enthusiastic about the concept of a sitting service (SSI 1998). One reason for their popularity is that they are often more acceptable to the older person than daycare outside the home. As Twigg *et al* wrote in 1990, “Respite provided in this way offers, potentially, the least disruptive form of service. This is true, both for the dependent person who is not required to go into a strange environment, and for the carer who is not required to organise and get their dependant out of the house” (Twigg *et al* 1990: 58). Twigg’s observations retain contemporary relevance. In a recent study of carers of older people with mental illness in Islington, a culturally-mixed area of North London, carers expressed a preference for 24 hour home respite schemes (Train *et al* 2002).

Access to in-home respite care

As already indicated, the availability of in-home respite care services is limited. Evidence from the early 1990s suggested that many schemes operated restrictions on the amount of help that any one carer might receive and that this could limit their usefulness for certain sorts of carer, for example, those who wished to work. A number of schemes also operated extensive waiting lists (Twigg *et al* 1990). More recently, the SSI in Merton found that carers lacked knowledge of what was available locally (SSI 1998). Access to sitting services might also be restricted by charging in that carers might be reluctant to use a sitting service where there is a charge. The SSI inspection of services for carers in York, for example, commented that some carers were reluctant to use a local sitting service provided by a voluntary agency for this reason (SSI 1997).

Access to sitter services may be limited for carers of people with advanced dementia. Evidence from the early 1990s suggested that volunteers found sitting with demented elderly people very demanding (Leat 1992). The SSI in the London Borough of Merton reported that the sitting scheme found it difficult to provide a service for those with challenging behaviour (SSI 1998).

Summary of results for in-home respite care

- In-home respite care offers flexible forms of respite in the older person’s own home.
- There is too little evidence to conclude whether or not in-home respite care is an effective intervention.
- There is, however, some evidence that sitting services are popular with carers, especially co-resident carers, and with cared-for older people.

- Access to sitting services is limited, with schemes by no means universally available.

Institutional respite care

Description of institutional respite care in England and Wales

Institutional respite care is used by carers of older people, particularly those with dementia, to give them an overnight break from caring (Twigg 1992). A number of different types of institutional settings provide respite: residential or nursing homes in the local authority, private or voluntary sectors, and community hospitals and intermediate care facilities in the NHS. Respite may be provided on a one-off basis or rotated so that the cared-for person has so many weeks in the institution and so many weeks at home. The majority of provision in England and Wales is of the one-off variety, with most carers receiving spells of one or two weeks a year (Tinker *et al* 1999).

Effectiveness of institutional respite care- outcomes for carers

Summarising the evidence relating to the effectiveness of overnight respite in institutions in the UK for the period before the community care reforms, Twigg (1992) concluded that:

“Evidence of the value of respite is clear. Carers praise it and see it as significant in their ability to cope.”

(Twigg 1992: 85)

Twigg cited a number of studies in support of this conclusion, including Allen (1983), Levin *et al* (1989), Boldy and Kuh (1984), Levin and Moriarty (1990) and Twigg and Atkin (1994). Evidence about the impact of overnight respite on carers’ psychological health was also cited by Twigg. The first NISW study provided evidence that regular or occasional relief breaks could improve carers’ psychological health (Levin *et al* 1989). The second NISW study, however, could find no evidence of a detectable effect of respite services, including overnight relief care, on the psychological health of carers (Levin *et al* 1994: 153-4).

Evidence collected since the community care reforms were introduced suggests that, with regard to caregiver burden, respite care has substantial effects for caregivers in some circumstances. Davies and Fernandez (2000) found that respite care, which was defined as overnight care in institutions, was found to have the largest marginal productivities (involving reductions in levels of carer stress associated with increases in use of respite care) where the care manager perceived the user to have cognitive impairment. These older people represented over half of the users of respite care (Davies and Fernandez 2000: 132). The marginal productivity was also estimated to

be substantial for users whom the care managers considered to be more reliant on caregivers than others in the same circumstances, a group comprising nearly 20 per cent of users (Davies and Fernandez 2000: 132).

International (US and Canadian) studies of institutional respite for carers of people with dementia, cited by Arksey *et al* 2002, also suggest evidence for the effectiveness of the intervention, with some decrease in perceived carer burden reported (Burdz *et al* 1988, Larkin and Hopcroft 1993).

Effectiveness of institutional respite care – effects on older people's admission to institutional care

There is evidence, from research carried out in the 1980s in the UK, that institutional respite care can increase the likelihood of admission to permanent institutional care. The NISW study of services for confused older people, which described overnight respite in institutions as 'relief care', found that "regular relief care strongly increased the likelihood of entry into permanent residential care" (Levin *et al* 1989: 263). Levin and her colleagues suggested that one reason for this was the use of relief care as a stop-gap by individuals who had expressed a wish for the older person to be admitted (Levin *et al* 1989). Other evidence from the 1980s in the UK suggested that respite could prevent admission where it was provided in a specialised context that emphasised its aim (Donaldson *et al* 1988, cited in Twigg 1992).

The post-community care reform study (ECCEP) in England and Wales by Davies and Fernandez (2000) found evidence that provision of respite care had a positive impact on length of time in the community for some older people, although the study also identified circumstances under which the reverse was the case. The study found that greater amounts of respite care provided to older people with three specific types of problem resulted in more time spent in the community (Davies and Fernandez 2000: 59). The three types of problem were: high numbers of problems performing Instrumental Activities of Daily Living (IADLs) (such as cleaning, cooking and shopping), behavioural problems and difficulties with washing (Davies and Fernandez 2000: 59). For older people with high numbers of problems with IADLs or problems with washing, one day a week of respite care (costing approximately £45 a week in 1996 prices) increased the time spent in the community by approximately 250 days, although there were significant decreasing returns to scale (Davies and Fernandez 2000: 60, Figure 4.2). For the 24 per cent of recipients of respite care with behavioural problems, time spent in the community increased steadily with the levels of input of respite. For these older people, one day a week of respite care increased the time spent in the community by approximately 400 days (Davies and Fernandez 2000: 60, Figure 4.2).

The ECCEP study also identified two groups of older people for whom the input of respite care was inversely correlated with length of stay in the community: those with 'bad user-caregiver relationships' and users judged by care managers to be 'more

reliant on others than the average clients in these circumstances'¹ (Davies and Fernandez 2000: 61). For these two groups, higher levels of respite care were associated with shorter lengths of stays in the community. One day a week of respite care decreased the time spent in the community by approximately 250 days for both groups (Davies and Fernandez 2000: 60, Figure 4.2). The authors suggested that these are characteristics that identify the subgroups that are typically associated with the subsequent breakdown of caregiving.

The fact that, for some carers, respite care hastens permanent institutionalisation has been identified in international studies, as well as in studies in the UK. In the US, it has been suggested that one reason why this occurs is that programs such as overnight respite may make it more acceptable for some caregivers, particularly of older people with dementia, to turn the care of their relative over to someone else (Scharlach and Frenzel 1986). As Zarit and Leitsch point out "Rather than delaying [nursing home] placement, good programs of community service might increase its likelihood by inadvertently helping some caregivers to let go of their relative" (Zarit and Leitsch 2001: S90). Factors such as these contribute to the limited success of respite interventions in lowering rates of nursing home placement.

Effectiveness of institutional respite care: impact on the user

Studies in the UK have suggested that older people are not always willing to use institutional respite care. As Twigg points out:

"The idea of going into an institution, however temporarily, is disliked by many disabled people, and carers understandably do not want to force the issue. As a result, respite is relatively rarely taken up where the cared-for person is mentally alert or where he/she is cared for by a spouse."

(Twigg 1992: 85-6)

In the NISW study of confused older people, Levin and colleagues found that, among those coping with dementia, daughters were particularly likely to have taken up relief care and spouses were very unlikely to have done so (Levin *et al* 1989: 266). Because of the unwillingness of some older people to use respite care, it is an ambivalent service for carers. As Twigg has argued:

"Respite represents more sharply than any other service the potential conflict between the carer and the cared-for person."

(Twigg 1992: 85)

In the ten years since Twigg's review, this has not changed. A recent study of carers of older people in Islington, to which reference has already been made, found that "residential respite was problematic" for carers of older people with mental illness (Train *et al* 2002).

¹ Older people who were 'more reliant on others' were identified through a questionnaire to care managers, who were asked the following question: 'Compared with similar users, does *name of user* want to rely on other people for help or does he/she try to help him/herself?' Respondents were given the following options: (1) tends to rely on others; (2) mixed; (3) tries to help her/himself. Older people were defined as 'more reliant on others', or over-reliant, when they answered (1) to this question (José Fernandez, personal communication).

Studies in the UK, and internationally, have also suggested that respite may not be in the best interests of the user because there is some evidence that it may lead to a deterioration in their condition. Some studies in the UK have shown that elderly people can become more confused and their behaviour and health decline as a result of respite (Twigg 1992). In addition, a Canadian study reported worse relationships between some carers and care recipients on return from respite care (Burdz *et al* 1988). However, there is also evidence that the functioning of the cared-for person can improve during short-stay placements, especially in those people looked after by highly stressed carers (Homer & Gilleard 1994).

The ECCEP study of community care in the UK since the reforms of the early 1990s found that increased levels of respite care increased user satisfaction with the service among married service users (Davies and Fernandez 2000: 68). The authors suggest that, for spouses, respite care is unlikely to be employed as a transition to permanent placement in an institution, and that spouses may appreciate that respite provides a break for the caring spouse. However, the productivity effect was only significant at the 3.8 per cent level, causing the risk of substantial sampling error in the estimate. Other evidence that older people may appreciate the benefits of respite care come from a smaller study of 40 patients using overnight respite care in an intermediate care centre in London, which reported high levels of satisfaction with the service from both carers and older people (Ashworth *et al* 1996).

Cost-effectiveness of institutional respite care

As already indicated, the study by Davies and Fernandez (2000) of the post community care reform period in the UK has implications for cost-effectiveness. One set of assumptions, under the 'optimisation analysis' carried out in this study, was that the number of days in the community would be optimised, while the overall budget remained fixed (Davies and Fernandez 2000). The input mix efficiency optimising length of stay in the community meant that, among other changes to services inputs, there would be more respite care utilised for all users with carers, except carers of the less dependent older people in the study (those with 'long interval' needs). This analysis suggests that it would be cost-effective to increase use of respite care for carers of more dependent older people, if users' length of stay in the community is to be maximised. The optimization analysis, optimizing a reduction in subjective carer burden, also suggested that, among other changes to services inputs, there would be more respite care utilized (Davies and Fernandez 2000: 298).

