

Review of Effectiveness and Outcomes

Home Care

Prepared for the
Centre for Evidence-Based Social Services



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Foreword

The social care field is almost wilfully bad at celebrating its achievements, among which I would wish to cite the large-scale rehabilitation and community care schemes in mental health and learning disability and those securing the care of frail elderly people in the community. In the latter case, our older fellow citizens are no longer carried along by the 'conveyor-belt' services which were once the norm – users proceeding in ratchet-like fashion from a crisis at home or in health to acute care, to nursing home, to residential care, and to death. Those with life left to live are now cared for at home – where most strongly prefer to be. This thanks to a combination of statutory and informal care, and to multi-disciplinary rehabilitation projects. These schemes have an almost military, logistical, aspect to them and have benefited from research and service-evaluations within which users and carers have had a chance to comment on what works reasonably well, what does not, and where there is scope for improvement.

You have in this publication, a rare beast – a systematic review of a basic, mainstream service. The authors have hunted down a large number of empirical studies of effectiveness in home-care; screened them according to pre-set guidelines regarding relevance and methodological sufficiency, and at every stage have done what Maths teachers used to urge, i.e., they have 'shown their working out'.

Here then is a review which condenses a wide range of scholarship into a limited space, and which discusses the practice implications of findings at every stage. It is written in a clear and accessible style, and is hereby recommended to practitioners, managers, policy makers and service-users and care groups – indeed all who have an interest in improving services for some of our most vulnerable fellow citizens.

One last thought. Few of us will ever need the child care services; only some of us will need the mental health services, but most of us will one day need the services reviewed here. So professional obligations aside, enlightened self-interest might be another reason for paying attention to what follows!

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Executive Summary

Setting the Framework

1.1 This review is concerned with the effectiveness of the provision of home help/home care services provided by local authorities, health services or independent agencies to persons in their own homes. For the purposes of this review, home care was defined as direct practical assistance with personal care, domestic support services such as housework and shopping, and home maintenance.

1.2 Home care in Britain has been subject to major policy changes over the last two decades, accelerated and reinforced through the implementation of the Community Care reforms. These explicitly sought to enable vulnerable people to remain in the community and to reduce/prevent long-stay institutionalisation. Other policy objectives have sought to achieve choice for service users through the stimulation of the market and to prioritise support for carers to ensure they can continue to provide care. These changes have led to an enormous shift in the type of support offered, its timing, and its pattern of allocation, organisation and delivery.

1.3 A key problem in locating and evaluating the evidence on the effectiveness of such services stems from the varied ways in which home care is conceptualized in the literature. In refining the review questions we sought to take these differences into account. Therefore, the review is organised around the following questions:

- > What is the evidence of the effectiveness of, and the outcomes of, three distinct models of home care, namely:
 - a) homemaker/home care programmes;
 - b) short-term home care programmes;
 - c) care managed programmes where domiciliary care is the main component?
- > How have users and their carers evaluated the quality of home

care provision, and how satisfied are they with the services provided?

- > What is the impact of home care provision on informal care?
- > What has been the impact of changes in home care organisation and delivery, particularly in respect of targeting; the diversity of providers, and the expansion of charging policies?

Review Method

2.1 Locating the Evidence

2.1.1 Searches were undertaken on seven databases (Helmic, PsycLIT, Social Science Citation Index, Sociofile, Cinahl, Medline and Cochrane Library). Citation tracking was used to identify additional material, and to undertake quality checks on the search strategies. In addition, searches for 'grey literature' were undertaken through Caredata, research organisations, and the World Wide Web. A hand search of four journals was also conducted (namely *Ageing and Society*, *Social Science and Medicine*, *Home Health Care Services Quarterly*, and *Research, Policy and Planning*).

2.1.2 A combination of freetext terms and relevant thesaurus terms were utilised to maximise accurate identification of relevant studies.. To accommodate the indexing policy of each database, differing search strategies were adopted. All were kept deliberately broad to reflect the exploratory nature of the search strategy.

2.1.3 A total of 7107 records were retrieved including duplicates, of which 49 were identified as meeting the study's inclusion criteria.

2.2 Evaluating and Synthesising the Evidence

2.2.1 All the studies that met the inclusion criteria and formed the focus for the review work were critically appraised using a set of quality criteria.

2.2.2 The key general criteria for assessing the quality of the evidence were:

- > Degree of methodological strength/control of bias
- > Relevance of the study's aims to topic area
- > Detail provided on the nature of the intervention
- > Relevance of the outcome criteria and measures
- > Sufficiency of follow-up period

2.2.3 In addition, and specifically in the context of home care services, the quality of the evidence was judged according to:

- > The relevance of the study in addressing the effectiveness of home support services, and/or user and carer views and/or issues around the organisation and delivery of home care.
- > The detail provided on the nature and components of support provided.

> Whether the study was longitudinal in design which would allow insight into both the short and long-term effects of the intervention.

2.3 The Quality of the Evidence Base

2.3.1 Research on the effectiveness of home care consisted mostly of either randomised-controlled trials, or quasi-experimental studies. A number of literature reviews were also located. For each of the other questions guiding the review – user and carer views, substitution of informal care, and organisational issues – qualitative and survey material predominated.

2.3.2 Difficulties encountered in assessing the evidence base included the various ways in which home care has been conceptualised, the appropriateness of the outcome criteria and measures used, and methodological issues arising out of the complexity of the intervention and consequent difficulties in conducting the research.

2.3.3 The literature highlights the range of different approaches to home care and conceptual variations in the content of programmes. Home care services have encompassed in-home health and supportive services, and have encompassed post-acute, long-term care, medical and social elements. They have also utilised the services of a range of professionals and volunteer workers. At the same time there has been a lack of detail within the literature of the nature, frequency and intensity of services, and of the variations in the provision across study populations. Few studies have attempted to specify service models and fewer still have made efforts to at least speculate about the links between particular outcomes and specific service inputs.

2.3.4 There was no research evidence that addressed the question of domestic support alone for people with low intensity needs, or which examined the impact of such services in reducing demand for more costly services.

2.3.5 Within the literature generally, there has been very little emphasis on the impact on service-user and caregiver well-being. Among the user/carer opinion studies, most were based on surveys using global measures of satisfaction. However service-users (mostly older people) tend not to express dissatisfaction because of low expectations, gratitude for receiving *any* service and fear of it being withdrawn.

2.3.6 The majority of studies evaluating effectiveness have focused their outcome criteria around the substitutability of home care for institutional care. It is not clear, however, that these are always appropriate target outcomes. Risk of institutional admission does not equate with high dependency needs. Other factors impacting on entry to long-term care include: not only the availability of informal care, but the relationship between carer and cared for; user motivation and the coping strategies employed both by caregivers and by those managing impairments. Thus, it is only insofar as the target population has been assessed as needing

residential/nursing home care that it is appropriate to consider diversion as a legitimate outcome criterion.

2.3.7 There is a lack of recent evidence on the effects and outcomes of home care. Most of the studies were published in the Eighties, prior to the policy changes. In terms of the impact of the community care reforms, whilst there is a good deal of descriptive information documenting changes in commissioning and purchasing activity, there is as yet little in the way of systematic research focusing on their impact on service delivery processes and outcomes for service-users.

Review Findings

3.1 Effectiveness of Home Care Programmes:

I Homemaker/Home care

3.1.1 Homemaker/home care programmes had a major emphasis on providing housework, help with chores, home help, and personal care services on a long-term basis. They were targeted primarily at older women who were chronically impaired in the activities of daily living, but who were not in need of 24-hour care or supervision. Subjects often had multiple health and social problems including personal care and home care difficulties.

3.1.2 The most widely used outcome criteria and measures focused on the potential value of home care to act as a substitute for institutional care. Outcome measures, therefore, included acute hospital admission, institutional admission, health status and functioning, mortality, subjective well being, and the quality and costs of care.

3.1.3 In terms of service outcomes, the programmes had no impact on the rate of acute hospital admission and/or rates of stay per hospital admission. On the rate of admission to nursing homes, the evidence was inconclusive.

3.1.4 With regard to clinical outcomes there was evidence of lower mortality rates among those receiving these programmes of care. In the one study in which functioning was measured, there was a significant decline in abilities such as dressing, bathing and continence. Interestingly, these users also reported significant improvements in their *perceptions* of their physical and mental health.

3.1.5 Homemaker/home care programmes were also associated with higher costs, an improvement in life satisfaction and a reduction in unmet needs. No favourable effects on carers were reported.

3.2 Effectiveness of Home Care Programmes:

II Short-term Schemes

3.2.1 Short-term schemes offered practical support to people in the home, often following discharge from hospital, with an emphasis on users achieving independence.

3.2.2 They were targeted at those discharged from hospital, often to enable timely discharge. Users were primarily older women impaired in activities of

daily living and not in need of 24-hour care. As short-term schemes, and in contrast to the other programmes of care, the implication was that the target population was one that was expected to restore or improve their functional status.

3.2.3 There was little consistency in the outcome criteria and measures used in the studies. There was no evidence of an impact on health and functioning, anxiety and depression, survival rates or on subjective well being. Evidence on the impact of rates of hospital readmission was inconclusive. The Centre for Evidence-Based Social Services, University of Exeter, has commissioned further research on this issue.

3.2.4 The Red Cross *Home from Hospital* scheme focused on the acceptability and impact on the users of the service. In particular it examined whether the support provided was consistent with clients' perceptions of their needs for help. It was clear that in its absence there would have been considerable unmet needs (with needs defined by users) in the areas of dressing, personal appearance, cleaning/tidying the home, and preparing meals.

3.3 Effectiveness of Home Care Programmes: III Case-managed Programmes

3.3.1 In these programmes individuals received a package of care through a case management framework of which domiciliary support was the main/major component. In contrast to the short-term schemes, they concentrated more on those with long term high dependency needs who were at risk of admission to residential/nursing home care.

3.3.2 The majority of programmes were targeted at those living in the community who were on the margins of institutional care. The typical service user was an older woman who lived alone and who was chronically impaired in activities of daily living and who frequently required help with dressing, bathing and walking.

3.3.3 One programme was explicitly designed for long-stay frail older inpatients. This group was less likely to live alone and had severe mobility and self-care problems.

3.3.4 A common feature of the programmes was the specific eligibility criteria and explicit exclusion of certain potential service-users. Account was taken of factors such as personality, motivation and family circumstances. It is arguable that inclusion was skewed towards those who would most likely benefit from remaining in their own homes.

3.3.5 The outcome criteria and other measures focused on the potential value of home care to act as a substitute for institutional care and so allow the individual to remain at home. Outcomes measured included institutional admission, health status and functioning, mortality, cost, subjective well-being and quality of care.

3.3.6 In terms of service outcomes, there was no evidence of favourable effects on rates of acute hospital admission.

3.3.7 Only the Community Care Demonstration projects showed a significant reduction in rates of long-term residential/nursing home care over the short-term (one year). Over the longer term it appears that their main impact may have been to delay rather than prevent institutional admission. In the one study that evaluated outcomes over a longer time span (the Kent scheme, with follow-ups of over four years), the rate of admission to residential/nursing home care was no different between the experimental and control groups at three years. Lost hopes aside, this is an important outcome. The New York Home Care project also found no impact on long stay institutional admission.

3.3.8 In terms of clinical outcomes, there was some evidence of a worsening in physical functioning, and no evidence of an improvement in survival rates.

3.3.9 There were, however, significantly favourable effects on subjective well-being with reports of improved life satisfaction, morale and decline in depression and loneliness. There was also an improved perception among programme recipients about their capacity to cope with daily living, and a perceived reduction in unmet needs.

3.3.10 There were few studies that examined the cost effectiveness of home care, and the evidence from those that did was inconclusive. The homemaker/home care programmes resulted in higher costs after a year. Whilst the Community Care Demonstration projects found home care to be less costly than institutional care, those targeted for inclusion tended not to be suffering from moderate to severe cognitive disabilities. Such users tend to be very costly in terms of community support. It is not possible therefore to deduce whether the favourable cost effectiveness outcomes of community based care are applicable to all users at risk of institutional admission.

3.3.11 In summary, the most consistent positive outcomes of home care relate to increased life satisfaction and an apparent reduction in unmet needs among older people. Home care also has the effect of delaying long-term institutional admission for those who are physically frail and assessed as being on the threshold of such care. There is some evidence however to suggest that the provision of home care to people with high dependency needs may reduce functioning in some activities of daily living.

3.4 User and Carer Perspectives

3.4.1 Across the studies that considered user perspectives on the dimensions of a good-quality service, a range of attributes were identified. These could be classified into those that related to the nature of the service (continuity, reliability, and responsiveness); the nature and demeanour of the staff (disposition, competence) and the nature of the process (quality of the relationship, awareness of needs, flexibility).

3.4.2 Users differed in the value they placed on different attributes. For those who were most dependent, for example, the highest value was placed on staff continuity. Women, including those who also had personal care needs, placed a high value on domestic tasks such as cleaning and housework.