Access to institutional respite care in the UK

Research carried out in the 1980s in the UK suggested that there was underprovision of respite care at this time. Levin *et al* (1989) in their study of carers of dementia sufferers found that only one in four of the elderly people cared-for had been admitted to homes or hospitals to give their supporters a break. Of the supporters who had never had relief breaks in any form, five in six had never been offered them and two in

five would have accepted breaks if offered (Levin *et al* 1989). A number of studies suggested that carers sometimes faced problems in gaining access to respite (cited in Twigg 1992).

The ECCEP study of post-reform community care in England and Wales found that access to respite care by highly dependent older people had increased since the mid-1980s. The study found that a higher proportion of the sample of very frail older people using local authority-arranged social services received respite care in the mid-1990s than had been the case in the mid-1980s, when the DCP study had been carried out (Bauld *et al* 2000: 251). In the mid-1980s, just 5 per cent of users had had short stays in residential care, but by the mid-1990s this had increased to 18 per cent, so that the proportion receiving respite had more than tripled in the ten intervening years. On average, users in the later study received 0.8 days of respite care a week, representing the equivalent of a one-week stay in respite every nine weeks (Bauld *et al* 2000: 251).¹ The ECCEP study found that respite care was targeted on users with greatest needs for care and on those with carers.

However, despite these increases in access to respite care, underprovision remains. The ECCEP study found that many carers were still unable to take a break from caring, particularly if the older person they cared for had a cognitive impairment, and particularly if they were co-resident (Bauld *et al* 2000: 387). Even when a care package had been put in place, one in three carers reported that they had not had a break away from home in the past six months, but wished they could take one. This proportion rose to four out of ten carers when the user had cognitive impairment or behavioural disorder. The need to take a break also arose in relation to unmet need among ECCEP carers. Respite care was the service most frequently mentioned as an unmet need, particularly among the carers of more dependent users (Bauld *et al* 2000: 387).

Moreover, national survey data does not indicate that there has been very much change in the availability of respite care since the mid-1980s. The GHS data on provision of informal care found that, in 1985, 57 per cent of carers devoting at least 20 hours per week to helping someone who lived in the same household reported that they had never had a break of at least two days since they had started caring. In 1995, this proportion had dropped by only 3 per cent to 54 per cent (Rowlands and Parker 1998). Although these figures do not take into account whether or not people actually wanted a break away from those they helped, nor the level of their caring activities, as Parker and Clarke have recently observed, “the change hardly signals a revolution in support for carers” (Parker and Clarke 2002: 349).

¹ The trend in intensity of respite care since the 1980s is difficult to establish. The publication arising from the DCP study, carried out in the mid-1980s, did not give a figure for the average number of days of short-term residential care that were received per week (Davies *et al* 1990: 66). This may have been because the sample size of recipients of respite care was small.

National figures on the numbers of older people receiving institutional respite care from the 1980s onwards are not available. Data are, however, available from the mid-1990s onwards for temporary admissions of older local authority-supported residents to care homes from the Department of Health. These data suggest that the numbers of temporary admissions (not limited to respite care) rose from 141,430 in 1995 to 165,336 in 2000, but then fell to 156,470 in 2002.

Innovative schemes

Mainstream services in the UK have not tended to include the more flexible community-based models of respite, which may be preferable to institutional care. These include care by a foster family and care by a substitute carer coming to stay in the home (Tinker *et al* 1999). In its evidence to the Royal Commission on Long Term Care, the Alzheimer's Disease Society argued that short stay institutional care is not necessarily the most effective or desirable for those suffering from dementia and that flexible, community-based models, such as family support schemes, would extend the range of options (cited in Tinker *et al* 1999).

Another flexible model is an innovative scheme which was tried in the UK in the mid-1990s, entitled Care and Respite for Elderly People with Support and Treatment (CREST) (Watkins and Redfern 1997). The service provided a night nursing service (in a night hospital) for elderly mentally confused people living at home, with the aim of providing relief to relatives. Care recipients were collected in a 'sitting' ambulance with a nurse escort in the evening and returned the following morning. The study identified the possibility that institutional respite could indicate the first step towards carers seeking permanent residential care.

Summary of results for institutional respite care

- Most international and UK studies reported in the literature suggest that overnight respite care is effective in reducing carers' subjective burden.
- However, a widely reported result in the national and international literature is that provision of institutional respite care can hasten permanent institutionalisation of the older person.
- The ECCEP study found that respite care reduced carer burden in relation to two specific groups of carers: carers of users with cognitive impairment (as perceived by care managers) and carers of more reliant older people.
- This study also found that provision of respite care had a positive impact on users' length of time in the community in some cases (for example, carers of users with behavioural problems), but a negative impact in others (in particular, those with bad user-carer relationships and more reliant users).
- Respite represents more sharply than any other service the potential conflict between the carer and the cared-for person, since many older people do not want to go into an institution, however temporarily.
- It may be cost-effective to increase respite care, in order to maximise either users' length of time in the community or reductions in carer burden.
- The ECCEP study of post-reform community care in England and Wales found that access to respite care by highly dependent older people had increased since the mid-1980s.
- However, the study also found underprovision of, and unmet needs for, respite care.

- National data show that there has been very little change in access by heavily involved carers to breaks from caring.
- Most recently (since 2000), there has been a decline in the number of temporary admissions of older local authority-supported residents to care homes.

Carer support groups

Description of carer support groups in England and Wales

Carer support groups are one of the few forms of support that are directly provided for carers. Groups can be organised in a number of ways. Some are offshoots of a facility, like a day hospital or adult training centre, others are free standing. Some are generic, open to all carers, others focus on a particular client group, even a particular medical condition. Some are very much for the carers; others have a shared emphasis on the carer and the cared-for person. Some are linked into national charities; others are strictly local. All share certain common features around the provision of mutual support and the sharing of information (Twigg 1992, Tinker *et al* 1999).

Effectiveness of carer support groups

In 1992, Julia Twigg reviewed the research evidence regarding carer support groups and concluded that,

“In general research suggests that groups are valued by those who attend them... Evidence that they produce direct improvements in the well-being of carers or in their ability to continue is however more equivocal.”

(Twigg 1992: 89)

Ten years later, Hilary Arksey and colleagues reviewed the evidence regarding the effectiveness of support groups for carers of people with mental health problems. They examined around ten different studies of carer support groups relating to carers of people with dementia and Alzheimer’s disease, including papers from the US, Canada and the Netherlands. None of the studies found any clear link between support groups and carer experience across a range of outcome measures. The conclusions drawn by Arksey and colleagues are, therefore, very similar to those drawn by Twigg ten years earlier:

“In sum, there does not appear to be any conclusive evidence regarding the effectiveness of support groups for carers of people with mental health problems... Findings across a range of standard outcome measures do not indicate any significant change in carer experience.”

(Arksey *et al* 2002: 55)

Qualitative studies of support groups examined by Arksey and colleagues have, however, identified positive aspects of group involvement, such as emotional support, the importance of sharing experience and helping carers to cope with their situation and develop a more positive outlook (Arksey *et al* 2002). Reported satisfaction with support groups is high.

Cost-effectiveness of carer support groups

No study addressing the economic aspects of carer support groups was identified by Arksey *et al* (2002). Carer support groups were not included in the study by Davies and Fernandez (2000).

Access to carer support groups

There is contradictory evidence about access of carers to support groups, with most research carried out in the US (Tinker *et al* 1999). Some studies have found that caregivers who seek out support groups have relatively few caregiver demands and low levels of stress (Zarit & Toseland 1989). Other research indicates that caregivers who are extremely distressed are more likely to seek out support groups (Monahan *et al* 1992). In practical terms, access to support groups can be restricted by difficulties that carers face in attending (Twigg 1992).

Research also suggests that, although groups are valued by those who attend them, not all carers wish to attend groups (Twigg 1992). Allen and colleagues' study of older people at risk of admission to residential care and their informal carers, found that the carers had little interest in attending support groups (Allen *et al* 1992). Some groups have difficulties in recruiting (Twigg 1992). Some carers prefer to use any free time that they get in other pursuits (Twigg 1992).

Summary of results for carer support groups

- Support groups are valuable as an opportunity for carers to share experiences with people in a similar situation and to exchange information and emotional support.
- There is no conclusive evidence regarding the effectiveness of support groups.
- There is no evidence that support groups produce direct improvements in the well-being of carers or in their ability to continue caring.
- No research has been carried out into the cost-effectiveness of support groups.
- Support groups are valued by those who attend, but not all carers wish to attend.

Social work and counselling

Description of social work and counselling in England and Wales

Julia Twigg's description of the role of social work in relation to informal carers, though written over ten years ago, is still relevant today:

“Social workers are the senior and dominant profession in social services departments, and as such they occupy a pivotal position in relation to community care.”

(Twigg 1992: 65)

Twigg identified two rather different roles that social workers play in community care. First, there is their casework role, and second, there is their role as assessors and mobilisers of packages of care or care managers. It is primarily in relation to their casework function that social workers perform a counselling role, which will be the focus of attention here.

Effectiveness of social work and counselling: outcomes for carers

It is common, in the international literature on interventions for carers, for counselling to be cited as an effective measure to relieve carer distress (Schofield *et al* 1998, Zarit and Leitsch 2001, Sørensen *et al* 2002). In their recent review of services to support carers of people with mental health problems, Arksey and colleagues examined a number of papers on counselling programmes for carers of people with Alzheimer's disease or dementia, most deriving from the US (Zarit *et al* 1987, Mittelman *et al* 1993, 1995, 1996, Whitlatch *et al* 1991) and one deriving from the UK (Sutcliffe and Lerner 1988). Their review suggested that benefits might accrue to carers undertaking counselling. An early study had suggested that treatments, including individual and family counselling, made no significant difference to outcomes for carers (Zarit *et al* 1987). However, in a now widely cited paper, a subsequent re-analysis of this study using more sophisticated statistical techniques, found that individual and family counselling was successful with the majority of caregivers on measures of psychiatric distress and perceived burden. The authors concluded that a program of individual and family counselling may have particular benefits in relieving distress (Whitlatch *et al* 1991). Subsequent studies have also reported that counselling services can reduce depression among carers (Mittelman *et al* 1995).

The study by Davies and Fernandez (2000) of community care in England and Wales in the 1990s also suggests that counselling may be an effective way of reducing carer burden. The authors found that long-run intensive social work had clear and constant marginal productivities for carer burden, and that relatively small amounts of input produced relatively large reductions in carer stress (measured on the Kosberg carer burden scale) (Davies and Fernandez (2000: 132). Elsewhere, they describe this type of intervention as “counselling/therapeutic social work additional to the tasks performed in care management activity” (Davies and Fernandez 2000: 125).

Effectiveness of social work and counselling: effects on older people's admission to institutional care

The evidence regarding the effectiveness of counselling for carers on the subsequent institutionalisation of the older person is mixed. In their review, Arksey and colleagues (2002) cite a number of US studies that suggest that counselling for carers might delay or postpone long-term institutionalisation, particularly during the early and middle stages of dementia (for example, Mittelman *et al* 1993, 1996). However, the recent study of community care in England and Wales by Davies and Fernandez (2000) found that social work was not effective in extending the users' length of time in the community (Davies and Fernandez 2000).

Cost-effectiveness of social work and counselling

The ECCEP study of community care in England and Wales suggests that social work may be a highly cost-effective intervention. The study found that social work and counselling were highly cost-effective in reducing subjective carer burden compared to other interventions. For example, a reduction of 2 points on the Kosberg carer-burden scale was achieved by spending around £3 (in 1996 prices) on therapeutic social work with the carer. In comparison, the same reduction was achieved by spending around £35 on daycare (provided to older people with severe cognitive impairment) or around £70 on respite care (provided to older people with cognitive impairment) (Davies and Fernandez 2000: 131-132; Figures 8.14, 8.15, 8.16). The 'unconstrained' optimisation analysis concluded that, if the goal was to optimise reductions in carer burden, social work would become an important element in the community care package (Davies and Fernandez 2000: 298, **Appendix 2**) It should be noted, however, that optimising carer welfare reduces the number of days that older people stay in the community. This is partly because of the effects of social work, which is effective in reducing carer stress but not in prolonging the users' length of stay in the community (Davies and Fernandez 2000: 299).

Access to social work and counselling in England and Wales

Over ten years ago, Julia Twigg summarised the evidence in relation to social work interventions for carers by saying that "Social workers are well placed to recognise and act upon the needs of carers. Few carers, however, come into contact with a trained social worker" (Twigg 192: 67).

The ECCEP community care study provides more recent evidence regarding the contact between qualified social workers and carers of older people (Bauld *et al* 2000, Davies and Fernandez 2000). The study suggests that only a minority of carers still probably have access to a qualified social worker. Thus, although therapeutic social work was highly effective in reducing carer burden, carers of only 18 per cent of users actually received this intervention (Davies and Fernandez 2000: 129). Moreover, although the largest single group of care managers were qualified social workers, they

only represented a third of all care managers and, even in the more complex cases involving highly dependent users, less than half of the care managers were qualified social workers (Bauld *et al* 2000: 117).

It is difficult to determine whether there has been any change in access by carers to therapeutic social work between the mid-1980s and the mid-1990s. The previous PSSRU study, the DCP study, carried out in the mid-1980s, does not seem to have collected data on therapeutic social work interventions, comparable to that collected in the later ECCEP study. Using other information from the DCP and ECCEP studies suggests that the proportions of clients receiving social work inputs, in general, may not have changed very much between the mid-1980s and the mid-1990s. The DCP study found that 40 per cent of client households received social work inputs, whereas the ECCEP study found that 35 per cent of care managers were qualified social workers (Davies *et al* 1990: 63, Bauld *et al* 2000: 117).

Summary of results for social work and counselling

- In the international literature on interventions for carers, counselling is cited as an effective measure to relieve carer distress.
- In England and Wales, counselling/therapeutic social work has been found to be effective in reducing subjective carer burden.
- In England and Wales, counselling/therapeutic social work may also be highly cost-effective in reducing subjective carer burden.
- Although evidence from the US suggests that counselling for carers might delay or postpone long-term institutionalisation, recent evidence in England and Wales has found that social work is not effective in extending the users' length of time in the community.
- Only a minority of carers England and Wales are likely to come into contact with qualified social workers.

The home help/care service

Description of the home help/care service in England and Wales

The home help service is the most important domiciliary care service in England and Wales. It has been described as “the foundation upon which most community care packages are built” (Bauld *et al* 2000: 249). In the ECCEP study of community care in the 1990s, home help was more widely received than any other service, with 70 per cent of users receiving help from a Social Services Department (SSD) home help in 1995 (Bauld *et al* 2002). In 1998, over a third of a million people aged 65 and over received local authority home help/care in England (Pickard *et al* 2001). It is important

to note that, in many local authorities, much home care is no longer directly provided by the local authority, and care managers now determine the hours of service that are to be bought from agencies, usually under block contracts.

In the past, the home care service provided a housework service to elderly people in their own homes. However, over the last fifteen years or so, it has increasingly focused on the provision of help with personal care. By the late 1980s, home help services had been redesignated 'home care' services in many authorities (Sinclair & Williams 1990). The aim was for the service to provide a more intensive form of support and thereby act as an alternative to residential care. The change from home help to home care involved a redefinition of the duties of the home helps, to include not just domestic tasks (such as cleaning and cooking) but physical tasks approximating to home care (such as dressing, washing and feeding clients) and social duties (including talking with clients, helping clients to maintain contact with family, friends and community, and assisting with shopping and recreation).

Effectiveness of home help/care: outcomes for carers

Research carried out before the community care reforms were introduced in the UK provided some evidence that receipt of home care was beneficial to carers' well being (Twigg 1992). Levin and her colleagues found that receipt of home help could improve the psychological health of carers looking after someone with dementia (Levin *et al* 1989). There was also clear evidence of the helpfulness of the home care service to carers. As Julia Twigg wrote in 1992:

"It [the home care service] is highly valued by its clients; and this positive estimation is found also among carers who receive its support...Home helps are often praised by carers for the practical help that they give. They are also valued for their company and emotional support. This is particularly important where carers are themselves elderly and looking after someone with dementia with whom they can no longer have a normal conversation. Visits from the home help can also allow the carer to have a break and to get out of the house for a brief period."

(Twigg 1992: 68)

Research carried out after the community care reforms were introduced has, to a large extent, confirmed this positive evaluation of the benefits for carers of provision of the home care service to some groups of older people. The ECCEP study found that subjective caregiver burden declined among carers of older people with mild and severe cognitive impairment (identified by the Katzman scale) with increases in the level of input of home care (Davies and Fernandez 2000: 130). Nearly half of the recipients of home care in the study were identified as having mild or severe cognitive impairment. In addition, subjective caregiver burden declined among carers of older people with increases in the level of input of home care, when used in conjunction with daycare. This was true for approximately a third of recipients of both home care and daycare in the ECCEP study (Davies and Fernandez 2000). However, the study

also found that home care inputs by themselves contributed less to the relief of caregiver burden than other services, such as institutional respite and daycare (Davies and Fernandez 2000: 175).

Not all recent research has found that home care benefits carers' psychological health. A study of an augmented domiciliary service for older people with dementia and their carers in north-east London, found no evidence of any appreciable reduction in psychological symptoms of carers (Riordan and Bennett 1998). However, the authors themselves argued that the small sample size (of only 19 client-carer pairs) affected the results and that the evaluation might not, in any case, have lasted long enough to capture changes in psychological symptoms in carers (Riordan and Bennett 1998: 142).

In summary, the evidence suggests that home care is a service that is highly valued by many carers. In addition, the more rigorous research evidence also suggests that home care contributes to caregiver welfare, although it may not be the most effective form of intervention for this purpose.

Effectiveness of home help/care: effects on older people's admission to institutional care

Research carried out before the community care reforms were introduced in the UK provided some evidence that receipt of home care could help delay institutionalisation of the older person (Twigg 1992). Levin and her colleagues found that receipt of the standard home help service reduced the likelihood that older people with dementia who were looked after by men would enter residential care (Levin *et al* 1989). A study of a specialist domiciliary personal care service provided to older people with dementia and their carers, the Support and Stay scheme in West Glamorgan, reported that the majority of carers surveyed said that they would not have been able to continue caring without the service (Whitby and Joomratty 1990).

The post-community care study by Davies and Fernandez (2000) found that provision of home care had a positive impact on the older person's length of time in the community. The study found that receipt of home care increased the length of stay in the community for 93 per cent of recipients of the service. In other words, for over 90 per cent of recipients, greater amounts of home care provided to the older person resulted in more time spent in the community (Davies and Fernandez 2000: 59). For example, for older people who could not do heavy housework, expenditure of approximately £20 a week on home care (in 1996 prices) increased the time spent in the community by approximately 100 days, although there were significant decreasing returns to scale (Davies and Fernandez 2000: 60). Overall, the study found that receipt of home care, and other services, had a large impact on users' length of time in the community, but that home care inputs had the greatest impact (Davies and

Fernandez 2000: 61). Home care had an impact on length of time in the community for users both with and without principal informal carers and for users with carers in all the dependency groups.

Other recent studies have also found that provision of home care can enable older people to remain in the community for longer. The main finding of the study of the augmented domiciliary service for older people with dementia and their carers in north-east London, referred to earlier, was that families in receipt of the Dementia Support Service were able to support their dependent relative with dementia for a longer period than matched pairs receiving 'traditional' services (Riordan and Bennett 1998: 142).

Effectiveness of home help/care: impact on the user

The main evidence concerning the impact on the older person of home care provided to households with carers comes from the study by Davies and Fernandez (2000) of community care during the 1990s. The study suggests that, with regard to user satisfaction with the level of services, there are significant productivities for all users of home care (Davies and Fernandez 2000: 67). For users with carers, substantial productivities are achieved by the initial units invested, but marginal productivities fall rapidly thereafter. In other words, the satisfaction of older people with the level of services they receive increases markedly with quite low levels of input (around £10 a week or around an hour a week), but further inputs of home care do not increase satisfaction very much further.