3.4.3 There were high global levels of satisfaction among users of home care services. However there were concerns and dissatisfactions related to specific aspects of the service, including unreliability, the lack of flexibility in the tasks undertaken, and the lack of continuity of care offered. It was notable however that despite the large differences in service delivery and allocation patterns, these were not reflected in user opinions from satisfaction surveys.

3.4.4 Only one study specifically addressed carers' views of the home care service. Expressed dissatisfaction related to the need for more help with lifting, bathing and housework and dislike of staff changes.

3.4.5 The available evidence does not support the view that providing formal support to vulnerable people will impact on the willingness of informal caregivers to provide care. Rather what is most likely is that informal support continues alongside formal help. The evidence also indicates differences in the preferred roles for formal and informal support networks with the former the preferred source for domestic support as opposed to personal care tasks.

3.5 Organisation and Delivery of Home Care

3.5.1 The evidence here related to the areas of targeting, the development of a mixed economy in domiciliary care provision and the extension of charging policies for care.

3.5.2 With regard to targeting, whilst firstly the overall trend has been for a more intensive service for people with high dependency needs, there exists considerable variation in the content, amount and allocation practices between local authorities and across different parts of the UK. Second, the meaning of targeting has differed as between local authorities. It has applied both to the needs of users and/or to the prioritisation of certain tasks over others, irrespective of the level of need. Third, domiciliary care remains focused primarily on people living alone.

3.5.3 The developing mixed economy in domiciliary care is marked by a high degree of instability and organisational mortality. From the little evidence available on user outcomes, diversity of providers does not necessarily increase user choice. Moreover, certain features of the market – dominance of spot contracts, purchase of care in small time units – are likely to result in service delivery processes that conflict with or are in opposition to, user conceptions of a quality service (continuity, relationship with user, competence in carrying out tasks).

3.5.4. In the period since the community care reforms, charging policies have both increased costs as well as catching in their net a wider group of

users. Although the evidence is weak, that which exists seems to indicate that the main impact in terms of withdrawing from service use is felt by those with less intensive needs. For those with higher levels of need, the impact is primarily one of resigned acceptance coupled with a reluctance to request further help, or apprehension about the future in the face of a degenerative or deteriorating condition.

Research and Policy Implications

4.1 Research Implications

4.1.1 The evidence base in respect of the effectiveness of home care is neither extensive nor very robust. Partly this reflects the complexity of interventions under the rubric of home care. Partly it relates to what are appropriate outcome criteria and measures to be used in evaluative studies. High quality research is needed that:

- examines effectiveness not only in terms of service outcomes, but in relation to user conceptions of maintaining valued life choices;
- explores the impact and outcomes of home care support for different users, and different kinds of informal carer relationships; different ethnic groups and socioeconomic circumstances;
- comparatively and longitudinally, focuses on the process of becoming a user and the factors involved in the movement between different levels and types of care. Why do some people access home care services when others with similar levels of dependency do not? What is the relationship between increasing disability (as a feature of ageing or a progressive condition) and movement between different levels and types of care?

4.1.2 A fundamental feature of home care provision is the complexity of the intervention. The inputs are multi-dimensional, offered by different kinds of staff, in the context of a relationship with the user, using different eligibility criteria and allocation practices. It seems crucial in order to gain an understanding of this complexity that research methodologies are refined and combined to enable insight into the processes producing particular outcomes for specific groups of users.

4.1.3 Changes in commissioning and purchasing of domiciliary care services pose the need for a sustained research endeavour to examine the impact of service delivery and outcomes for users and carers. A specific area of interest, given the recent focus on prevention is the impact and outcomes of targeting services to users with different levels of need.

4.2 Service Development Implications

4.2.1 A major achievement of the community care reforms has been the penetration of the market and the diversity of providers in domiciliary care provision. A key issue for commissioners is ensuring that such diversity increases user choice and perceived quality of care. The admittedly, limited evidence that exists suggests that neither choice nor improved quality has followed diversity. Indeed, there are specific features of the developing

market that potentially act as a barrier to quality care in the terms that users and carers perceive it.

4.2.2 The focus on home care as an alternative to institutional admission has had a major impact on who gets home care and the nature of the support received. First, not only have users with particular kinds of needs been targeted, but services have also prioritised particular kinds of tasks over others. Consideration needs to be given to the impact of targeting (both kinds of users and tasks) in relation to other policy objectives such as assisting informal carers, preventing dependence and providing rehabilitative support. Monitoring systems need to be put in place that address both the unintended as well as the intended consequences of targeting on users and carers.

Introduction

This work was commissioned by the Centre for Evidence-Based Social Services, at the University of Exeter. The overall aim was to review the research findings on home help/home care services. It was intended to address the following questions:

First, what evidence exists on the effectiveness and outcomes of home care services and what criteria are used to assess effectiveness?

Second, what does the research indicate about user and carer perspectives on the outcomes of home care and levels of satisfaction with the service provided?

Third, what is known from research about the type, intensity, organisation and process of delivery of home help/home care provision? Specific issues of interest here include: the criteria for eligibility for services used by different providers; the costs of and charges for services and the extent of overlap between health and social services in the provision of personal care.

In commencing the review, we started with a broad definition of home care. This encompassed the following: direct practical assistance with personal care and tasks such as housework, shopping and home maintenance (but excluding professional services and advice and counselling) provided in the person's own home by the local authority, health services or independent agencies.

Overview of the Report

The report is organised in four parts. The first part, set out in Chapter 1, describes the policy context within which the review is located and presents the initial scoping of the literature. It then goes on to refine the research questions and the search strategy, being mindful of the need to address both current policy concerns and the nature of the evidence base.

The second part of the report considers the methodology of the study. Chapter 2 outlines the search strategy employed, the criteria used for assessing the quality of the evidence and the approach to synthesis adopted. Chapter 3 reviews the scope and quality of the evidence base and identifies some methodological and conceptual difficulties encountered in reviewing the studies.

The third part presents the substantive content of the review. Chapter 4 examines the evidence on the effectiveness of three different types of home care programmes, namely homemaker/home health aid programmes where the major emphasis is on housework, chores, and personal care support on a continuing basis; short term home care programmes offering support to people on discharge from acute hospital care; and case managed programmes wherein domiciliary care is a main component, although other services may also be provided.

Chapter 5 focuses on user and carer conceptions of service quality and their views of existing provision. It also considers the evidence on the possible substitution effect of formal for informal care, a key issue of relevance to policy. Chapter 6 explores some key aspects of the current organisation and delivery of home care as it has developed with the community care reforms and their impact on service use. These centre on targeting, the mixed economy of care, and charging policies.

The fourth part of the review, set out in Chapter 7, presents the main conclusions and the policy, practice and research implications of what we have found.

Home Care Services: Setting the Framework

Home Care Provision

In most European countries, including Britain, home help services developed in the immediate aftermath of the Second World War. They emerged primarily as a family service aimed at maintaining the labour force intact, by relieving housewives in times of sickness and childbirth. However, the pattern of demand and use of the service changed through a combination of factors, for example the increased number of women participating in the labour force, the changes in household structures and living arrangements and the growing numbers of older people in the population. In Britain as elsewhere, by the end of the 1960s, the vast majority of home help users were older people (around 90%). Home helps provided a low intensity cleaning and shopping service to some one in five of those over 75 years (Gorbach & Sinclair 1989; Salvage *et al* 1988).

Research carried out on the home help service during the 1970s and 1980s presented a picture of the typical user as an older woman (on average aged 80 years), living alone, receiving two or three hours support weekly to provide a cleaning and/or shopping service. She was generally very satisfied with the help received, apart from the fact that she would have liked extra assistance with heavy cleaning and gardening (Salvage *et al* 1988). The home help service was therefore intimately bound up with support for older people generally, and for those living alone specifically.

Shift from 'Home Help' to 'Home Care'

From the middle of the 1980s, the home help service came under intense and critical scrutiny by policy makers at national level. A series of reports from the Social Services Inspectorate (SSI 1987; SSI 1988) questioned the appropriateness of an extensive, low level domestic support service, toward enabling vulnerable older people to remain in the community. Certainly, the amount of help offered, and the essentially domestic nature of the tasks undertaken by home helps, was inadequate to meet the intensity and complexity of need of people on the threshold of institutional care. In practice, this had been recognised in part with the development of personal

care or intensive domiciliary support schemes alongside the traditional home help service (e.g. Barton *et al* 1990; Crossthwaite 1989). However, these tended to be small scale, pilot schemes and locally based.

Underpinning the critique of home help provision was the view that the policy objective of the service should be more explicitly defined to prevent or delay institutional admission for those vulnerable people at its boundary. Targeting a more diverse and flexible service at those people who would otherwise require institutional care would, it was proposed, facilitate their improved quality of life. Translating this into service development terms and thereby effecting a transition from 'home help' to 'home care', was seen to require substantial changes in *who* got services, *what* kinds of support they received, and *when* they received it. Specifically what was required was:

- i) A shift in the type of care provided – from domestic support to personal care (including such tasks as dressing, washing and feeding);
- ii) diversifying the service to allow the 'flexible delivery of domestic, personal and social support to people', providing a service as and when needed, including evenings and weekends;
- iii) meeting the needs of people with physical disabilities and learning difficulties as well as older people for whom institutional and residential care alternatives were increasingly regarded as inappropriate.

Thus, local authorities were required to address key issues regarding: the strategic objectives of the service, assessment and allocation practices, and the management of the service as a central component of community care support. Desirable service outcomes of home care were conceived of as preventing or delaying institutional admission for vulnerable people at risk of long-stay care.

The corollary to this policy change was that the provision of modest support – particularly the domestic cleaning and shopping services – to enhance the quality of life of frail older people who had difficulty with such tasks was no longer a priority objective. It is notable that in outlining the consequences of such a policy for the casualties of these changes, organisations campaigning in support of people with disabilities (Age Concern 1992; Radar and Arthritis Care 1991) placed emphasis on quality of life outcomes. In a joint report produced by Radar and Arthritis Care it was argued that:

"... the home help service ... has enabled many people to remain in their own homes with a degree of dignity and self respect ... a shift of emphasis and priority ... to people who require personal care ... should not be at the expense of the basic home help service which is required by so many people." (p.1)

And,

"There appears to be genuine lack of understanding in social services departments about how important a clean home is to people who, in many cases, have to spend the majority of their lives inside their homes. Apart from their distress in living in what they see as unhygienic surroundings, they also feel painfully humiliated at having to sit and look at what they see as degradation and being told that housework is unimportant" (p.1).

The explicit policy focus on domiciliary care to reduce/prevent long-stay institutional admission was not confined to Britain. Rather, it pre-occupied social policy and service development across Europe and North America. At its heart was the changing pattern of need and demands from older people. Two factors in particular fuelled the debate although its precise timing and contours reflected political and socio-economic considerations. *First*, there was the decline in economic growth starting in the 1970s following the sustained economic expansion in the aftermath of the Second World War. *Second*, there was the absolute and relative growth in the population of older people, especially of the very old, who were most likely to make demands on formal services. This latter demographic change was seen to present a major social policy and fiscal challenge.

The Appropriate Balance of Formal and Informal Care

Separate from, but feeding into the discussion on the role of domiciliary care in preventing institutionalisation, has been a pre-occupation in social policy with what should be the appropriate balance between the respective roles of the state and the family in providing care to vulnerable people (Jamieson 1991).

From the middle of the 1980s, there has been an explosion of research unearthing the contribution of informal carers in the provision of care to frail older people and those with disabilities. Attention has also been drawn to the immense social, psychological and economic burden placed on the family in providing such care. Moreover, research has shown that systems for allocating services were biased against those with an informal carer. It was noted above that the traditional home help service was targeted on older people living alone. Not only were those with moderate to severe disabilities receiving support from an informal carer from outside their household, unlikely to receive such help, this also applied to disabled older people living with a spouse only (Parker 1985). Yet, the greatest burden of caregiving has been demonstrated as falling on those, often older people themselves, living in the same household as the person with a disability, both in terms of the number of hours contributed and the complexity of the tasks involved (Martin *et al* 1988; Parker 1992).

From her work on informal care, Twigg (1992) identified a typology of relationships between service providers and informal carers. These were: firstly, *carers as resources*, where the caregiver is essentially taken for granted and treated as a free good; secondly, *carers as co-workers*, where the carers' needs are recognised by service providers, but only in the context of enabling informal care to continue; thirdly, *carers as coclients*, in which

the caregiver is regarded as in need of help in his/her own right; and finally, *superseded carers* where either to promote the independence of the cared for person, or to secure the well being of the carer, the caring relationship is transcended. In Britain, it could be argued that there has been a shift within social policy discourse regarding the way in which informal carers have been perceived *vis a vis* the formal service system. Thus, the view of *carers as resources* dominated in the period prior to the implementation of the community care reforms, whereas the concept of *carers as co-workers* was emphasised in the Griffiths Report (1988) and in the subsequent White Paper *Caring for People* (DoH 1989). Different patterns of relationships are evident in other European countries. In Denmark, for example, systems for allocating domiciliary care are not based on either normative or legal assumptions that families should provide care (Holstein *et al* 1991). In Sweden, on the other hand, whilst there is no legal responsibility on families to support vulnerable relatives, recent changes in home care allocation policy have meant that where people have access to informal support, they are less likely to get formal assistance (Sundstrum & Tortosa 1999).

These issues are important in considering the research evidence on allocation practices and on eligibility criteria in respect of domiciliary care, as well as when reviewing the evidence on the substitutability of formal for informal care.

The Community Care Reforms in Britain

Whilst the policy shift from home help to home care in Britain pre-dated the community care reforms, the latter reinforced and accelerated its implementation.

The reforms (*Caring for People* 1989; *NHS and Community Care Act* 1990) were a watershed in the development and organisation of community care in Britain. This articulated several explicit policy objectives *viz*:

- > maintaining vulnerable people in their own homes and keeping them out of residential care wherever possible;
- > extending the choices for service users and their carers through the stimulation of the market;
- > effecting a needs-based approach through assessment and care management systems that were also to act as a gatekeeping mechanism for residential care (particularly for those who required financial support);
- > prioritising support for carers so that they might be able to continue to provide care, thereby delaying or possibly avoiding altogether, long-stay residential admissions.

Underpinning the reforms were two competing and potentially conflicting goals, namely, containing public expenditure, and improving access to home-based care (at least for *some* people). Further, a key factor in facilitating choice for service-users, and securing cost effectiveness in provision was seen to lie in the stimulation of a 'mixed economy' and the introduction of market disciplines into the public sector.

Thus the policy shift from home help to home care was related to a more explicit focus on targeting the service on those most dependent; this to achieve such outcomes as preventing or delaying institutional admission, and more recently, preventing or reducing the length of acute hospital admissions. The issue of supporting independence and quality of life has only recently re-emerged onto the policy agenda, with the renewed interest in preventive strategies and services.

The impact of these policy changes on who gets a particular service; on what kinds of services are received, and on the nature of the market, are considered below.

The Impact of Policy Changes on Service Provision

Who gets Help?

The vast majority of home care users are older people, mostly over the age of 75 years. In recent years however there has been a small increase in the proportion of younger adults receiving home care. Whereas between 1992 and 1998 the proportion of older people receiving home care declined from 90% to 83%, there was an increase among younger people with disabilities, from 9% to 16% (Laing & Buisson 1999).

Community Care Statistics do not offer a breakdown on the type of households within which users live. It is therefore not possible to deduce whether changes have occurred in the type of household for which home care support is provided, and by implication, the impact of the targeting policy on informal carers.

What Kind of Domiciliary Support is Provided?

Trends in activity levels in home care provision between 1992 and 1998 (at least in England) indicate that there has been a shift toward a more intensive service. Over this period, there was a 52% increase in the number of home care hours purchased or provided by local authorities¹; a decrease of 16% in the number of households receiving home care; and an increase in the weekly average number of hours per household from 3.2 in 1992 to 5.8 in 1998 (Government Statistical Service: Community Care Statistics). At the same time, the number of households receiving low-intensity care (defined as one visit of less than two hours, or up to five visits totalling less than one hour) declined from 44% in 1992 to 27% in 1998. Since 1993 there has been a continued reduction in the overall level of support given to people who are seen as having low-dependency needs. Such needs are generally for help with cleaning and shopping, as opposed to the personal care support that is most likely to be provided to high dependency users.

From the foregoing, a number of points are worthy of emphasis. *First*, whilst the most recent information published by the Department of Health indicates a slight decline in local authority purchased home care hours between 1997 and 1998, it is too early to postulate whether this reflects a short-term pattern or is indicative of a trend. It does appear, however, that budgetary constraints on local authorities are leading to a tightening of eligibility criteria and the capping of domiciliary care packages at or near the cost of a residential care place. From their study of 17 local authorities, the Audit

¹ It is interesting to note that whereas between 1992 and 1997, there was a sustained year on year increase in the total number of hours home care purchased or provided by local authorities, 1998 saw a 2% reduction in local authority purchased home care for the first time.

Commission (1996) found that nearly half set a ceiling at either the gross or net cost of the institutional alternative; only 21% operated no ceiling. Edwards and Kenny (1997) have also shown from their sample of 39 local authorities, that the proportion of local authority expenditure on day and domiciliary care fell from 40% in 1995/6 to 34% in 1996/7.

Second, it should be understood that these patterns reflect general trends in England but that there is considerable local variation between authorities on the one hand and across different parts of the United Kingdom on the other (Government Statistical Service: Community Care Statistics; Laing & Buisson 1999).

Third, as far as need for help is concerned, successive General Household Surveys have shown that it is domestic tasks that cause people more difficulty than self care, and that these problems are exacerbated with increasing age. Thus, a significant proportion of older people (from under a fifth of those in the 75–79 age group, to nearly half of those 85 years or more) are unable to manage shopping on their own. A similar proportion cannot manage such tasks as hoovering and cleaning floors. With regard to self-care tasks, the main difficulties experienced by older people are bathing, showering or washing all over, and matters of personal hygiene and comfort such as cutting toenails. Moreover, the primary sources of support for older people requiring help with tasks of daily living are informal (entailing reliance on relatives or neighbours), many have to manage for themselves and cope with difficulties.

Pattern of Home Care Provision

As a result of the community care reforms, there has been a noteworthy shift in the nature of the domiciliary care market. From a tiny 2% share of local authority funded care in 1992 in England, the independent sector share increased to 46% by 1998. This increase has been mainly in the private sector. At the same time, the independent sector tends to provide more intensive care packages than direct local authority provision. Thus, whereas the former provided a weekly average of 7.3 hours per household in 1998, this compared with an average across all providers of 5.8 hours, and 4.9 hours for local authority direct provision (Laing & Buisson 1999).

Even so, the penetration of the market into domiciliary care is not uniform throughout the UK. In Scotland for example, 89% of home care funded by local authorities is provided directly by themselves, and in Wales, local authorities purchased, on average, only 19% of the home care which they funded. Moreover, in the former case, the intensity of care packages across all providers was lower than in England (5.1 hours); in Wales it was slightly higher (6.5 hours) (Laing & Buisson 1999).

Summary of Home Care Trends

It is evident from the above that changes in the pattern of domiciliary care, particularly since 1993, have meant that:

> fewer people are receiving more intensive packages of care;

- > help with household tasks is taking a back seat to personal care support; reflecting both a shift in the nature of the support offered and in the targeting of users with high dependency needs;
- > there has been, particularly in England, a major change in the nature of the home care market, with nearly half of current market share being held by independent, predominantly private-sector providers. This has occurred in the absence of any statutory/regulatory framework for the domiciliary care industry.

Scoping the Review

Organisation and Systems for Service Allocation and Provision

The initial scope of the literature on home care revealed (as set out above) that it has been subject to major policy change, particularly over the last two decades. In Britain, the changing nature of the home care service as it has developed since the beginning of the last decade – these changes accelerated as a result of the community care legislation from 1993 – has resulted in considerable changes to the types of support offered, as well as to its timing, pattern of allocation, organisation, and delivery. Whilst the content of the service corresponds to similar provision elsewhere (for example in Sweden and Denmark), its precise form and its mechanisms for delivery reflect the specific socio-economic and political framework operating in this country.

This dual understanding of the international commonalities and differences in home care provision has strongly influenced our search strategy in respect of the review questions presented to us by the CEBSS. Thus, for some of the questions posed for review, namely the nature and extent of client problems, the organisation of provision, the needs met, and user and carer perspectives on the quality of services, it struck us that it would be most useful to focus on research that is pertinent to a consideration of the impact of the community care legislative changes, i.e., research carried out since 1990. Similarly, because of the specific nature of some of these legislative changes (in particular those concerning the organisation and delivery of care) the search strategy has concentrated on studies carried out in Britain. There are other aspects of the review where it has seemed appropriate to draw on research carried out within a cultural and policy context similar to that of Britain. These include, for example, studies on the impact of targeting services on those considered most dependent, and upon conceptions gathered from service-users and their carers as to what a high quality home care service would look like.

Effectiveness and Outcomes of Home Care Services

With regard to the effectiveness and outcomes of home care a number of issues were posed at the outset from our work on the scoping of this topic.

What is home care?

It was apparent that research interest in the effectiveness of provision was intimately bound up with the policy objective of reducing reliance on institutional care. The focus on home care was therefore part of a wider movement toward community-based care in both Europe and North America. Despite variations in emphasis across countries, a general consensus has emerged on the desirability of maintaining vulnerable people in their own

homes for as long as possible, notwithstanding differences in how this is to be achieved. It is not surprising then, that from the late 1970s there has been considerable research interest on the impact of domiciliary support services in delaying or preventing institutional admission. Much of the evidence here relates to studies carried out in the United States.

However, a major difficulty in locating and assessing the evidence on effectiveness was the different definitions of home care adopted across different studies. For example, within the American literature, home care is defined loosely, or is included as one of a broad set of home and community-based services that encompass such diverse interventions as alarm systems, day care, foster care/family placement, or care management. Home care itself appears to encompass high technology home health care, hospice care, personal care and domestic support. In part this reflects the different funding streams for care here and abroad. Thus, in the United States, public funded programmes (e.g. Medicaid) and health care insurance (Medicare), cover personal care and homemaking only as part of the provision of skilled nursing care and for short-term acute illness. Long-term, continuous support is often unobtainable unless very high-technology care is also being provided. As a consequence, home care packages tend to encompass a range of services including: in-home health care, medical and rehabilitation inputs, as well as personal assistance and help with domestic tasks. In Sweden and Denmark on the other hand, the concept of home care embraces both personal assistance and domestic help and is offered as an integrated service. In Holland, these are discrete services offered by different care providers.

Care co-ordination

A major issue of interest in respect of home care has been the extent of fragmentation of the service, and in particular the degree to which separate provision and funding of health-related care and social care impact on outcomes for service users. Thus, much of the research on the outcomes of community care in Britain has focused on systems for co-ordinating multidisciplinary assessment. However, in terms of the actual services offered, these have primarily embraced help with personal care and the tasks of daily living. Thus the content of provision is home care, although the research focus has tended to be on care management as a process for co-ordinating care.

Setting a Framework for Examining Effectiveness

In order to address the question of the effectiveness of home care as set out in the working definition, we had to devise a way of organising the studies and the evidence therefrom, in order that we might be in a position to draw conclusions about what aspects of services were producing given outcomes. In particular, we were mindful of both the lack of consensus within the literature as to what constituted home care and the diverse systems for co-ordinating care across a range of needs to facilitate community living. We therefore sought to classify the published studies and reviews in an attempt to impose some order on this complex evidence. This approach sought to delineate the different

models of home care provision in which domiciliary support services were a major component.

The categorisation of home care programmes has been undertaken in some earlier literature reviews published in the United States. Hughes (1985), for example, classified US studies evaluating community-based long-term care programmes into:

- > “skilled” home care programmes – which provided expert nursing care to patients following admission to hospital;
- > “expanded” home health care programmes – offering both medical and social services support i.e., supplementing medical or nursing care with homemaker or home health aide services;
- > “case-managed” community care programmes.

Parr (1996) in a systematic review of community based care categorised services into three broad models of care on the basis of what kinds of services were provided, and the target population:

- > The acute care substitution model – where home care met the needs of people who would otherwise have to remain in, or enter, acute care facilities.
- > The long-term substitution model – where home care met the needs of people who would otherwise have required institutionalisation.
- > The maintenance and preventive model – where home care was targeted at people with health and/or functional deficits, with the aim to maintain their ability to live independently, and in many cases to prevent health and functional breakdowns which might have meant eventual institutionalisation.

Given the policy framework within which this review was being conducted, neither of these approaches offered a fruitful way forward. Instead, we have drawn on aspects of each. Our focus however has been primarily on those service components relating to personal care, home help and home maintenance. Thus, we have organised the evidence to consider the outcomes of, and effectiveness of:

- > Homemaker/Home Care programmes: These had a major emphasis on providing housework, chore, home help and personal care services on an ongoing basis.
- > Short-term home care programmes: These offered practical support to people in the home, often following discharge from hospital, with an emphasis on users achieving independence.
- > Case/care managed programmes: Where individuals received a package of care through a case-management framework, in which domiciliary support was the main/a major component.

It should be noted that we were unable to locate any studies that examined specifically the outcomes of domestic assistance on its own. This is perhaps not surprising given the centrality in policy terms of domiciliary care to reduce/prevent long-stay and institutional admission. Focus on primary and secondary preventive services/interventions has only recently emerged on the policy agenda. As a review of the literature on the effectiveness and outcomes of preventive services (Godfrey 1999) makes clear, there are also considerable conceptual and methodological challenges involved in undertaking research in this area. Even so, this does not obviate the need for a sustained research endeavour.