There is little evidence in the literature of conflicts of interest between carers and older people regarding receipt of home care. Rather it is seen as a service that is valued both by older people and carers (Twigg 1992).

Cost-effectiveness of home help/care

As indicated earlier, the study by Davies and Fernandez (2000) of the post community care reform period in the UK has implications for cost-effectiveness. The 'unconstrained' optimisation analysis carried out in this study suggested that, if the number of days spent by older people in the community were to be optimised, then there would be a concentration of resources on three services: home care, daycare and respite care (Davies and Fernandez 2000: 218). The analysis also suggested, however, that of these three services, levels of home care services would be reduced and that similar quantities of services would be allocated to all user groups. The reason for this conclusion was that, although the study found a productivity effect for home care that applied to 93 per cent of users, the marginal productivities were small beyond a low threshold (Davies and Fernandez 2000: 202). The study suggested that an input of home care costing around £20 a week in 1996 prices (that is, around 2 hours home care a week) would be the optimal for all user groups. The authors do suggest some caution with this result, pointing out that, "The growth of independent

supply undertaking a wider range of tasks with greater flexibility of timing may change the productivity curve and so make this finding out-dated” (Davies and Fernandez 2000: 202).

In contrast to the optimisation analysis for maintaining older people in the community, the analysis optimising reductions in carer burden suggest that home care is not a cost-effective intervention (Davies and Fernandez 2000: 308). The ‘unconstrained’ optimisation analysis suggests a concentration of resources on four services (daycare, meals, respite care and social work) which do not include home care. The authors argue that, although home care contributes to caregiver welfare, it is not as cost-effective in doing so as combinations of inputs that exclude it. The point needs to be emphasised, however, that reducing carer burden in this analysis also reduces users’ length of time in the community (Davies and Fernandez 2000: 299).

The optimisation analysis carried out in the ECCEP study therefore suggests that home care forms an essential part of a cost-effective community care package that optimises the time spent by older people in the community. However, it is not so clear that home care is a cost-effective way of reducing carer burden. A similar conclusion regarding the effectiveness of home care was reached by Arksey *et al* in their review of services to support carers of people with mental health problems. This review concluded that: “The evidence suggests that provision of domiciliary care can postpone or reduce permanent institutionalisation. Domiciliary care may therefore be a useful additional service alongside other interventions for carers, which may help with overall coping and perceived levels of burden” (Arksey *et al* 2002: 61).

Access to home help/care in the UK

Carers of older people have historically found it difficult to access home care. The home care service has in the past been directed away from support for carers. The service has essentially been directed at unsupported older people living alone (Henwood and Wistow 1999, Parker 1999, Pickard 1999). In recent years, under heightened debate about carers, the home care service has included support for family carers among its aims. However, because of the scarcity of resources, most home care is still targeted on those who live alone (Bebbington & Davies, 1993).

A number of studies relating to the 1980s indicated the way in which home care tended to be directed away from older people with carers. These studies showed that disabled older people living alone were far more likely to receive home care than older people with similar disabilities living as married couples or living with others (Evandrou 1987). The household structure in which the older person lived was therefore found to be a more important factor in determining receipt of home help services than the disability of the older person (Evandrou 1987). Similar results were found in a number of major studies carried out in the 1980s (Arber *et al* 1988, Davies *et al* 1990, Bowling *et al* 1991, 1993).

Studies carried out during the 1980s suggested that the bias towards living alone meant that the home care service was directed away from situations that were known to be extremely stressful for carers and where many would have valued support (Twigg 1992). Living with someone with dementia was cited as a prime example of this. Levin and her colleagues in their study of the supporters of people with senile dementia found that carers who were dealing with faecal incontinence, disturbed behaviour and who showed the greatest strain were far less likely to receive home help than were the less heavily burdened. This arose because of the bias in allocation against those who shared a household (Levin *et al* 1989). There was evidence that more carers would have liked the home care service than received it (Levin *et al* 1989).

Studies in the 1980s also showed that, where home care was provided, the intensity of support was low. Research undertaken in the 1980s indicated that the most common allocation of home care was for two hours a week, with little variation by dependency level (Davies *et al* 1990).

The aim of the community care reforms was to change services like the home care service so that they were more responsive to need. It is clear that the home care service has changed considerably in the past decade or so. Department of Health data show that home care has become more intensive, providing a higher level of help to fewer users. The number of older people's households receiving home help/care in England fell from approximately 450,000 in 1995 to approximately 380,000 in 1998 (Pickard *et al* 2001). At the same time, the intensity of support has increased. In the community care studies carried out by the PSSRU, the average hours of help received by the most dependent users increased from five hours per week in the mid-1980s to over nine hours per week in the mid-1990s (Bauld *et al* 2000). The ECCEP study also shows how home care is now targeted on those with greatest disability and points to striking differences between the average number of hours of home care received by the most disabled older people compared to the less disabled (Bauld *et al* 2000).

It is not so clear, however, whether this has benefited disabled older people with carers to the same extent as it has benefited older people without carers. The ECCEP study certainly shows that users who do *not* have a carer are receiving home care more frequently than those with a carer, although the differences are not great (Bauld *et al* 2000). The ECCEP study, however, only focuses on older people in receipt of services and therefore does not tell us about those who are not receiving services. For this information, national survey data can, however, be used.

Analysis of national survey data suggests that, since the community care reforms were implemented, there seems to have been a redistribution of home care resources away from disabled older people with informal carers. The analysis used GHS data on people aged 65 and over to examine changes in receipt of home care between 1994 and 1998 (Pickard *et al* 2001). The 1998 GHS data were the first GHS data to reflect the community care changes; the 1994 data were collected too soon after the changes were fully implemented for their impact to be observed in household surveys.

The analysis focused on older people with some level of disability or dependency, measured by difficulty with, or inability to perform, personal care or domestic tasks. The results suggest a redistribution of resources away from disabled older people with informal care to those without informal care. 41 per cent of all the home help/care hours received by disabled older people per week in the 1994 GHS sample went to married/cohabiting couples; in 1998, the figure was 13 per cent. During the same period, the proportion of home help/care hours received by dependent older people living alone without informal help increased from 18 per cent to 42 per cent (Pickard *et al* 2001). Between 1994 and 1998, Department of Health data suggest that the annual hours of local authority home care (provided to people of all ages) increased from 1.8 million to 2.6 million. Allowing for the change in the number of hours of home care, the analysis of the GHS data between 1994 and 1998 by Pickard and colleagues implies that there was a very large increase (+174 per cent) in the absolute number of hours allocated to older people without informal care and a smaller absolute reduction (-17 per cent) in the number of hours allocated to older people with informal care.

These results suggest that older people with informal carers have not been the beneficiaries of the targeting of home care on more dependent users. Rather, the analysis suggests that home care has been directed away from older people with carers. Indeed, it suggests that home care is even more likely to be directed away from older people with carers than before the community care changes were introduced.

The post-reform concentration of home care resources on older people without carers is illustrated by an analysis of a sub-group of dependent older people identified in the 1998 GHS data on people aged 65 and over (Pickard *et al* 2001). This sub-group of dependent older people was defined by the fact that they needed 'regular daily help with things that fit and healthy people would normally do for themselves'. The sub-group constituted some of the most dependent older people in the community. Trend data were not available for this group as the GHS asked about them for the first time in 1998. The sample size of this group in the GHS was quite small, with only 182 individuals identified in the 1998 GHS. The analysis suggested that, among frail older people living in the community who needed regular daily help in 1998, 80 per cent of those who lived alone without informal help received the home help/care service. By contrast only 9 per cent of those who were married/cohabiting, and only 11 per cent of those living with others, received the home help/care service (Pickard *et al* 2001).

Summary of results for home help/care

- The home help/care service is the central building block of most community care packages in the UK.
- The evidence suggests that home care is a service that is highly valued by both carers and older people.

- The more rigorous research evidence also suggests that home care contributes to reductions in carer stress, although it may not be the most effective form of intervention for this purpose.
- Provision of home help/care to older people with carers can postpone or reduce permanent institutionalisation.
- The evidence suggests that home care should form an essential part of a cost-effective community care package that optimises the time spent by older people in the community.
- It is not so clear, however, that home care is a cost-effective way of reducing carer burden.
- The home help/care service has not historically been made available to carers.
- The home help/care service is still not widely available to carers of frail older people living in the community.
- There is evidence that home care is now even more likely to be directed away from disabled older people with informal carers than before the community care changes were introduced.

Multi-dimensional approaches

Description of studies

A number of studies have evaluated community care programmes for older people and their carers. These programmes have included a number of different services of potential benefit to carers. The programmes have all utilised a case management approach, which is designed to deliver a more integrated and co-ordinated package of care to older people and carers. Cost-effectiveness is a major concern in all these studies. Case managed support for carers has been evaluated in a number of countries, including the US, the UK, Canada and Italy (Johri *et al* 2003). Two recent examples are considered here: the Medicare Alzheimer Disease Demonstration and Evaluation (MADDE) from the US (Fox *et al* 2000, Newcomer *et al* 1999a, 1999b, Yordi *et al* 1997) and the care management approach adopted in the UK and evaluated by the ECCEP project (Bauld *et al* 2000, Davies and Fernandez 2000).

MADDE: the US example

The purpose of MADDE was to test a Medicare-funded case management and community care benefit targeted for persons with dementia (Fox *et al* 2000). The primary goal of the intervention was to assist families providing care for people with dementia. MADDE operated in eight different sites across the US between 1989 and 1994. It enrolled 8,095 beneficiaries and, although some were excluded from subsequent analyses, the evaluation still included over 5000 beneficiaries.

The rationale behind MADDE was outlined succinctly by Fox and colleagues:

“When the demonstration was initiated in 1989, it was hoped that if case management and service price reductions were provided, then formal services would be more accessible to caregivers of demented Medicare beneficiaries. It was thought that the initiation of formal service assistance would relieve some of the burden associated with caregiving. This would allow the informal support system to remain intact for a longer period of time. The demonstration was planned to accomplish this by providing case management assistance, education and training, and service price reductions. The Health Care Financing Administration also desired the intervention to, at minimum, demonstrate budget neutrality. This goal was anticipated to be achieved by earlier identification of, and intervention in, preventable client and caregiver health problems.”