Refining the Review Questions

The review is organised around the following questions:

- > What is the evidence on effectiveness and outcomes of three distinct models of home care:
 - a) homemaker/home care programmes?
 - b) short-term home care programmes?
 - c) care managed programmes where domiciliary care is the main component?
- > How have users and their carers evaluated the quality of home care provision and how satisfied are they with the services provided?
- > What is the impact of home care provision on informal care?
- > What has been the impact of changes in home care provision, particularly in respect of targeting, the diversity of providers, and from charging policies?

Methods

This chapter summarises the methods adopted in the systematic review. It delineates the literature search strategy; the development of the inclusion and exclusion criteria; and the approach to evaluating the evidence collected; and the way the evidence was synthesised.

Locating the Research Evidence

The initial task in finding pertinent research evidence was to develop some broad inclusion and exclusion criteria in order to 'scope' the topic area. The aim was to identify empirical studies which focused on *the provision, and outcomes of home help/ home care services*.

Searches were undertaken on a wide range of social/psychological and medical databases (Hemic, PsycLIT, Social Science Citation Index, and Sociofile, Cinahl, Medline, and Cochrane Library). Given the potentially broad range of home and domiciliary support services that could be provided across all vulnerable client groups (ranging from, for example, gardening and home maintenance to shopping and bathing), a very general search strategy was adopted to locate the potentially useful literature. In order to identify and place the UK based research literature within the wider international context, and to provide insight into the types and nature of research questions around home care which had been addressed in other countries, the search was broadened to include non-UK literature. In addition there was no attempt to limit the search to specific research designs given the range of evidence required to address the review questions. Thus, we included both quantitative and qualitative studies and then looked at the attributive confidence of each type given the nature of the research questions (see Macdonald & Sheldon, 1992).

A combination of freetext terms (for example home care and home help) and relevant thesaurus terms (for example home-care services) were utilised to maximise recall, and reflect alternative terminology used in other American and European studies (Appendix 1 gives an example of a search strategy). To accommodate the indexing policies of each database, differing search

strategies were adopted, although all were kept deliberately broad to reflect the exploratory nature of the initial searches.

7107 records were retrieved, including duplicates. They were visually sifted, judging their potential relevance from the detail provided in the abstract. If insufficient information was available for their classification - as irrelevant or definitely relevant - the article was obtained and a decision then made. From an examination of the abstracts, it was evident that most of the articles identified in the search were not pertinent to the topic under review. A large number of studies focused, for example, on providing medical care in the home, 'hospital at home' schemes, and on home nursing for those with a terminal illness. A further complication arose in classifying the relevance of North American and other European literature because of the different conceptualisations of home care. Within the North American literature, as indicated in Chapter 1, home care is defined very loosely as encompassing a broad range of home and community based services that could involve such diverse interventions as alarm systems, day care, financial services and care management. Home care also tended to include high technology home health care and hospice care as well as personal care and domestic support. Although domestic support is a legitimate component of home care, it was rarely provided and/or evaluated independently of a range of other more complex interventions in these studies.

The sifting process through the abstracts of the retrieved records consequently led to the elaboration and refinement of the inclusion and exclusion criteria (see Appendix 2).

The focus became:

Any intervention provided in the home, to those who required support in order to live in their home environment, which involved personal care assistance and/or help with cleaning, shopping, laundry and/or home maintenance services, but where the primary focus was not on acute or terminal care.

Given the nature of social care research, it was recognised that some potentially relevant evidence may not have been published, or made available by traditional means. Attempts were made, therefore, to access this 'grey literature' via specific databases (Caredata), research organisations, and the World Wide Web. A hand search of four journals was also undertaken, namely *Ageing and Society*; *Social Science and Medicine*; *Home Care Health Services Quarterly*, and *Research, Policy and Planning*. With the exception of the latter where the search extended to the first issue in 1985, hand searching was confined to issues published from 1990 onwards. This was partly to check the extent of the coverage of databases (a problem in our field) in addition to locating further evidence.

An early concern that there was a lack of recent research material being located, particularly studies that evaluated the outcomes of domiciliary care, led to additional searches of, for example, local libraries, the National Research Register, and the Department of Health Digest of Current Research.

From this array of different sources a total of 226 papers were requested as potentially relevant to the topic, and were assessed for inclusion. Many of these were subsequently excluded for the following reasons:

- > They were not really empirical research studies.
- > They did not meet the inclusion criteria for the review.
- > They were not pertinent to the definition of home care employed.
- > They had serious methodological problems (for example, studies that purported to be generalisable yet drew on convenience samples).

Following this latter sifting process a total of 49 studies were identified for inclusion in the study. As a further check on the searching procedure, and as an additional reference source, the citations of included research were scanned to identify further studies. 13 citations were subsequently included.

At the time of finalising the review a number of additional papers from the American or Grey literature which we needed to undertake relevance checks had not been received (34). These were unavailable from the British Library.

In summary, a complex, thorough, and iterative approach was adopted to identify literature relevant to the topic under consideration. Box 1 gives an overview of the stages involved in the searching approach. It was a multi-staged approach with continual relevance checks being made, and with the refinement of inclusion and exclusion criteria occurring in tandem with additional electronic searches.

Box 1

1. Broad inclusion criteria were developed to scope the topic area
2. A range of health and social care databases were searched
3. Relevance checks were undertaken on the retrieved abstracts
4. The inclusion criteria were refined
5. The searches were rerun
6. Relevance checks were continued as full reports of the studies were obtained
7. Citations from identified studies were checked
8. Inclusion criteria continued to be refined and elaborated upon
9. Selected journals were hand searched
10. The search was extended to identify 'grey literature'
11. The search was extended to locate the most recent research papers

Box 2

Databases

Helmic
Sociofile
PsycLIT
Social Science Citation Index

Medline
Cinhal
Cochrane Library

Grey Literature

Caredata
Joseph Rowntree Foundation
National Research Register
Department of Health Digest of Current Research

Evaluating the Evidence

All the research studies that met the inclusion criteria were critically appraised using a set of quality evaluation tools (see Appendix 3). These sought to describe and evaluate their conceptual and methodological strengths and weaknesses, and their practice and policy implications. The resultant critical reviews were subsequently entered onto a database, and they formed the source documents for drawing together this synthesis of the literature.

Synthesising the Evidence

A narrative approach to synthesising the evidence was adopted separately for the three areas: effectiveness of home care services; user and carers' views; and issues regarding the organisation and delivery of home care.

In research within the health care field, the quality of studies is often assessed according to the 'hierarchy of evidence' model which places greatest weight on well-designed randomised controlled trials. Given the nature of social care research and the interest in both quantitative and qualitative, experimental and non-experimental research studies, a number of key criteria were utilised in judging the overall contribution of the evidence:

- > Relevance of the study's aims to the topic area.
- > Detail provided on the nature of the intervention.
- > Relevance and robustness of the outcome criteria and measures.
- > Sufficiency of follow-up period.
- > Degree of methodological strength/control of bias.

Specifically, in the context of home care services, the quality of the evidence was judged according to:

- > The relevance of the study in addressing the effectiveness of home support services, and/or user and carers' views and/or issues around the organisation and delivery of home care service.
- > The detail provided on the nature and components of the support provided. This was particularly essential in evaluating the effectiveness of home care, considering the different ways in which it has been conceptualised.
- > Whether the study was longitudinal in design which would enable insight into both the short and long term effects of the intervention.
- > The relevance and appropriateness of the outcome criteria and measures.

The Scope and Quality of the Evidence

This chapter provides details of the types of studies included in the review in respect of the following: effectiveness of different types of home care programmes; service-user and carers' perceptions of service quality, including the relationship between formal and informal care; and aspects relating to the purchasing and commissioning of services that influence the organisation and delivery of services.

Scope of the Evidence Base

Effectiveness of Home Care

Research on the effectiveness of home care has been conducted in the United States, the United Kingdom, and Canada. Of the 13 research papers that met the inclusion criteria, ten were published in the UK and three in the USA. However, the ten UK research papers related to five discrete studies. Of the three papers reporting on research in the USA, each referred to a different study.

In addition, a total of seven literature reviews were included. All of these were published in Canada or the United States and reported on research carried out in North America.

If we had focused only on the UK literature regarding the effectiveness of home care, the evidence base would have been extremely narrow. Moreover, the main thrust of the UK studies was on home care within the context of care managed programmes. It was thus essential and appropriate to include studies from countries with similar cultural settings in this systematic review.

Table 3.1 illustrates the number of papers and studies located for review. The majority of studies adopted either experimental or quasi-experimental designs.

Table 3.1:
Type and number
of studies

| Study type | Home maintenance /home care | | Case managed | | Short term schemes | |
|---------------------------------|-----------------------------|-----------------------|----------------------|-----------------------|----------------------|-----------------------|
| | <i>No. of papers</i> | No. of studies | <i>No. of papers</i> | No. of studies | <i>No. of papers</i> | No. of studies |
| Systematic review/meta analysis | 3 | | 1 | | 1 | |
| Literature review | 2 | | | | | |
| RCT | 1 | 1 | | | 1 | 1 |
| Quasi-experimental | 1 | 1 | 8 | 4 | 1 | 1 |
| Survey | | | | | 1 | 1 |

User and Carer Opinion Studies

With regard to service-user conceptions of a good quality home care service, the studies encompassed UK research as well as research carried out in the United States and Sweden. This was seen as appropriate here since the issue under consideration was not user evaluation of provision but perceptions of the dimensions of quality in home care. Of the five papers found (relating to four different studies), three referred to research carried out in England (two different studies); one was carried out in the United States, and one in Sweden.

For user/carers views of current home care provision, only studies that were carried out in Britain were included. Nine papers, relating to seven discrete studies were located and included in the review. Two qualitative studies evaluated user perceptions of the home care service within a considerably broader research brief, as did the cohort study. The remaining qualitative study focused on carers' perceptions of the home care service.

Three studies were located which directly explored the impact of providing home care by statutory (publicly funded) agencies, on the support and care offered by informal carers, friends and relatives. Three others examined related questions concerning potential clashes between formal and informal services, associations with level of disability, and the effects of a reduction of 'chore services' on carer stress. All the studies were undertaken in the USA. Two used a cohort design; one was a case comparison study, and the others were cross-sectional surveys (see Table 3.2).

| Study type | User/carer conceptions of a quality home care service | | User/Carer views of services provided | | Substitution of formal for informal care | |
|-----------------|---|----------------|---------------------------------------|----------------|--|----------------|
| | No. of papers | No. of studies | No. of papers | No. of studies | No. of papers | No. of studies |
| Qualitative | 3 | 2 | 4 | 3 | | |
| Cohort | | | 2 | 1 | 2 | 2 |
| Survey | 2 | 2 | 3 | 3 | 3 | 3 |
| Case comparison | | | | | 1 | 1 |

Table 3.2:
Type and Number of Studies

Organisation and Service Delivery

The evidence here relates to three aspects of the organisation and delivery of home care namely: targeting; the penetration of the market; and charging policies. Changes in the way services have been commissioned and purchased following community care implementation have had a dramatic impact in respect of each of these areas. It seemed pertinent therefore to consider how these developments might have impacted on service users.

| Study type | Targeting | | Diversity of Providers | | Charging | |
|-------------|---------------|----------------|------------------------|----------------|---------------|----------------|
| | No. of papers | No. of studies | No. of papers | No. of studies | No. of papers | No. of studies |
| Qualitative | | | 2 | 2 | 3 | 2 |
| Survey | 4 | 3 | 3 | 3 | 5 | 4 |
| Cohort | 1 | 1 | | | | |

Table 3.3:
Type and Number of Studies

Quality of the Evidence Base

In assessing the quality of the evidence base, weaknesses were evident at a number of different levels. First, there was the level of variation in the way home care was conceptualised. Second, there was the appropriateness of the outcome criteria and measures employed in the studies. Third, there was a range of methodological issues arising out of the complexity of the intervention and the difficulties of carrying out research in this field. These are summarised below.

The nature of the studies

Although British and American settings are culturally similar, there are important differences in how their respective health and social care systems are organised. In the United States, for example, home care is covered via health care insurance for short-term, acute illnesses or through publicly funded Medicaid programmes. Support in the home is often specifically excluded unless high technology medical/nursing care is also offered. Social care coverage for older and disabled people is thereby limited. Thus, in order to obtain home care many people are driven into the medical system. Since the majority of home care packages, therefore, incorporate medical elements, it was essential for us to ascertain just how much health care is provided within individual packages. However, this information was not always available in sufficient detail for us to make a secure judgement.