(Fox et al 2000: 88)

The MADDE intervention differed in a number of respects from previous long-term care demonstrations in the US, the most important of which was the Channeling experiment. The Channeling experiment was a national test of expanding public financing of home care conducted from 1982 to 1985, which had sought to substitute case-managed care at home for care in nursing homes, thereby reducing long-term care costs and improving the quality of life of older people and their families (Kemper et al 1987). The Channeling experiment had targeted disabled older people (aged 65 and over) who were at high risk of nursing home placement (Kemper et al 1987). Unlike the Channeling experiment, the MADDE intervention was mainly designed to support the primary caregiver and the informal care network (Fox et al 2000: 88). Compared to the Channeling experiment, MADDE focused more on the effect of case management on caregiver burden and depression.

In the design of the MADDE demonstration, eligible applicants were randomly assigned to treatment and control groups. Services that were covered by MADDE included daycare, home maker/housekeeping, heavy cleaning and personal care. Specific caregiver support services included education and training, support groups, mental health and counselling. The demonstration tested two models, which differed in terms of the number of cases per case manager and financial benefits (Fox et al 2000).

Effectiveness of MADDE: outcomes for carers

Participants in a subset of MADDE sites were found to have had statistically significant but small reductions in caregiver burden and depression. These results were persistent whether measured at 6 months, one year or across all three years of the demonstration. However, treatment and control group differences were not statistically significant when all sites were considered together (Newcomer et al 1999a).

Effectiveness of MADDE: effect on older people's admission to institutional care

The provision of case management and community services in the demonstration was not sufficient to change the rates of nursing home entry or to delay institutionalisation (Fox *et al* 2000). This result had been anticipated because earlier community-based long-term care demonstrations had reported similar findings (Kemper *et al* 1987, Weissert *et al* 1988).

Cost-effectiveness

The demonstration produced statistically significant but not budget-neutral reductions in Medicare expenditures (Fox *et al* 2000). Those who received the MADDE intervention, the treatment group, had significantly lower Medicare expenditures than did people with comparable health status in the control group. The average annual difference between the treatment and control expenditures was approximately \$500. However, these savings were not large enough to compensate for the case management and social and health service intervention costs incurred to achieve them. Even in sites where Medicare savings had been made, total expenditures were usually around \$2,000 short of the estimated annual reductions needed for the demonstration to approach budget-neutrality (Fox *et al* 2000).

Evaluation of MADDE

Those involved in the evaluation studies have suggested a number of reasons why MADDE did not produce more beneficial effects. They have argued that it might have been more effective if the demonstration had targeted caregivers at risk of caregiver burden and depression, had offered more flexible service delivery or had provided more intense or more focused services (Fox *et al* 2000). Others have also suggested that large-scale demonstrations of this kind may fail to provide services at sufficient intensity to produce noticeable effects (Zarit and Leitsch 2001, Gaugler *et al* 2002). It is certainly the case that case management interventions elsewhere have produced more beneficial effects, including favourable impacts on rates of institutionalisation and costs (Johri *et al* 2003). As a recent synthesis of the evidence on international experiments in integrated care for the elderly concluded, “the cost-effectiveness of the intervention depends largely on the system of care within which it is introduced” (Johri *et al* 2003: 231). Nevertheless, as the researchers involved in MADDE themselves point out, the sheer size of the sample involved in the intervention lends credence to its conclusions (Fox *et al* 2000).

Care management in the UK

Background

The case management model was brought to Britain in experimental form in the 1980s and was particularly associated with the Kent community care experiment. The evaluation of this and associated developments suggested that case management for

older people on the brink of admission to a residential care home could deliver a more efficient and effective response than standard services (Davies and Challis 1986, Challis and Davies 1986).

Under the title care management, this approach has formed the central plank in the community care reforms, associated with the 1990 *NHS and Community Care Act*. A continued commitment to care management is evident in more recent policy documents (Department of Health 1998). The principle advantages of care management are described in terms of: the ability to move services towards a needs-led as opposed to a service-dominated approach; the provision of care planning at an individual level, specifying desirable outcomes; and the provision of a more integrated service response and one that draws on a wider range of services across the statutory, voluntary and private sectors. Balancing the needs of users and carer is recognised as one of the tasks of the care manager (Twigg 1992).

The ECCEP study, to which this review has already referred extensively, was designed to evaluate the community care changes. An earlier study, the DCP was the first stage of the study of community care before and after the introduction of the 1990-1993 reforms. An important aim was to establish service productivities. The results, which were reported in *Resources, Needs and Outcomes* (Davies *et al* 1990), found productivities generally to be low. The central issue for the post-reform evaluation, the ECCEP study, was whether this had changed and whether there were now substantial productivities for outputs of greatest policy importance (Davies and Fernandez 2000). The ECCEP study, published in *Equity and Efficiency Policy in Community Care*, concluded that there had been considerable change: “what the analysis has discovered is a large number of service productivity effects for the entire group of authorities” (Davies and Fernandez 2000: 404).

The underlying argument of the ECCEP study, then, is that the community care reforms have made a real difference to the efficiency of community care. Care management is a central plank of the reforms. The ECCEP study argued that care management had served as the mechanism for matching services from a range of providers with the needs of users and carers (Bauld *et al* 2000: 378). While evidence from other PSSRU studies has found that the core tasks of care management have been interpreted and implemented in different ways in different parts of the country (Challis *et al* 2001, Weiner *et al* 2002), the ECCEP study found that crucial aspects of care management were reflected in the outcomes identified in the study (Bauld *et al* 378). In particular, the pattern of assessment evident in the study reflected the targeting of resources towards more dependent users and reflected the increased needs-led orientation of assessment (Bauld *et al* 2000: 378).

The issue then arises as to how far the introduction of case management has benefited carers. As this review has already shown, the increased service productivities identified in the ECCEP study applied to services of benefit to carers as well as users. The ECCEP study has suggested that a number of community care

services are effective in improving the well-being of carers. The question also arises as to whether the changes in the patterns of service delivery associated with the community care reforms *overall* have also benefited informal carers. In other words, what has been the overall effect of the introduction of the community care reforms on the well-being of carers?

Effectiveness of care management in England and Wales: outcomes for carers

The results of the ECCEP study suggest that the effects of the community care changes have not, on the whole, benefited carers. First, the study found that the average stress of caregivers (measured by the Rutter scale) was actually higher after six months of receiving a community care package than before the care package was implemented (Davies 1997, Davies and Fernandez 2000: 130). Second, although the mean stress score for all carers, measured on the Kosberg Cost of Care Index, declined during the course of the study, this was not true for the carers of the more dependent users (Bauld *et al* 2000: 346). The study found that among those looking after more dependent users, there was an increase in the level of stress. This was true of both carers of people with cognitive impairment and carers of users with critical interval needs (the most dependent older people). Third, it was not just on measures of stress that the well-being of carers, especially carers of the more dependent users, suffered. It was also on a range of indicators relating to carer employment, breaks from caring and the user/carer relationship (Bauld *et al* 2000: 386). As Bauld *et al* concluded:

“In particular, those looking after more dependent users, particularly users with a cognitive impairment, were experiencing more problems following care management intervention than they had before the new care package was in place, at Time 1. By the second interview, the carers of more dependent users recorded higher stress scores overall, reported increased burden, were less likely to have taken a break in the past six months than other carers, and reported a deterioration in their relationship with the user. Combined with the lower rates of satisfaction with services reported by these carers..., it is evident that the benefits which more dependent users demonstrated by Time II as a result of targeted service inputs were not shared by their carers.”

(Bauld *et al* 2000: 386)

The ECCEP study, Bauld *et al* pointed out, had shown how more dependent users had benefited from higher levels of services and demonstrated some improvements in functional ability, mental health and quality of life indicators (Bauld *et al* 2000). However, the equivalent improvements had not been evident among their carers. As they concluded:

“This suggests that the community care service system put in place following the 1990 reforms has succeeded in maintaining more dependent older people in their own homes, but has failed adequately to support their carers.”

(Bauld *et al* 2000: 386)

Bauld *et al* identified three areas where improvements were needed: support with specific tasks which carers find difficult, the carer's right to have their own health needs met and the chance for more carers to take a break from caring.

The ECCEP study suggests, therefore, that care management has not, so far, enhanced the well-being of carers in this country. The study also suggests, however, that particular services are effective in supporting carers. It is not, therefore, the case that case-managed services in this country are intrinsically ineffective. Rather it seems more likely to be the case that carers are not receiving effective services in sufficient quantities to make an appreciable difference to their well-being overall.

Effectiveness of care management: effect on older people's admission to institutional care

The effects of care management on older people's admissions to institutional care were explored by the ECCEP study, although the results have not been published (Davies and Fernandez 2000). The study found evidence that more care management time improved the way services were mixed, which in turn brought about improvements in older people's length of time in the community (José Fernandez, personal communication).

Access to care management

The ECCEP study found that the majority of care packages (54 per cent) were intended to support the carer, at least in part (Bauld *et al* 2000). The study was, however, concerned only with older people using local authority-arranged social services and therefore did not include those not in receipt of services. Since the ECCEP study was carried out, the *Carers (Recognition and Services) Act (1995)* and the *Carers and Disabled Children Act (2000)* have respectively established and then strengthened the rights of carers providing substantial and regular care to an assessment. However, the literature widely reports that only a minority of carers nationally are actually receiving assessments (Department of Health (DoH) 2001b, Carers UK 2003). A recent survey of carers' assessments in England by the national organisation representing carers, which generated 1,695 replies from carers, found that only a third had actually had a carer's assessment (Carers UK 2003). This suggests that carers' access to care management, in spite of recent legislation, is still restricted.

Summary of results for multi-dimensional approaches

- Although the MADDE intervention in the US produced reductions in caregiver burden and depression in a sub-set of sites, these were not significant when all sites were considered together.
- In England and Wales, the ECCEP study found that average stress of caregivers increased during the period when they received a community care package.

- The ECCEP study also found that carers of more dependent users experienced more problems on a range of indicators following care management intervention than they had before the new care package was in place.
- However, the ECCEP study also identified a number of services that are effective in supporting carers. This suggests that it is not that case-managed services are intrinsically ineffective.
- Rather it seems more likely to be the case that carers in the ECCEP study were not receiving effective services in sufficient quantities to make an appreciable difference to their well-being overall.
- Self-evaluation of the MADDE intervention also supports this conclusion: the evaluators of MADDE suggested that the intervention might have been more effective if more intense or more focused services had been offered.
- The majority of carers in the UK do not currently have access to care management.

Part 3

Summary and Conclusions – The effectiveness and cost-effectiveness of support and services to informal carers of older people

Summary

This literature review has looked at the evidence for the effectiveness and cost-effectiveness of the following types of support and services of potential benefit to informal carers: daycare, in-home respite care, institutional respite care, carer support groups, social work and counselling, the home help/care service and multi-dimensional approaches. Other services of potential value to carers, including meals-on-wheels and community nursing, have not been evaluated here (due to time constraints).

The primary focus of the literature review has been on recent studies of the effectiveness of services in England and Wales, in order to reflect current community care policies. The summary here refers in particular to evidence relating to community care services in this country at the present time. Evidence from other countries, and from earlier studies in this country, are summarised in the descriptions for each service.

What follows is a summary of the evidence relating to, first, the effectiveness and then, the cost-effectiveness of the services evaluated here. Where there are important caveats to these summaries, they are also included, but full details of exactly which carers benefit most from which services are included in the descriptions for each service.

Effectiveness of services

Effectiveness of services: outcomes for carers

In the context of current community care policies and practice in England and Wales, there is evidence to suggest that the following forms of support and services can be effective in reducing the negative psychological effects of caring for carers and therefore have some positive outcomes for carers:

- daycare;
- home help/care;

- institutional respite care; and
- social work/counselling.

Effectiveness of services: effects on user's admission to institutional care

In the context of current community care policies and practice in England and Wales, there is evidence to suggest that the following forms of support and services can be effective in delaying admissions to institutional care:

- daycare;
- home help/care; and
- institutional respite care (though see conditions below).

Conditions:

Institutional respite care can increase the probability of admissions to institutional care for some carers. This well-established relationship was also found in the post-reform community care study of England and Wales in the mid-1990s. The ECCEP study (Davies and Fernandez 2000) found that provision of institutional respite care increased the length of time spent by the older person in the community in some cases (for example, carers of older people with behavioural problems), but decreased it in others (in particular, those with 'bad user-carer relationships' and more reliant older people) (For more details, see section on institutional respite care above).

Effectiveness of services: impact on older people

In the context of current community care policies and practice in England and Wales, there is evidence to suggest that older people may feel *ambivalent* about using the following forms of support and services:

- daycare (see conditions below); and
- institutional respite care.

Conditions:

Large amounts of *daycare* (beyond about 2 days a week) are associated with reductions in user satisfaction with services.

Many older people do not want *institutional respite care*, because they do not want to go into an institution, however temporarily.

Insufficient evidence to evaluate effectiveness

There was one service, *in-home respite care*, about which there was insufficient evidence to evaluate effectiveness. The lack of evidence about in-home respite care was unfortunate because this is a form of service that older people and carers particularly value and for which there are expressed unmet needs.

No evidence of effectiveness

There was also one service, carer support groups, about which no evidence of effectiveness could be found. There was no conclusive evidence to suggest that *carer support groups* are an effective intervention for carers. Again, however, the literature suggests that support groups are valued by those who attend.

Cost-effectiveness

Cost- effectiveness of services: outcomes for carers

In the context of current community care policies and practice in England and Wales, there is evidence to suggest that the following forms of support and services can be cost-effective in reducing the negative psychological effects of caring for carers¹:

- daycare;
- institutional respite care; and
- social work/counselling.

Cost- effectiveness of services: effects on user's admission to institutional care

In the context of current community care policies and practice in England and Wales, there is evidence to suggest that the following forms of support and services can be cost-effective in delaying admissions to institutional care:

- daycare;
- home care; and
- institutional respite care.

Overall summary of effectiveness and cost-effectiveness of services for carers

Of the six services evaluated here, evidence was therefore found to suggest that four were effective and/or cost-effective for carers in terms of one or more of the outcomes examined here. These were: daycare, home help/care, institutional respite care and social work/counselling.

Access to effective services for carers/older people with carers

The main question examined in the literature review has been whether access to effective services has increased since the introduction of the community care reforms.

The following evidence suggests that access to services for carers of older people has increased since the community care reforms were introduced:

¹ Although not considered in detail in this review, Davies and Fernandez also identified the meals-on-wheels service as cost-effective in reducing carer burden. They suggested that if carer well-being was maximised within existing budgets, there would be substantially increased levels of meals to all users (Davies and Fernandez 2000: 308).

- *Daycare* is now more targeted on frail older people with carers than before the community care reforms were introduced.
- Access to *institutional respite care* for carers of frail older people has increased.

The following evidence suggests that access to services for carers either has not changed or has declined since the community care reforms were introduced:

- There has been a decline in the intensity of *daycare* received by frail older people, including those with carers.
- There is evidence of a shift of *home care* resources away from dependent older people with carers.
- There has been very little change in access to *institutional respite care* for heavily involved carers nationally.
- Most recently (since 2000), there has been a decline in the number of temporary admissions of older local authority-supported residents to care homes.
- There is continuing underprovision of, and unmet needs, for *institutional respite care* by carers of frail older people.
- There is a continuation of a situation in which only a small proportion of carers have access to *therapeutic social work*.

Conclusions

Effectiveness/cost-effectiveness of services to support carers

One of the issues that the literature review aimed to explore was whether it is more effective to support carers by supporting the older people that they care for or whether it is more effective to support carers by providing specific carer services.

The evidence presented in the literature reviewed here suggests that both services aimed at the older person, such as the home help/care service, *and* services aimed at the carer, such as daycare/institutional respite care, can be effective in improving the welfare of carers and reducing the negative psychological effects of caring. The literature also suggests that both types of service can also be effective in delaying the admission of the older person to institutional care and both are consequently in the interests of older people who wish to remain in the community. It is, therefore, clear that both forms of service should be available to older people with carers.

The literature also suggests that both services aimed at the older person and carer specific services are cost-effective ways of supporting older people with carers to remain the community for longer periods of time. Indeed, daycare, home care and institutional respite care were the three services that were *most* cost-effective in maximising older people's length of stay in the community (Davies and Fernandez 2000). The literature also suggests that daycare and institutional respite care are cost-effective in reducing carer stress and that, although the evidence in this respect for

home care is more equivocal, other services provided to the older person, like meals-on-wheels, are cost-effective. Taken together, the literature suggests, again, that both services aimed at the older person *and* carer specific services can be cost-effective. And again, this supports the conclusion that both forms of service should be available to older people with carers.

On balance, however, services aimed at the older person may be more acceptable to both to the older person and the carer. Services provided for the older person are much less likely to raise issues of conflict between older people and their carers than are specific carer services. There is evidence that older people are often ambivalent about services such as daycare and institutional respite care. For example, daycare that is provided primarily to benefit the carer may not be what the user wants, especially when this involves frequent attendances at a day centre. Equally, many older people do not want to go into an institution, even if this is just for a short stay.

This suggests that, if anything, there should be a preference in favour of services provided to the older person. Current government policies, however, currently favour specific carer services, such as breaks from caring. In terms of current community care practice, while there is some evidence that access to respite services for carers of older people increased during the 1990s, the same does not seem to have been true of home care services. The home care service is the bedrock of community care in this country and yet it is still primarily directed at older people without carers. In the 1998 GHS, older people needing regular daily care who lived alone without informal help were nearly ten times more likely to receive home care than older people who lived with their spouses/partners. This, in turn raises more general issues about access to services.

Access to services for older people with carers

The evidence from the literature review, summarised above, suggests that, on the whole, access to effective services relating to carers of older people has not increased very much since the community care reforms were introduced. Indeed, it has also suggested that the intensity of some services of benefit to carers has diminished.

It should be noted in this context that much of the evidence in the literature presented here utilises data collected before the introduction of some recent policy initiatives affecting carers. This is true of major studies used extensively here, such as the ECCEP study. It is also true of national data sets, like the GHS data on people aged 65 and over. The analysis of the most recent (2001) GHS data on older people was still in progress at the time of writing this report. Much of the data considered here does not yet, therefore, reflect the introduction of the special grant to enable carers to take short-term breaks from caring, which was introduced in 1999. Nor does it reflect the introduction of the 2000 Carers Act. However, by the same token, policy analysts have

cast some doubt upon the extent to which some of these changes may have affected the structures of support for carers of older people. As Parker and Clarke wrote recently in relation to the carers' special grant, "It was real money, but £140m over three years and over the whole of England, did not signal a major change in support structures" (Parker and Clarke 2002: 354). Although the carers' grant has since been extended, as Parker and Clarke suggest, a time-limited grant is unlikely to result in sustainable changes in support structures.¹ This suggests that the current available literature is still of relevance.

The literature currently available suggests, then, that the community care reforms have, on the whole, failed adequately to support the carers of frail older people (Bauld *et al* 2000). A similar conclusion was more recently reached by senior social policy analysts who observed that, in spite of nearly a decade of "so much rhetoric and, indeed, real development in services", there has been very little effect in terms of shifting service support towards carers (Parker and Clarke 2002: 349). The literature in general reflects this, with continuing periodic reports of unmet needs for services among carers of older people (Philp *et al* 1995, Katbamna *et al* 1998, Winter 2000, Train *et al* 2002).

The failure to shift service support towards carers of older people may in part have been a consequence of the policy of targeting resources on those most in need in the community. In practice, this seems to have meant that some services have been targeted on the most disabled older people *without informal carers*, rather than on the most disabled older people as a whole. Indeed, the literature suggests that the community care reforms may actually have shifted important resources, such as home care resources, away from disabled older people with carers.

From this it is difficult to resist the conclusion that, as some social policy analysts feared, under the care management system, carers are being treated as a 'free good', a resource within the community whose input they can assume and so need not support (cf Twigg 1992). Moreover, the evidence in the literature also suggests that the community care reforms may have increased the tendency to treat carers as a free resource. The costs of community care for older people may, subsequently, have increasingly been shifted onto unpaid carers, whose costs are less visible.