Further, funding sources and mechanisms within US programmes are diverse; they often include social health management organisations (SHMOs) that have coupled casemanagement with the provision of inhome services aimed at supporting individuals with impairments in activities of daily living. They also include: non-health care providers, such as the Department of Ageing; secondary health providers, like the Department of Rehabilitation; and demonstration projects (e.g., Robert Wood Johnson Foundation). Because of the diversity of providers and programmes, access and targeting strategies are very varied. Indeed, a common feature of the organisation of home care in the United States and current provision in Britain, is the diversity of providers and the large proportion of for-profit providers.

Use of appropriate outcomes to measure effectiveness

The majority of studies have focused their outcome criteria on the substitutability of home care for institutional care and the relative costs of such care. There has been much less emphasis on the impact of home care on the well being and satisfaction of service-users and those who help to care for them.

It is not clear, however, that outcome criteria relating to the substitutability of home care services for hospital and nursing home admission, are appropriate. Concern centres on the pattern of use of these different forms of care. How certain is it that people who receive home care might otherwise have entered residential/nursing home settings? Whilst the research evidence clearly indicates that the risk of institutional admission increases with severity of impairment and a lack of social support, these factors only account for a small measure of the variation in use. Thus, Opat and Pahl's (1993) secondary analysis of OPCS Disability Survey Data, found that among those who were seen as most dependent (short/critical interval needs, living alone with dementia), just under a third (32%) were admitted to residential/nursing home care. Similarly, the issue of informal support is considerably more complex than the question of availability, or the level of objective burden experienced. There is extensive evidence indicating that it is not the objective burden of caring which causes carers to give up but a combination of factors. These include: the nature and quality of the relationship with those being looked after (Lewis and Meredith 1988); the perceived acceptability of long term institutional care (Levin *et al* 1994); the coping strategies adopted; and the level of acceptance of the current situation and the motivation to care (Blom & Duijnste 1997; Duijnste 1994). It would seem that high dependency need does not equate straightforwardly with risk of institutional admission. Therefore, only insofar as the target population has been assessed as needing residential/nursing home care, is it appropriate to consider diversion as a legitimate outcome criterion. Very few studies sought to distinguish between people with high dependency needs and those at risk of institutional admission, a conceptual error, in our view.

Furthermore, it appears that the case mix within the residential/nursing home population is becoming more severely impaired over time. As a result, it has been suggested that more appropriate research questions may be the

following. *What is happening to persons with lower impairment levels who used to be able to access residential/nursing home care? Are they being supported at home with domiciliary care services and, if so, with what quality of life outcomes?*

A further aspect that needs to be taken into account is whether policies aimed at reducing the use of one type of care may result in greater use of another, whether intended or not. It is conceivable for example that people maintained in their own homes as an alternative to residential/nursing home care may make greater use of acute hospitals to cope with short-term crises.

The question of how to target domiciliary services most effectively and then to examine outcomes, is therefore more complex than might be thought.

There has also been concern about the appropriateness of improved functioning (most commonly measured by *Activities of Daily Living* (ADL)) measures to evaluate the effectiveness of home care. But these appraisals are only appropriate in those specific instances when the prognosis indicates that improvement is plausible, often where substantial amounts of physical or occupational therapy are being provided. Furthermore, it has been recognised that the measurement of ADL scores could lead to an over reporting of disability, because questions refer to receipt of help rather than ability to perform an activity. This raises the more general point that it is difficult precisely to specify outcome measures so as to adjust for the natural progression of disease, disability, or ageing.

Information on costs does not tend to include all provider, patient and social costs. Average costs do not reflect differences in case severity.

Many of the studies on user/carer opinions of home care were based on surveys using global measures of satisfaction. However, older people (and most of the studies on home care related to older people) are reluctant to express dissatisfaction because they tend to have low expectations of provision, are grateful for what they get, and may be fearful that the service might be withdrawn. Only when views are probed more deeply can one ascertain specific concerns and difficulties. It was notable for example, that user satisfaction surveys carried out in authorities with quite different patterns of provision, revealed similar global levels of satisfaction with the service provided, when one might have expected noteworthy differences to emerge.

Lack of information in studies about potential confounding factors

Differences across studies in patient health status at intake, as measured by physical function, mental status, medical prognosis, and use of health care services in the period immediately prior to study entry, could each be important in affecting outcomes. Other potential confounding factors around unmeasured differences in the characteristics of the services offered and received, include the objectives, frequency, intensity and timing across the followup period. Yet information on such variation did not tend to be

provided, and the fact that it was not, was a major impediment to any systematic synthesis of this literature.

Heterogeneous population

The populations who require home care are usually older people and/or are physically disabled. Their needs are extensive, intensive, and heterogeneous. They vary in their personal experience of dependency; the times and frequencies for which they require assistance; the amount of informal and social support available to them, and regarding their individual mental health and personality characteristics. Yet little insight is provided by current investigations of these variations; how home care packages differ across individuals; and the impact of interventions across sub-populations. For example, people with a cognitive impairment such as dementia pose an enormous challenge to community-based care. Yet most of the studies on effectiveness excluded such users. Also, there is little research that attempts to understand how race, ethnicity, cultural values and norms interact with need, and influence the way in which needy people use such services as are available.

The nature of interventions

Earlier we referred to the different ways in which home care has been conceptualised. As indicated in Chapter 1, we sought to try to create some order in the face of this complexity by categorising the programmes into three specific types. Even so, it was apparent that the interventions offered within each of these broad categories varied in terms of their specific inputs and degree of co-ordination. Thus, home care can encompass in-home health and supportive services, post-acute and longterm elements and medical and social components. The lines between these service models are often rather blurred. Post-acute care is often medical and recuperative in character, while long-term care involves the delivery of health, personal, and social care to persons with impaired functional capacities. Home care can also utilise the professional and interpersonal skills of nurses and therapists, housekeepers, chore and volunteer workers. Despite this, most studies fail adequately to describe the nature of the services being delivered and the variations in these services across study populations. Few have attempted to specify service models within home care. Fewer still have made efforts to at least speculate about those particular service elements that yielded positive or negative outcomes.

Contamination in experimental studies

Another area in need of methodological attention is the frequent finding that study participants have not remained in the experimental categories to which they were assigned, with experimental subjects not receiving any services, and control patients receiving similar services to those in the experimental group but under different auspices. Clear reporting of any crossover is required in order to judge how accurately outcomes reflect intervention effects (see Sheldon & Macdonald, 1999).

Appropriate follow-up period

How appropriate was the follow-up period of each study has been little

considered within the literature. The majority of the studies have examined outcomes over 12-months. Yet the time-interval selected must be chosen in view of the purpose at hand. For example, where the aim is to prevent institutional care, outcomes may only be evident over the longer term. At the same time, examining outcomes in the medium to longer-term future has the attendant risk of other factors distorting the evidence. Thus, as the duration of time from the initial baseline point lengthens, so too is there an increased risk of new care needs arising, complicating the attribution of outcomes to a particular type of antecedent care. For short-term care schemes where there is an explicit aim to return people to maximum independence, there is a need to consider both short-run and longer-term outcomes.

There was a paucity of longitudinal research designs that focused on complete episodes of care, involving transitions from one functional state to another, or from one care setting to another, or from one service package to another.

Pilot projects and mainstream services

Many of the studies reviewed evaluated demonstration or pilot projects. However it is important to consider that results from pilot programmes may reflect unique personnel factors or situations that are not likely to be generally reproducible in other settings. For example, the PSSRU home care schemes (Challis & Davies 1986) evaluated in Kent, Gateshead and Darlington were relatively small-scale ventures, kept small through gatekeeping. In the context of mainstream provision, home care services will cater for a much wider clientele. The question here is how far are findings from special projects conducted in relatively propitious circumstances, reproducible in everyday circumstances.

In terms of current home care provision, a different issue arises in respect of the generalisability of the findings. Many of the studies reviewed were carried out in individual local authorities. Yet, it was untypical for studies to provide a detailed picture of the service context in which they were conducted. To take the example of home care charges, there is enormous variation in the nature and types of charging policy and practice. Yet, how can one make sense of the impact of such charges on service-users if information on the specific policies in place is not provided?

The available literature

There were very few studies on effectiveness located relating to the last decade. Most of those included were published in the late 1980s reflecting evaluations of programmes of care in the earlier part of the decade. It was notable, but perhaps not surprising, that despite changes in commissioning, purchasing, allocation, and service delivery systems in home care since the implementation of the community care reforms, there is a paucity of research evidence on outcomes. Thus, whilst there is a good deal of descriptive information documenting the changes, their impact on service delivery processes and user outcomes has not been as yet subject to systematic research. The wise words of Sir Frederick Seebomh come to

mind at this point:

The personal social services are large-scale experiments in helping those in need. It is both wasteful and irresponsible to set experiments in motion and to omit to record and analyse what happens. It makes no sense in terms of administrative efficiency, and however little intended, indicates a careless attitude towards human welfare.

(Seebohm Report 1968: 142)

Uniqueness of home care

Home care is unique in several ways that make it complex to attribute outcomes to the care provided. Care is offered in the privacy of the person's home and the home carer is essentially a guest of the user. In addition, and as with other care services, the relationship between provider and user is an important element of the service, alongside the specific inputs offered. Similarly, features of the home environment such as layout and accessibility, and the nature of the social environment (friends, relatives, informal caregivers) may be important factors in securing independence, improvement, or maintenance of function and therefore important to consider when attributing interventions to outcomes.

In summary, the evidence base in home care is of variable quality. It is, moreover, subject to methodological and conceptual difficulties. It is important to recognise however that these, in part reflect the very real problems and challenges in conducting research in respect of complex problems and interventions. There is, therefore, a need for research that not only focuses on outcomes but also elucidates the processes producing those outcomes.

Notwithstanding the difficulties with the nature and extent of the evidence on home care, the review does provide clear answers to some of the questions of interest to service commissioners and providers. It also helps to clarify those questions to which only provisional answers can be offered at this point, as well as identifying more precisely what are the gaps in the evidence. It therefore reduces the margin of uncertainty for commissioners and providers, and, where they are properly brought into the effectiveness debate, for service-users and carers.

Outcomes of Home Care Programmes

In Chapter 1, we set out the rationale for organising the evidence base to consider the outcomes and effectiveness of:

- > **homemaker/home care programmes** with a major emphasis on providing housework, chore, home help and personal care services on an ongoing basis;
- > **short-term home care programmes** offering practical support to people in the home, often following discharge from hospital, with an emphasis on the users achieving independence;
- > **case managed programmes** wherein individuals received a package of care through a casemanagement framework, in which domiciliary support was the main/or a major component.

In this chapter we review the evidence on effectiveness and outcomes of four homemaker programmes, three short-term care programmes, and four case-management programmes. Whilst the programmes within each category are similar in certain key respects (for example in that the focus is on care offered within the individual's own home), it is necessary to be mindful that they can also differ in, the people targeted; the objectives of care, and the specific service inputs¹.

¹ See Appendix 4 for specific details on each of the programmes of care including aim, characteristics of those receiving the services and the service inputs.

Homemaker/Home care programmes

The Nature of the Programmes of Care

A total of two studies and five literature reviews provided information on the four programmes, all of which were undertaken within the United States. The *Homemaker* and the *Chicago Five Hospital Homebound Programme* were described as long-term comprehensive services, which involved a number of providers. Services included personal care and certain household duties such as changing beds, light cleaning, food shopping, and help with cooking, all in order to support people with high dependency needs to manage within their home environment (Hughes *et al* 1984; Weissert *et al* 1980). The *Five Hospital Homebound Programme* in Chicago also included telephone

reassurance and visits from volunteers (Hughes *et al* 1984). As a consequence of the United States health care insurance system, domestic support in the homemaker programme was provided alongside nursing, or another type of skilled service (Weissert *et al* 1980).

The *Chronic Disease* and *Home Aide* programmes were relatively low intensity schemes. Both provided personal care, housekeeping and help with shopping. The *Chronic Disease* programme was provided through an interdisciplinary team to persons living in, or about to be discharged to, community settings who needed assistance with bathing, walking and/or dressing.

| PROGRAMME | SERVICE INPUTS | TARGETED AT |
|---|--|--|
| Homemaker (Weissert <i>et al</i> 1980) | Homemaker services including chore, personal care, shopping, and escort. | Those discharged from hospital, not needing 24hour supervision, to restore or maintain functional ability. Long term. |
| Home Aide (Hughes <i>et al</i> 1985; Weissert <i>et al</i> 1988,) | Home aide services, escort, housekeeping, personal care, leisure and health care. | Those discharged from geriatric rehabilitation hospital to the community, and those not already receiving organised home aide or homemaker services. |
| Chicago Five Hospital Homebound Programme | | |
| (Hughes <i>et al</i> 1984) | Multidisciplinary team providing personal care, shopping, cleaning and other services such as telephone reassurance and volunteer friendly visiting. | Chronically impaired older persons requiring maintenance care. Homebound. Long-term. |
| Chronic Disease (Weissert <i>et al</i> 1988) | Light housekeeping and therapeutic exercises provided through social worker, health assistant and physician. | Those in need of relatively low intensive home-care services. Discharged to or living in community. In need of assistance for at least three months. |

Table 4.1:
Homemaker/Home Care Programmes

At Whom were the Models of Care Targeted?

The *Home Aide* and the *Homemaker* services were explicitly targeted at those who had recently been discharged from a treatment and/or rehabilitation setting to the community. Eligibility for the *Five Hospital Homebound* and the *Chronic Disease* programmes was not dependent upon prior hospitalisation, and services were provided to those already living in their own homes.

In general the users of the different schemes were:

- > older persons;
- > those who were chronically impaired in activities of daily living. In addition the majority of those receiving care reported multiple health and social problems, including personal care and house care difficulties, and general frailty;
- > women;
- > those not in need of 24-hour support or supervision.

The Outcomes of the Programmes of Care

The outcome criteria across the studies focused on the potential value of home care to act as a substitute for institutional care. Outcomes measured, therefore, included acute hospital admission, institutional admission, health status and functioning, mortality, cost, subjective well being, and measures of the quality of care.

When compared to alternative services the evidence from the programme indicated the following:

- > There was no impact on the rate of acute hospital admissions and/or rates of hospital stay.
- > The effect on the rate of admission to nursing homes was inconclusive, in that only the *Five Hospital Homebound* scheme and the *Home Aide* programme reported significantly favourable effects. The *Chronic Disease* and *Homemaker* programmes had no impact.
- > The *Five Hospital Homebound* programme was the only study to find a significant impact on health as measured by activities of daily living, and this was in the opposite direction to that anticipated. Thus, those receiving the service experienced a significant reduction in abilities regarding dressing, bathing and continence. Interestingly, these service users also reported significant improvements in their perception of their physical and mental health. The authors of the study hypothesised that regular assistance with difficult or painful tasks improved their subjective health status whilst reducing their ability to engage in activities through lack of experience of so doing (Hughes *et al* 1984).
- > There was some evidence that the programmes were associated with lower mortality with the *Homemaker* and *Five Hospital*

Homebound programmes reporting a significantly favourable effect.

- > The programmes resulted in higher costs after one year.
- > Despite a lack of evidence in respect of subjective well being, there was evidence of a favourable impact on life satisfaction.
- > There was a significant reduction in unmet needs among those receiving the *Five Hospital Homebound* and *Home Aide* programmes. This was reported both over the short and longer term (two years in the former case).
- > Disappointingly, there were no favourable effects on carers in terms of morale or levels of stress.

Short-term Schemes **The Nature of the Programmes**

Three schemes which provided home help and personal care services were short-term and aimed to support those discharged from hospital when they returned to their own homes. These were: the *Care Attendant* scheme (Townsend *et al* 1988); the *Rhondda Special Care* scheme (Victor *et al* 1986); and the *Home from Hospital* scheme (Waddington & Henwood 1996). All three were based in the United Kingdom.

Two of the programmes involved collaboration between health and social services. In one, care attendants provided help for up to 12 hours a week for two weeks after hospital discharge. This included support with practical care; encouraging patients to look after themselves, and help to mobilise social support from family, friends and statutory services (Townsend *et al* 1988). In the other, staff provided older people with additional home help services and night sitting following hospital discharge (Victor *et al* 1986).

The third programme, the British Red Cross *Home from Hospital* scheme (which operated across 17 different locations) was funded through contracts with health and/or social services, and provided practical and personal support through trained volunteers. A detailed discussion of the scheme is provided within the evaluation report (Waddington & Henwood 1996). The project was complementary to the home care services within health and social care agencies. It had the aim of ensuring that people did not find themselves alone and unsupported following hospital discharge, particularly those whose needs did not meet statutory service eligibility criteria. Volunteers typically undertook the following tasks for a period of between four and six weeks after discharge:

- > preparing the home for the return of the occupant;
- > keeping the person company;
- > housework;
- > preparing meals;
- > practical help around the house;
- > shopping;

- > collecting pensions and/or prescriptions;
- > providing support and relief for carers.

Volunteers did not undertake personal care tasks as such, but they did support persons engaged in self-care. Most service-users were not visited intensively. Only 6% were visited four times, although 3% were being visited up to 21 times a week.

At Whom Were the Programmes Targeted?

All three programmes sought to help those discharged from hospital. Two explicitly aimed to enable safe and timely discharge of older people (Townsend *et al* 1988; Victor *et al* 1986). The majority of *Home from Hospital* schemes did not select according to age, and recipients spanned the age range 30 to 87 years. Most were older people however, and the mean age of service users was 73 years.

In general users across these schemes were:

- > women;
- > those not in need of 24 hour care;
- > older persons;
- > those impaired in daily living activities.

As short-term schemes, and in contrast to the other studies included in this review, the implication was that the target population was one that was expected to restore or improve its functional status. Townsend *et al* (1988) made it explicit that the aim of the service was to return the older person to optimal independence by ensuring that they were adequately supported.

The Outcomes of the Programmes of Care

In contrast to the Homemaker/Home care programmes there was little consistency in the outcome criteria and measures used within the studies. Moreover, outcome measures were few and there were methodological problems associated with each of the studies. The *Special Care* scheme, for example, was highly selective in considering who was eligible. Further, those who were not referred to the scheme tended to have relatively high levels of depression, anxiety and mental health problems (Victor *et al* 1986).

When compared to standard services:

- > The *Care Attendant* and *Special Care* schemes had no significant impact across a range of outcomes including measures of health and functioning, anxiety and depression and survival rates. Nor was there any evidence of any favourable effects on subjective well being.
- > There was, however, some evidence of a reduction in hospital readmission rates for those who lived alone and were supported by the *Care Attendant* scheme at the 18 months point. In addition the scheme led to a lower rate of utilisation of other health and social services. Favourable cost data were, therefore,

reported. The *Special Care* scheme, however, had no significant impact on rates of acute hospital admissions or on costs.

The evaluation of the Red Cross *Home from Hospital* programme focused on the acceptability and impact on the users of the service. In particular it examined user satisfaction (discussed in Chapter 5) and whether the support provided was consistent with clients' perceptions of their needs for help. Six of the 17 schemes were selected for evaluation purposes and a sample of 33 users were interviewed.

Both the patients' and hospital staff views on the need for support following discharge were ascertained. 85% of people served by the scheme felt they were in need of help with cleaning and tidying the house; 85% with shopping; 70% with bathing and/or showering; and a further 70% felt they were in need of companionship. 67% felt in need of help with their laundry, cooking and with preparing meals. A considerably lower proportion of people felt that they needed help with other personal care tasks. 27% felt that they needed help with dressing; 27% with washing their hands and face; and 12% with going to the toilet.

There was evidence of the effectiveness of the *Home from Hospital* scheme in providing the type of support consistent with users' self-assessed needs for help. The scheme provided more help with cleaning the house and preparing meals, for example, than did family or friends or any statutory service. It also provided more care with dressing, personal appearance and washing hands and face which data were also consistent with the clients' own assessments. With respect to providing companionship, the scheme was assessed as being more important than family and friends, although both provided help consistent with the needs of those assessed.

In the absence of the *Home from Hospital* scheme, it is evident that there would have been considerable unmet needs (as defined by service-users) in respect of dressing, personal appearance, washing hands and face, cleaning/tidying the home and preparing meals.

Case-managed Programmes

Short-term schemes focused on the immediate and temporary aftercare needs following acute inpatient admission. By contrast, case-managed programmes concentrated more on those with long-term, high dependency needs who were also primarily at risk of institutional admission. These programmes sought to develop services to enable people to live in their own homes wherever possible, and targeted resources on those who were most in need. Nine research papers and three literature reviews provided information on four case-managed programmes of care, three of which were; *Community Care Demonstration* projects undertaken in the UK (for example Challis *et al* 1986, 1989, 1990, 1991b) and one a programme based in the United States (Brill & Horowitz 1983). It is the nature and the type of care and services provided within each of these case-managed programmes which renders them as pertinent to this review.

The Nature of the Programmes

East Kent and Gateshead 'Stage One'

The first Community Care project undertaken in the UK was the East Kent scheme. This was followed by the development of the Gateshead case-management programme, which encompassed two stages. The provision of social care provided through social services predominated in the first stage. The Kent and Gateshead programmes were similar as they sought to provide effective community-based long-term care to frail older people who faced extreme difficulties in coping at home and whose needs placed them on the margins of institutional care. Effective care was to be achieved through case-management. These procedures aimed to tackle both the inappropriate content of previous services, and the fragmentation and lack of co-ordination of service delivery. Case-managers deployed a decentralised budget which could be spent on a variety of services not normally available through social services, set at two-thirds the cost of a place in a residential home.

The principal service development, alongside the implementation of case-management, and provided within both programmes of care to almost all users, was the support from 'helpers'. 'Helpers' were not intended to replace home helps but to provide additional assistance across a range of activities that was both wider in type and time of response than would be typical of a domiciliary care service. For example helpers were available to provide care in the evenings and at weekends.

The principle tasks, which were undertaken by helpers at both sites, included:

- > help with household tasks – light housework and shopping;
- > ensuring an adequate diet – heating meals, preparing snacks and monitoring food and drink consumption;
- > personal care activities – check-up visits intended to minimise solitude, helping with toileting, bathing, with rising from and retiring to bed.

Although the schemes were very similar in Kent and Gateshead, a greater proportion of helpers' time in the latter was spent assisting with personal care needs, and correspondingly less time helping with housework and shopping.

The other services which case managers most frequently used and/or liased with included:

- > Home help;
- > General Practitioners;
- > Community Nurses.

Gateshead 'Stage Two'

The second scheme to be developed in Gateshead involved additional resources, provided by the District Health Authority, for a pilot Health and Social Care Scheme. The Social Care team had identified a constraint to effective long-term care for those on the margins of institutional care, which

arose from the complexity of some of their health care needs. Dealing with incontinence, immobility and managing episodes of acute illness were particular problems identified by helpers. In response, additional skills, training and knowledge were supplied to helpers through a closer working with staff who had medical, nursing and paramedical expertise. Consequently 'helpers' became 'multipurpose carers' and a larger proportion of their time was spent on personal care tasks. There was also greater contact with general practitioners and community nurses than in the previous scheme.

Darlington

The Darlington project was one of 28 pilot schemes that was centrally funded under the Government *Care in the Community Initiative*. It built on the case management approaches undertaken in Kent and Gateshead, in particular in its use of the principles of case management. The approach was, however, developed to enable the discharge of long-stay hospital patients. Instead of 'helpers', 'home care assistants' were recruited to provide extensive levels of home support. They acted as multipurpose carers in order to reduce the duplication of tasks, and spanned the roles of home help, nursing aide and paramedical aide. In practice the home care assistant also acted as an auxiliary to a wide range of specialised community staff including district nurses, physiotherapists, occupational therapists, speech therapists and dieticians, depending on the needs of each individual. The aim was to provide both an extension of service, and a reduction in the number of individuals providing care. A survey of activities undertaken by home care assistants during one week, two years after initiation of the programme, revealed that the most frequent personal care tasks were toileting, transfer, management of medication, dressing and washing. The most frequent domestic care tasks were housework, cooking and laundry.

The New York City Home Care Project

This programme sought to enable homebound older people to maintain a satisfactory existence at home, and prevent or deter unnecessary institutionalisation. As with the UK demonstration projects, case management was utilised to co-ordinate existing community resources, health and social services. The maintenance services, provided for between eight and 20 hours per week, included homemaker, personal care, assistance with medication, the organisation of social activities and non-emergency transportation.

At Whom were the Case Managed Programmes Targeted?

The Kent and Gateshead Community Care Demonstration projects were targeted explicitly at those living in the community who were on the margins of institutional care (Challis *et al* 1986, 1990a). The New York City Home Care project was focused on frail and homebound older persons residing in the community (Brill & Horowitz 1983).

Across these three schemes recipients were usually:

- > older people;
- > chronically impaired in activities of daily living, having difficulty with managing at home. The sample populations frequently required help with dressing, bathing and walking;
- > women, constituting up to 80% of the samples;
- > living alone. In the UK schemes the majority of those receiving the intervention, between 69% and 75% of the sample, lived alone. This was a much higher proportion than the national average. For example in 1996 an estimated 47% of those aged over 75 years lived alone (Living in Britain: results from the General Household Survey 1996). In contrast, however, only 30% of those who received the New York City Home Care Programme lived alone;
- > receiving support from an informal carer. This was evident for over 70% of the Gateshead samples, and 50% of the Kent sample despite the latter being located in a retirement area. The New York City Home Care Programme required that service users had, at a minimum, a close proximate caregiver.

The third UK Community Care Demonstration project in Darlington targeted frail older persons in hospital. These recipients were less likely to be women and to live alone (38% were discharged to live alone). They also tended to have severe mobility and self-care problems with only 6% of older people able to move unaided, and 65% who were incontinent.