The hidden costs of caring

The evidence concerning the cost-effectiveness of services relating to carers in this country, reported in this literature review, has mainly derived from one source, the ECCEP study of equity and efficiency policy in community care (Davies and Fernandez 2000). There is nothing wrong in principle with relying on a single study of this calibre, given its relevance to the Audit Commission's interests and given the lack of alternative sources.

¹ Indeed, there is some evidence that the carers' grant may have actually worsened access to respite care for some carers (see Arkey *et al* 2003a). The figures cited in the present report suggest that, since 2000, there has been a decline in the number of temporary admissions of older local authority-supported residents to care homes.

However, as the ECCEP study did not attempt to put a value on informal care inputs, it did not make visible the hidden costs of caring, which were identified as so important in the introduction to this review. It is very difficult to say what difference to the conclusions about the cost-effectiveness of different services it would have made if these costs of caring had been taken into account. Important aspects of the hidden costs of caring, such as the extent of employment disadvantage due to caregiving, were not reported in the equity and efficiency study. It is to the credit of the study that data on the employment disadvantage due to caregiving were collected at all, but, tellingly, there were too few employed caregivers in the sample to estimate production functions (Davies and Fernandez 2000: 34).

Nevertheless, the evidence presented in this literature review does allow some conclusions to be drawn about one aspect of the hidden costs of caring: the costs associated with the stress of caring. As the section on multi-dimensional approaches above showed, in the context of current community care policy and practice in England and Wales, the implementation of a community care package is likely to be associated with an increasing level of stress for the carer. The fact that, as this review overall has shown, a number of services are effective in supporting carers suggests that the stress associated with the implementation of a community care package may arise because carers are not being allocated sufficient quantities of effective services to make an appreciable difference to their well-being (cf Bauld *et al* 2000). While this continues, increasing reliance on community care is likely to be associated with increasing levels of stress for carers and this, in turn, suggests increasing hidden costs of caring. These increasing hidden costs affect carers as individuals, because they imply additional psychological distress to carers. They also potentially affect the actual costs of sustaining carers, in terms of costs to the NHS of treating carers' mental health problems. Unless far more is done to allocate services to older people with carers, implementing community care packages may imply cost-savings for local authorities, compared to admissions to institutional settings, but may transfer hidden costs to private individuals and to the NHS.

Appendix 1

A note on the concept of carer burden

The potentially negative effects of caring on the mental health of carers is widely recognised in the national and international literature on caring. The literature has recently been summarised very well by Bauld and colleagues:

“There is now a significant body of literature relating to the mental health of carers, focusing primarily on concepts such as burden and stress. This research stems from the understanding that informal carers can be subject to extreme pressures resulting from the demands of providing care. The nature of these demands is determined by such factors as the dependency of the care recipient, the time and effort needed to meet their needs, the economic costs of providing care, and a lack of respite for the principal carer. Emotional strain and restrictions on time and freedom are prevalent, all of which have an impact on mental health.”

(Bauld et al 2000: 104)

The negative effects of caring on the psychological health of the carer are all aspects of a concept summarised as *caregiver burden* (Fox et al 2000). Psychological manifestations of caregiver burden include depression, anger, anxiety and guilt (Fox et al 2000). The literature suggests that the negative effects of caring are particularly acute for carers of older people with dementia (Bauld et al 2000, Fox et al 2000).

There is a huge literature in the US on caregiver burden and stress, which has been dominated by a psychological methodology (Twigg and Atkin 1994). The impetus behind the pursuit of measures of burden and stress has partly been one of establishing in concrete and visible form the personal costs of caring, and partly developing objective measures of the impact of different interventions (Twigg and Atkin 1994).

There are a number of measures of carer stress and burden. Although these measures capture different aspects of the effects of caring on the psychological health of carers, the concepts ‘carer stress’, ‘carer burden’ and ‘carer strain’ tend to be used interchangeably in the literature. The ECCEP study used two well-validated instruments to measure the mental health of carers: the Rutter Malaise Inventory (Rutter et al 1970) and the Kosberg Cost of Care Index (Kosberg and Cairl 1986, Kosberg et al 1990, Kosberg 1996) (Bauld et al 2000).

The Kosberg Cost of Care Index was described in one of the main publications of the ECCEP project as follows:

“The Kosberg Cost of Care Index was specifically designed as a care management tool for assessing the potential and actual consequences of caring for an elderly person by informal care givers... The index was developed with twenty items to measure five dimensions found in the literature to be related to the ‘costs’ of providing care to dependent elderly persons, such as personal restrictions, economic costs and psychosomatic consequences. Each of these dimensions is composed of four items, to which the carer responds by checking one of four categories: ‘strongly agree’, ‘agree’, ‘disagree’ or ‘strongly disagree’.”

(Bauld et al 2000)

All carers in the ECCEP study were assessed using the Kosberg scale. Overall they had a mean score of 4.92, indicating a moderate level of stress. The Kosberg score was higher, however, where carers looked after the most frail older people (those with critical interval needs) and where they looked after someone with cognitive impairment or behavioural disorder (Bauld et al 2000). Carers looking after someone with a physical dependency and cognitive impairment had the highest scores (> 6.5).

Interventions are aimed at reducing the level of stress of carers for two main reasons. First, reducing the level of strain of carers may help them to continue caring and thereby prevent institutionalisation of the older person. Second, reducing the negative effects of caring on the carer is regarded as important in its own right. Relieving the personal costs of caring for the carer implies treating the carer as a ‘co-client’ (Twigg 1992). It is an approach that is implied by the national strategy for carers (DoH 1999a, Pickard 2001). Failure to address the negative effects of caring on the psychological health of carers may incur personal costs to the carer that may be largely immeasurable in financial terms. However, it may also lead to financial costs, associated with increased demands by carers on the health service. The MADDE study (reported in the review) found that those who received the MADDE intervention had significantly lower Medicare expenditures than did people with comparable health status in the control group, amounting to \$500 (approximately £300) a year less per carer. These savings were not enough to compensate for the costs of the interventions in the MADDE study (Fox et al 2000). This does not mean, however, that wider use of a highly cost-effective intervention like therapeutic social work might not lead to cost savings in this country.

It is important to note that the emphasis on carer burden has been the subject of criticism in the literature (Twigg and Atkin 1994). Measures of burden and stress have been presented as chimeras whose pursuit yields increasingly diminishing returns. Stress or burden have been reified, pursued in ways that are detached from how people cope with their lives. Criticism of the emphasis on burden has come from academics and lobbyists who argue that this is not how many carers perceive their situation and that the language is pathologising (Twigg and Atkin 1994). Recent North

American literature has stressed that the overwhelming focus in care giving research on burden should be supplemented by an emphasis on quality of life, using the concept of well-being as distinct from burden (Chappell and Reid 2002).

Appendix 2

A note on the ‘hidden’ costs of caring

What follows is an attempt to summarise some of the literature on the hidden costs of caring relating to the questions addressed in this report. No claim to comprehensiveness is made.

Attempts to quantify the hidden costs of caring

Attempts to value the costs borne by carers have been made in the British literature since the early 1970s (Knapp 1984). These attempts were, however, initially discouraged by policy-makers. Wright and colleagues, for example, in the early 1980s, reported that their research project had made no attempt to cost the contribution of the informal caring network “because our research sponsors [the Department of Health and Social Services (DHSS)] requested us not to do so” (Wright *et al* 1981: 23-4, cited in Knapp 1984). There have now been a number of studies that have attempt to quantify the costs of caring. There is, however, at present no agreed methodology for calculating the costs of informal care (Brouwer *et al* 2001, McDaid 2001, Schneider *et al* 2003).

Estimation of replacement costs of informal care

The most common methodology for estimating the costs of informal care is to calculate the replacement costs, by calculating the time spent by informal carers and multiplying it by the cost of a paid worker. This methodology is, however, problematical because it usually involves attributing a market value to informal care, whereas the nature of informal care is that it is unpaid activity which lies outside market relationships. Problems are encountered in establishing both the time spent on caring and the cost to be attributed to it.

The method originally used by the Family Policy Studies Centre (1989) valued informal care at the average hourly cost of local authority provided care, on the grounds that if family and friends failed to provide informal care then local authorities would have to do so through their own directly provided services. Using the methodology developed by the Family Policy Studies Centre, William Laing calculated in 1993 that the value of informal care in the UK was £39.1 billion a year (Laing 1993).

The Institute of Actuaries valued informal care in Great Britain at £33.9 billion in 1994 (Nuttall *et al* 1994). This figure was based on data on the number of hours of informal care, derived from the 1985 GHS, and an estimate of the cost of providing informal care at market rates of £7 per hour.

The recent Carers UK estimate, which valued informal care at £57 billion in 2002, is an updating of the calculation carried out by Nuttall *et al* (Carers UK 2002b). Carers UK updated the results using data from the 1995 GHS on the provision of informal care and an hourly rate of £9.95 per hour. Carers UK explained the increase in the value of informal care since Nuttall *et al*'s study in terms of a number of factors, including the rise in home care costs; a more detailed method of calculating hours of care; and an intensification of informal care provision since the community care changes were introduced.

Calculations of the replacement costs of informal care have not just been used to provide estimates of the total value of informal care. They have also been used in costs of illness studies. Again, however, such estimations are subject to a great deal of uncertainty (McDaid 2001). Key sources of uncertainty relate to both the estimation of the time spent on informal care and the value that should be attributed to informal care time. For example, a recent study by Lowin *et al* 2000 estimated the gross annual costs of Alzheimers disease in the UK to be between £7.06 billion and £14.93 billion. This high level of uncertainty was generated primarily by using a number of different assumptions about the volume and value of informal care. The amount of time spent per week on informal care for people with Alzheimers Disease in private households was estimated at either 25.2 hours or 45 hours. The hours of informal care were costed at either the minimum wage of £3.50 per hour or the costs of face-to-face contact with a home care worker of £9.39 per hour (Lowin *et al* 2000).