A common feature of these home care programmes was the specific eligibility criteria and explicit exclusion of certain potential users. Among the community care demonstration projects, for example, account was taken of factors such as personality, motivation and family circumstances. Older people had to have the desire to return to and/or remain in their home. They were considered unsuitable if they were in a chronic anxious state, suffered from chronic depression, required care at night and/or suffered from dementia which appeared 'not amenable to intervention'. Moreover, they were all specifically targeted on those assessed as at *risk* of institutional care. The New York City Home Care project excluded persons who did not have a relatively strong informal caregiver network. Whilst focusing on people with high dependency needs, they were not necessarily at risk of institutional care. It is arguable then that these programmes were skewed towards those who would be most likely to benefit from remaining in their own homes.

The Outcomes of the Case-managed Programmes

The outcome criteria across these studies focused on the potential value of home care to act as a substitute for institutional care and allow the individual to remain at home. Outcomes measured consistently across the studies, therefore, included institutional admission, health status and functioning, mortality, cost, subjective well being, and quality of care.

The evidence indicated that when the programmes were looked at alongside comparison services:

- There were significant favourable effects on rates of admission to long-stay nursing homes among the Community Care Demonstration Projects after 12 months. This finding was not, however, replicated in the New York Home Care Programme, which provided care for over five times the number of older people. The reasons for the lack of consistency in the findings could be the result of the methodology used and/or the selective eligibility criteria noted above.
- Rates of institutionalisation may have been delayed rather than prevented. Admissions to institutional care in the Kent scheme were measured over a period of four years. After three years the rate of long-term institutionalisation among both groups was almost identical.
- There was no evidence of an improvement in physical functioning. Indeed there was some evidence of a decline in functional ability among those receiving the New York City Home Care Programme and the Kent Community Care scheme.
- The only study to measure the impact on the rate of acute hospital admissions (New York City Home Care Programme) found that it had no significant impact. Whilst there was a significant decline in the average length of stay per hospitalisation for those receiving the intervention at six months, this was no longer apparent at 12 and 24 month follow-up (Weissert *et al* 1988).
- There was no evidence of a beneficial impact on survival rates. The only significant finding occurred as a result of the Darlington scheme. A significantly higher proportion of the intervention group had died by six months. As the potential explanations for this are unclear, further investigation is required.
- There were significantly favourable effects on subjective well being. The UK demonstration projects measured a range of subjective well being outcomes through interviews with older persons. There were reports of significantly better life satisfaction, a decline in depression, improved outcomes regarding loneliness and morale, and an improved perception among programme recipients about their capacity to cope with daily living.
- There was a reduction in unmet needs across physical and mental health domains, types of services received and the perception of the reliability, adequacy and effectiveness of care received.
- These favourable outcomes regarding subjective well being and unmet needs occurred alongside an absence of significant differences between the costs of case managed programmes and standard services.
- Although based on small samples, there was some evidence that the UK demonstration projects had positive benefits for carers.

Outcome scales were not consistently used across the studies and applied at various time periods, but they suggested that carers' subjective views of the demands of domestic routine and social life improved as a result of the intervention programmes. There was no difference, however, in the amount of informal care provided.

Summary

In this chapter we have reviewed the evidence that exists on the effectiveness and outcomes of home care programmes which placed an emphasis on service inputs relating to personal care and home help services. We have highlighted the range of conceptions of home-based care in the literature both in terms of the specific service inputs provided, and the targeted user groups. For this reason we organised the material into three different types of programmes:

- > long-term
- > short-term
- > case-managed

Some general comments can be made regarding the findings.

- > The studies focused on outcome criteria and measures that centred on the potential value of home care to act as a substitute for institutional care. However, many of the studies, whilst focusing on people with high dependency needs, had not assessed people as being at risk of institutional care.
- > The evidence indicated that there was very little impact on rates of acute hospital admission, or on lengths of hospital stay.
- > The UK case management programmes reported significantly positive outcomes in respect of preventing or at least delaying admission to long-stay nursing/residential homes. A key factor in producing such positive outcomes seemed to be that people in the schemes were assessed as at risk of institutional care. Where programmes did not target those on the boundary of institutional care, there was no significant impact on institutionalisation.
- > Outcomes relating to physical functioning and subjective well being were less consistently applied.
- > There was some evidence of a decline in abilities concerning activities of daily living (particularly to personal care tasks). This may indicate that home care workers, by taking on specific tasks, rather than helping people do things for themselves, increase dependency. This, clearly, is an area requiring further research, particularly given the current policy emphasis on encouraging optimal independence.
- > Studies showed a consistent and significant impact on users' life satisfaction among those receiving home care support. However, evidence of improvement in subjective physical and mental health was inconclusive.

- There was consistent evidence of a reduction in unmet needs (as defined by service-users and providers).
- There were no favourable effects on carers in terms of morale or levels of stress.

User and Carer Perspectives on Home Care

This chapter offers a consideration of the research evidence on user and carer perspectives on the outcomes of home care and levels of satisfaction with the service. Because of the enormous shift in the nature of home care provision since the community care legislative changes, attention has concentrated on studies undertaken since 1990.

Dimensions of a Quality Home Care Service

Henwood *et al* (1998) employed both individual and focus group interviews within three local authority areas to elucidate conceptions of service quality held by older users and their carers. Thus the emphasis was not on people's level of satisfaction with particular services, but those features of service delivery that mattered most to them and, conversely, those with which they were least happy. The majority of people in the study were over 70 years and there was one focus group of caregivers. The service users had a range of disabilities and needs for assistance and received varied levels of intensity of support.

Whilst users and carers indicated a variety of factors that were important to them, those most valued included the following:

- Staff reliability
- Continuity of care and of staff
- Kindness and understanding shown by care workers
- Cheerfulness and general manner of care workers
- Competence in undertaking specific tasks
- Flexibility in responding to changing needs or requirements
- Knowledge and experience of the needs and wishes of the user and/or carer
- Availability of clear Information about the services that will be provided

The following service features were perceived as a source of dissatisfaction:

- > Incompetence and lack of initiative
- > Unreliability
- > Frequent changes of home carer
- > Unsuitability of home carer
- > Inflexibility and unresponsiveness of service
- > Lack of appropriate training
- > Poor value for money
- > Workers in too much of a hurry
- > Failure to provide help with specific tasks
- > Inability to provide help out of office hours
- > Disruption of service through changes of contracts

Caregivers views about what constitutes a quality home care service were similar to those of users. An additional aspect for them was that care workers be sensitive to the needs of other people living in the same household as the user.

Woodruff and Applebaum's (1996) considerably larger study of consumer perspectives on home support services in the United States (evidence from 270 users across four pilot regions and six indepth case studies), came to similar conclusions. Here, what seemed significant in terms of a quality service was whether the mode of delivery facilitated older people maintaining control over the services received, in particular, whether it was reliable, delivered competently, and was responsive to what people needed.

Edebalk *et al's* (1995) study of older people receiving home help services in three different localities in Sweden (a large town, a small town and a rural area) used an innovative methodological approach (Multi-Attribute Utility Technology) to examine the relative importance attached to valued characteristics of the service. The authors also sought to examine how these evaluations of quality varied between different groups. Drawing on previous qualitative research, a 'tree diagram' was constructed comprising attributes of home care at three levels of specificity. At the most general level, five major quality attributes were identified (similar to those drawn out by Henwood *et al* and Woodruff and Applebaum) namely: influence/control, personal relationship, continuity, availability/time, and suitability of the home help. These were further broken down into more specific qualities at the second and third levels. They found that:

- > at the most general level, continuity, stability and the quality of the personal relationship with the home help, were accorded the highest value.
- > for those who were most dependent (older, receiving more hours help, in poorer health), the highest value was attached to continuity, specifically staff continuity over time.

- > whilst suitability was accorded considerable importance, the specific aspect valued was professional competence in carrying out the tasks as opposed to the personal disposition of the home help.
- > housework was accorded higher value by women and those receiving most home help hours. Even among those receiving personal care, housework was given a high evaluation by women.
- > older people who were less dependent valued influence (i.e. the extent to which they decided what the home help would do and how) more highly than those who were most dependent.

The high value accorded to housework by women in this research, was supported by Clark *et al's* study (1998). This sought to examine the value older people gave to low level care and support services. 51 people were interviewed in their own homes, a number on more than one occasion, across three local authority areas. Whilst the importance of domestic help was stressed by these older people, for women in particular, having a clean home was viewed as a key factor in maintaining their sense of dignity and self-respect. Men, on the other hand, did not express the same level of concern about the appearance of their home, nor did help with housework appear to be so central to their notion of independence. Further, some older people viewed as crucial the assistance provided with home renovation and maintenance toward enabling them to remain in their own homes. Since the study does not provide information about the characteristics of users interviewed, it is not possible to ascertain whether such views were consistent across the range of need.

User Satisfaction with Home Care

A number of studies focused on user satisfaction with the home care service received. Cooney (1998, 1999) surveyed a random sample of around 100 home care users during two successive years. They were generally very happy with the service provided with around 60% of respondents reporting that they were 'very satisfied' with cleaning/shopping/collecting prescriptions. A slightly smaller proportion (around 50%) indicated they were 'very satisfied' with such personal care tasks as bathing and washing. The surveys revealed lower levels of satisfaction among Asian users compared to people from other ethnic groups. There were no differences between contracted and inhouse providers in terms of levels of satisfaction reported.

Given the structured nature of the survey and the fact that it did not attempt to elucidate the meaning of the responses for users, one cannot deduce why those receiving personal care were generally less satisfied than those in receipt of domestic help/shopping. Neither can one ascertain why there were differences between ethnic groups in the levels of satisfaction reported. Both are topics requiring further investigation.

Two points are worth noting here since they provide a context to the findings. First, home care within this local authority offered a less intensive service than the average for England as a whole. Second, a considerably higher proportion of users received help with domestic tasks such as

cleaning and shopping than appears from the national picture. This is described more fully in Chapter 6.

High overall levels of satisfaction with home care emerged from a review of the home care service in Leicestershire. This study included both a questionnaire survey of a random sample of older users as well as more in-depth interviews with a small sub-sample (Herbert *et al* 2000). However, high levels of global satisfaction concealed concerns among a large minority of users in key areas deemed central to perceived quality of care. Thus, in a service that was mainly targeted at providing personal care to those with high dependency needs, nearly half of the users (41%) did not have either one regular worker or a group of regular workers, providing assistance. The majority of people expressed concern about the ensuing lack of continuity of care. Another area giving rise to dissatisfaction was the fact that the service had been reduced or withdrawn domestic assistance.

In addition to the studies above that specifically explored user satisfaction, there were two other research studies that examined user views of home care as part of a wider evaluation of home care services (Godfrey 1995; Waddington and Henwood 1996).

Godfrey (1995) carried out a qualitative study focusing on the experience of use of the home help service in one London borough and the likely impact of the shift to a home care service for those whose needs were for domestic help. In-depth interviews were held with 52 older people, all of whom had been allocated two hours or less home help per week. The sample was stratified to include both men and women living alone, those in dual person households, Asian elders, those eligible to pay for the service, and those on low incomes. Half of the sample was assessed by home care managers as likely to retain the service after its transformation to home care, the rest were likely to lose it. In evaluating the service, users made a distinction between the individual home help and the nature of the service. They were generally very satisfied with the former. What they valued was someone with a pleasant but not intrusive disposition with whom they felt comfortable, but who, above all, carried out tasks thoroughly and competently. Their experience of the service was more problematic. It was unreliable (nearly half of them had missed at least one week's help in the previous four); they did not know from one week to another if the home help would come and when; and some of them had a different person every time. The extent of unreliability of the service related to the fact that home care managers prioritised allocation daily on the basis of the tasks to be undertaken, with cleaning being accorded the lowest priority, in stark contrast to the high priority that service-users regularly give to it.

All of the studies above relate to long term home care support. Waddington and Henwood's (1996) study was of a short-term home from hospital scheme. It was also different in that it targeted people with low intensity needs who were not eligible for home care services. The scheme was staffed by volunteers. Here, the specific features of the service that were valued by users was their ability to choose what they wanted done, the flexibility of the

workers and the practical assistance and befriending help that was provided. The downside was the short term nature of the help.

Carer Views of the Home Care Service

Only one study specifically addressed carer views of the home care service (Davies *et al* 1991) in an outer London borough. It is interesting in that it sought to explore the perceptions of non service-users as well as carers who were receiving up to two hours care weekly. The findings must be considered *very* tentative however, because of the self-selected nature of the samples and the low response rate among service users (a two-thirds attrition rate).

Non-users were recruited to three focus groups; users were identified through home care lists. Two points are worthy of note here. First, carers receiving home help support were very different from non-users in certain key respects: *viz* the former were more likely to be parents of the dependent person (58%), with just over a quarter being the spouse. Among non-service users, the majority, were older people themselves, providing 24 hour care, and most were spouses (two thirds). Their reasons for not seeking help were the perceived lack of flexibility in tasks, the expense involved, and the fact that some of them had been turned down in the past. Among those receiving home care most help was required with cleaning, bathing and housework. Satisfaction related to the competence of home helps and their disposition. Dissatisfaction was associated with unmet need and the dislike of temporary staff. The possibility raised in this study that allocation practice may reflect assumptions about which kinds of carers should be supported by formal services, requires further investigation. However, it may simply be an artefact of research design and execution.