Estimations of the replacement costs of informal care based on the methodology described so far have been criticised on a number of grounds (House of Commons Health Committee 1996, Wittenberg *et al* 1998, Laing and Buisson 2002). First, there has been criticism of the assumption that all informal care hours are likely to be replaced by statutory provision. Research carried out in the US suggests that formal care does not replace informal care fully on an hour for hour basis and that not every informal hour is replaced by formal services (Tennstedt *et al* 1996). There is evidence that hours of informal care and hours of formal services are not time-equivalent (Tennstedt *et al* 1996, Davies *et al* 1998). It has been suggested in this country that some informal care hours would not be replaced at all, some would be replaced by (cheaper) 'grey' market cash-in-hand arrangements and some would be replaced by statutory provision of either home care or residential care (Laing and Buisson 2002).

Second, a broader, related set of problems arise from the difficulty of assessing the number of hours of informal care that are relevant (McDaid 2001). Caregivers may be able to perform additional activities whilst simultaneously providing care or supervision. This 'joint activity' could include work benefiting the whole household

and not just the person cared for. Caregiving time could also include hours spent on outings or other leisure activities with the person cared for. It could be argued that such hours would not be replaced by formal services and that it would seem inappropriate to value them on the basis of wage rates.

A rather different method of calculating the replacement cost of informal care was suggested by the Department of Health for the Select Committee on the Future Provision and Funding of Long Term Care in 1996 (House of Commons Health Committee 1996). This method was based on a set of assumptions on how much informal care would be replaced by what sort of formal care (to maintain an adequate standard of care) and priced according to the cost of that formal care. It was assumed that a client being cared for by an informal carer for between 20 and 40 hours a week would be allocated approximately 15 to 20 hours of home care, at a cost of £120 a week. Clients being cared for by informal carers for 40 hours a week or more were assumed to qualify for residential care, at a cost to local authorities of £250 a week. The Department of Health qualified their methodology as follows: “It is important to note that these are stylised assumptions for the purposes of this analysis and are not a statement of what level of service is expected, nor an indication of the value of informal care” (House of Commons Health Committee: 271). Using this methodology, Laing and Buisson estimated the annual informal care replacement costs for the UK to be some £21 billion in 1999 (Laing and Buisson 2000).

More recently, an estimate of the market valuation of personal care provided informally to older people in Scotland and the rest of the UK was carried out for the Care Development Group in Scotland, in connection with the implementation of the policy of ‘free’ personal care (Leontaridi and Bell 2001). The estimate introduced the concept of an ‘exchange rate’ of informal for formal care hours. The exchange rate was regarded as necessary because it was argued that market-based provision was likely to be more efficient than informal provision of care. The exchange rate chosen was that, up to 28 hours of informal care, hours would be ‘exchanged’ on a one-to-one basis, but beyond that, informal care hours would be discounted on the argument that the authorities would seek to find alternative ways of reducing costs for cases that involved more than 4 hours of daily home care. The resulting calculation produced an estimate of the market value of informal personal care of between £174 and £215 million in Scotland and between £1.8 and £2.2 billion in the rest of the UK.

Opportunity costs of informal care

The opportunity cost approach to valuing informal care involves a standard economic approach whereby the carer identifies the opportunities forgone as a result of caregiving (McDaid 2001). Typically, caregivers are asked to identify the next best use of their caregiving time, which is then valued using the wage rate, rate for contribution to household production or rate for leisure time.

Opportunity costs have been calculated in a number of studies (Nissel and Bonnerjea 1982, Netten 1990, Joshi 1995). Joshi calculated examples of the opportunity costs of caring in terms of forgone pay and pensions (Joshi 1995). Joshi used the case of carers in their 50s, for whom induced effects on subsequent pay could reasonably be ruled out. According to Joshi's calculations, a woman in her fifties who would otherwise work full-time and earn £15,000 a year, who gives up employment entirely for a 5-year stint of caring (the median reported in the Retirement Survey) would forgo £15,000 a year for each of the five years (assuming no inflation), a total of £75,000. If she had been an otherwise fully paid-up member of an occupational pension scheme, expecting two thirds of her final salary at age 60, (£10,000), this will be reduced by her lost years of contribution to £8,750, a forgone pension stream of £1,250 per annum. Joshi also considered the case of a man, whose annual salary would be somewhat higher, whose forgone earnings would amount to £85,000 and forgone pension stream at 65 to £1,420. Forgone earnings and pensions for part-time workers were also calculated by Joshi. The actual figures presented by Joshi are now nearly ten years out of date. Moreover, Joshi did not provide an overall estimate of the forgone earnings and pensions for people who had reduced their employment as a result of caring.

An extension of the opportunity cost approach is the friction cost approach (Koopmanschap *et al* 1995, Brouwer *et al* 2001). The friction cost approach is a method of estimating the short-term indirect costs to the economy of absence from work, due to disease or to the provision of unpaid labour. It looks at the consequences of short-term absence from work for labour productivity and production. In the friction cost approach, it is assumed that lost productivity costs are temporary. Lost productivity costs are assumed to consist of the costs of covering for a temporary absence from work, plus worker replacement costs. This approach would reduce the estimation of the costs to society for caregivers of working age. The friction cost approach is difficult to apply in practice. It does, however, have the advantage of avoiding the trap of generalising micro assumptions (for example, about the costs of a formal care hour) to the macro level, in the way that the replacement costs method does.

Other informal care costs

There are a number of other costs potentially incurred by carers that are identified in the literature (McDaid 2001). These include the following:

- Direct financial expenditure on goods and services, such as additional household expenses or extra lighting/heating (Glendinning 1992, Netten 1993).
- Accommodation costs: where the cared-for person moves into the carer's house, the cost of the room can be costed in terms of the opportunity to earn a market rent (Netten 1993).
- The financial impact of difficulties in returning to work after caring has ceased (McLaughlin and Ritchie 1994).

- The service cost consequences of the impact of caring on physical and mental health.

Cost-effectiveness studies using informal care costings

The cost-effectiveness of home-based versus residential provision was examined in an early study by the Health Economics Research Unit (HERU) (Spoor 1988). The study was based on an option appraisal of services for older people with psychiatric disorders (EPD patients) in Grimsby. It identified and measured the costs and benefits involved in alternative care packages for various types of patients, including a valuation of carers' time. A figure of £120 a week was chosen as the value of carers' time, based on the local average gross labour cost of £3 per hour for women aged between 40 and 49 (Spoor 1988: 27). Including the value of informal care in this way, the study found that existing community provision was more costly than existing Part III residential accommodation. The value of carers' time was subjected to sensitivity analysis, but it was found that only very large changes altered the rankings of the critical options. The study concluded that, "these results may cast some doubt on whether domiciliary care is the least costly or the most efficient mode of care for EPD patients" (Spoor 1988: 25).

A similar result was reported in a study conducted 20 years later by Schneider *et al* (2003). The study explored the costs of formal and informal care for people with dementia, using a sample of 132 people with dementia and their carers living in the community in south London in 1997-1999. The market value approach to costing carers' time was utilised, with the market value of care being estimated at the home care unit cost (£10.30 per hour) for caring tasks and at the minimum wage rate (£3.60 per hour) for general tasks and supervision. The study found that "the costs of domestic care, *including* informal inputs, are higher than the costs of non-domestic [residential] care" and concluded that "Considering the total costs to society, it therefore appears that non-domestic care might be a cost-effective option for some people with moderate to severe dementia" (Schneider *et al* 2003: 321-2).

One of the most widely used estimates of the costs of informal care is that produced by Netten of the PSSRU (Netten 1990, 1993). Netten distinguished between the *cost to the carer* and the *cost to society as a whole*. Netten calculated an average cost to the carer of £31.42 a week overall in 1990. The average social opportunity cost was £29.98 a week overall. Allowance was made in these costs for direct financial expenditure on goods and services; forgone non-waged time; forgone waged time; forgone career prospects; and forgone accommodation costs (Netten 1990). The social opportunity cost was lower than the cost to the carer primarily because it did not contain an estimate for housing costs. In general, Netten thought that these figures were probably underestimates of the costs incurred.

The figures produced by Netten, uplifted for inflation as appropriate, have been the basis for the calculations of the costs of informal care in a number of subsequent studies (for example, Kavanagh *et al* 1995, Bosanquet *et al* 1998, Lowin *et al* 2000). Kavanagh *et al* (1995) used Netten's work to calculate the average weekly costs of packages of care for people with dementia. The study calculated that, in 1992/3 prices, the average weekly informal care costs for people with dementia living alone were £49.23 and for people living with others, £69.14. Total costs of care (including health authority, social services, informal care, personal accommodation and accommodation costs) for those living with others in private households amounted to £243.51 per week (Kavanagh *et al* 1995). This figure was higher than the equivalent cost for people in some residential accommodation, in particular, private and voluntary residential homes, for which the costs were £240.51 per week (Kavanagh *et al* 1995). The study explored a number of different policy options, including an option of improving respite support to older people living with others in a private household. This option increased the total costs of care to £289.71 a week, due to higher health and social services spending, although no allowance was made for a corresponding reduction in the costs of informal care under this option.

More recently, an evaluation of the cost effectiveness of intensive case management for people with dementia (Challis *et al* 2002) included a valuation of the costs to carers. The study found that "a significantly higher level of service provision was offered to older people and their carers receiving the case management service but the effect of this in the total was to some extent offset by the lower cost incurred by carers as a result of receiving the experimental service" (Challis *et al* 2002: 322). Case management reduced the average costs to carers to approximately £4,000 a year, compared to over £5,000 a year in the control group. Overall, however, the average costs of intensive case management (£23,402 a year) were higher than the average costs for the control group (£19,053 a year). The main reason why case management costs were higher than expected was because, at the time that the cost data were collected, case management had not had a great deal of impact on institutionalisation rates, although over a longer time-scale this changed.

Costs of the stress of caregiving

Charnley (1989) examined the relationship between carer stress and the opportunity costs of caring. Carer stress was measured on the Rutter Malaise Inventory and carers were divided into those who were "stressed", with a malaise score greater than 5, and those who were not stressed using this definition. Overall the stressed carers had a significantly higher level of opportunity cost. The average weekly cost of stressed carers was £36.92, compared to £28.63 for the carers who were not stressed. The costs of social services to carers who were stressed were also significantly higher than to those who were not stressed. The average weekly costs of social services to carers who were stressed were £20.31, compared to £13.79 for those who were not stressed.

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