The ECCEP (Evaluating Community Care for Elderly People) study (Bauld *et al* 1999) discussed in more detail in Chapter 6, examined carer satisfaction with overall community support, as opposed to home care specifically. Whilst a vast majority of carers reported that they were satisfied or very satisfied, carers of those who were most frail and suffered a cognitive impairment were least satisfied, with one in four describing themselves as having mixed feelings, being dissatisfied, or very dissatisfied.

The Relationship between Formal and Informal Care

Despite any benefits that home care services might potentially have in preventing or delaying admission to institutional care, it is important to consider the relationship between formal and informal care. Given the changes in length of life, declining family size, and population mobility, it is crucial to know what, if any, are the consequences of the provision of publicly funded services to care for and support vulnerable people in their own homes. The central question for policy makers can be stated in the following terms.

In what ways, if at all, does the provision of home care services by statutory agencies replace or substitute for the informal support provided by carers, friends and relatives?

Is there Evidence of Substitution?

Tennstedt *et al* (1993) report on findings from the Massachusetts Elder Health Project. This comprised a representative sample of older people (aged 70 or over) from towns and cities in eastern Massachusetts. Its broad aim was to explore their needs for assistance with activities of daily living (ADL) over time and to examine the sources and patterns of formal and informal help and support. Data were collected at four points over a seven-year period (1984–1991) from both the elders and the main providers of informal care.

This carefully conducted study showed that while initially there was some evidence of substitution of formal for informal services, this did not persist over time. Figures varied from 20% in the first time period (1984/5 to 1988/9), 14% in the second period (1988/9 to 1990/1) and 15% at the third follow-up point (1990/1 to 1991).

The amount of substitution varied by area of care. It was highest for the area of '*help with arranging services*'. In the first time period, substitution effects were apparent in 40% of cases, falling to 14% in the second time period and rising again at the seven year point to 23%. It was lowest for '*housekeeping*' (17% at the first follow-up point) and '*transportation*' (9% seven years on). In general, the pattern was of a decline over time. For example, for the area of '*personal care*' substitution varied from 23% to 17% and 13% respectively, and '*housekeeping*' from 18% to 15%.

The study also indicated that the most common predictor of service substitution was loss of the primary care giver. Older persons who lost their primary caregiver, either through bereavement or a necessary geographical move, were 9 to 35 times more likely to substitute formal for informal services. Living alone or starting to live alone increased the rate of service substitution. To a lesser degree, a change in caregiver also resulted in higher rates of substitution. Finally, an increase in disability was also linked to service substitution. It appeared therefore that what substitution did occur was most likely the result of changing need-related circumstances and other such justifiable factors.

Two other studies come to similar conclusions (Hanley *et al* 1991; Moscovice *et al* 1988). In their modelling exercise, drawing on one year's prospective evaluation data from the Minnesota Pre-Admission Screening /Alternative Care Grants Programme in 1984, Moscovice *et al* (1988) found that case managers allocated formal services based primarily on client need, itself judged in relation to activities of daily living. The amount of informal care provided to users did not significantly affect the decisions of case managers and was not significantly affected by the amount of formal services received. Similarly, using data from the National Long-Term Care survey of 1982, Hanley *et al* (1991) found that, for all disabled older people with paid home care, the amount of formal care they got in the previous week did not significantly reduce the amount of informal home care received during the same period.

In summary, these three studies, drawing in two instances on prospective data, provide evidence of a limited substitution effect. However, drawing on

the one study with extended follow-up for seven years, there was no evidence of a persistent substitution effect.

What Other Effects Does Formal Service Provision Have?

As part of a larger study of formal home care provision, Kaye (1985) explored (through an interview based survey), the home care workers' perspective of ways in which informal support networks influence formal service delivery, and who was best at providing which services. While the informal support network was perceived to be the preferable source for most home care aid, formal intervention was seen as preferable for housekeeping functions, specialised duties and repetitive tasks for those who were housebound.

Another study (Kemper 1992), exploring the determinants of the amount of home care used, drew on data from the ten-site Channelling Experiment, itself examining whether public financing of home care would reduce long term care costs (Kemper *et al* 1988). A strong relationship was found between the total hours of care received and the number of impairments in respect of activities of daily living (ADL). The use of formal care also increased with income. African Americans and Hispanics used less formal care and more informal care than whites. Finally, the availability of immediate family increased reliance on informal care.

Other evidence comes from a useful case comparison study (Hooyman *et al* 1985) of the way in which a reduction in provision of household chore services affected family caregivers. The study, conducted one year after the policy change, comprised 42 relatives of users whose chore services were terminated and 38 relatives of those for whom the services were continued. The authors found that the presence or absence of homemaking services was not associated with the extent of caregiving involvement, perceptions of burden or stress. On average, 72 hours per month of care was provided by family caregivers. At the same time, very few caregivers felt that their own lives had improved while caring for their relative. Over a half reported that the present situation had resulted in an increase in the amount of stress in their lives.

Further, the types of tasks performed were better predictors of burden than were the frequency or length of time that a family member provided care. The performance of personal care or body contact tasks (bathing, feeding and toileting) was strongly correlated with increased burden. Less personal tasks (such as shopping, laundry and house cleaning) – traditionally provided by in-home programmes – were not.

In summary, these three studies provide associated evidence on the possible substitution effect of formal for informal care. Differences in preferred roles and activities are illustrated. In particular, and pertinent to the changing content of home care provision in Britain, formal services appear to be a preferred source for domestic support as opposed to personal care tasks. In addition, Kemper's study (1992) raises important equity choices about who should receive publicly funded services.

There were no specific studies located that were carried out in the UK examining the effect of substitution. Whether or not these findings can be generalised to the UK is, therefore a matter of judgement. In the study cited earlier, Godfrey (1995) found that many of the older people in her sample were reliant on other sources of support apart from the home help to maintain independent living. Families – sons and daughters in particular – were the main providers of practical help and this supplemented and augmented formal assistance. However, access to informal help depended on the availability and geographical proximity of children. Even so, where older people were receiving regular, practical, informal help, they expressed concern and anxiety about placing too great a burden on those relatives providing it.

Summary In drawing conclusions about user and carer experiences and conceptions of the home care service, it should be noted that most of the evidence located relates to older vulnerable people. The findings are therefore most robust in respect of such users.

In considering user conceptions of a quality home care service, the evidence points to the following conclusions. *First*, quality attributes can be classified into those that relate to the nature of the service (continuity, reliability, responsiveness); the nature of the staff (disposition, competence) and the nature of the process (quality of the relationship, awareness of needs, flexibility). *Second*, users differ in the value accorded different tasks. Thus, women, including those with high dependency needs place a high value on tasks such as cleaning and housework.

Whilst studies seeking evaluations from users (those located all related to older people) indicate high global levels of satisfaction with services, this conceals elements of anxiety and dissatisfaction related to the unreliability of the service, the lack of flexibility in the tasks undertaken, and the lack of continuity of care offered. Yet, these are precisely the dimensions that are perceived as most important in users' assessments of what a quality service would look like.

There was a paucity of research on carers' conceptions of quality in home care provision or their views of the services received. The one study located that focused on the latter has a problematic methodology. It did suggest, however, that carers receiving home care support might differ from those not receiving such services. Thus, it seemed that it was not the need for care that differentiated those receiving formal assistance from those not receiving it, but rather the relationship of the caregiver to the persons receiving care, and whether informal care was provided from within the same household or outwith the dependent person's household. This is at least suggestive of the need for further and more systematic exploration of the impact of targeting on carers' access to home care.

Finally, the evidence available does not support the view that providing formal support to vulnerable people will impact on the willingness of informal caregivers to provide care. Rather, what is most likely is that informal

support continues alongside formal help. At the same time, the evidence suggests that older people do not necessarily view formal help as a last resort when informal support is unavailable and/or depleted. This may reflect changing conceptions of independence where being independent is conceived of as not placing too great a burden on family members.

Organisation and Delivery of Home Care

One can identify three broad themes in the literature that have dominated discussion of home care in Britain since the implementation of the community care reforms in 1990. These are:

- > targeting (who should receive help and what kind of help should be offered?);
- > the development of a mixed economy in the provision of home care;
- > charging policies.

Each of these themes has relevance also to the question of the effectiveness of co-operation between health and social care in the provision of support to vulnerable people at home.

Evidence on Who is Getting Home Care Services

Very few research studies were located that focused on the nature and extent of client problems regarding services provided to home care users since the introduction of the community care reforms. A small number of local studies were identified that examined the nature and range of services received by home care users. Only where these drew on representative samples have they been included in the review. Even so, they reinforce the pattern of variation across local authorities revealed in Chapter 1. We have also drawn on interim publications on the *Evaluating Community Care for Elderly People (ECCEP)* project, currently being carried out by PSSRU (Bauld *et al* 1999; Davies *et al* 1998). Whilst this is intended to provide evidence on outcomes of community care, the focus of the work published to date is on the characteristics and needs of users and the package of services received.

A survey of home care users carried out in the London Borough of Newham in 1998 and repeated in 1999 (Cooney 1998; 1999) provides some information on who they were and what kind of help they received. The study was based on interviews with a random sample of 103 service users in

1998 and in 1999. Around three-quarters were older people, somewhat lower than the national average for home care recipients and two thirds lived on their own. Of those who lived with others, more than half lived with a spouse or partner and the rest with other family members. Just over a fifth were from a minority ethnic group (primarily Asian or Afro-Caribbean). Half the users were receiving a low intensity service (up to 2 hours a week), nearly twice the national average.

A similar survey carried out in Leicestershire of 251 home care users (Herbert *et al* 2000) found that just under two thirds were living alone and of those sharing a household, just over half lived with a spouse or partner (a similar pattern to that revealed in the Newham study). In comparison with the former however, the service provided appeared considerably more intensive to people with high dependency needs. Personal care tasks predominated among the tasks undertaken, with over three-quarters receiving help with personal care. Overall, a third were visited at least twice a day and 88% at least once a day. Nearly threequarters had a service over the weekend. By contrast, less than a fifth received help with housework; a further third relied on informal support and around a quarter had private help. Despite their high dependency needs however, over a quarter of the users received no help with housework, whether informal, formal or private. The Leicestershire service exemplified a pattern of provision that not only aimed at those with high dependency needs, it was one moreover that prioritised personal care support over housework and shopping. Even so, a large minority of users had no access to either informal or private help for domestic care tasks.

The ECCEP study differs from those above in that its focus was community care generally, as opposed to home care. It is included here because most users in the study received home care (83%). The study is currently underway in ten local authorities. The achieved sample of 492 older people was selected on the basis of a multi-cell sampling matrix based on such factors as level of need (critical interval, short interval and long interval), the extent of service provision and living arrangements. A separate carer sample was selected by asking users participating in the study to identify a principal informal carer. Data obtained from interviews with users and carers was weighted using information obtained during the screening process to achieve population representativeness where appropriate.

As far as service users were concerned, the majority of them were women (73%) and the average age was 80.8 years. Most lived alone (60%) and a further third lived with a spouse. Those with the highest level of need (critical interval need) tended to live with others. Significantly too, considerably more of those with moderate or severe cognitive impairment lived with others (83% of those with moderate cognitive impairments and 91% of those severely impaired, compared to 74% of those unimpaired). In terms of service provision, home care was less frequently received by those with a principal informal carer. Similarly, where the user was cognitively impaired and had no principal informal carer, home care was also less frequently received although day care was more likely to be a component of the service package.

On the basis of these studies, a number of points can be drawn in respect of targeting. First, all the studies indicate that home care support is primarily targeted on those living alone. Nearly twice as many older people living alone receive home care than one would expect on the basis of their population profile (around a third of older people generally live alone, although there is variation by ethnicity and degree of geographic and social mobility, see Phillipson *et al* 1998). Second, those living with a spouse are half as likely to be receiving home care as one would expect (nearly half of older people in the population live with a spouse). This pattern prevails despite the difference in intensity of home care provision. Third, the ECCEP study suggests that home care comprises a smaller component of the overall care package for those with cognitive impairments and no principal carer compared to those without such an impairment.

Before leaving this issue, we refer to a study that explicitly examined the impact of a rationing strategy for home care that prioritised those considered to be most dependent. Whilst the study was carried out in one Swedish city, it is pertinent to the discussion here, since Sweden, like Britain, has been pursuing a policy of intensive provision to those with high dependency needs. Lagergren (1994; 1996) examined changes in the pattern of home care provision between 1985 and 1991. This was only possible because of the existence of an information collection system which recorded all services received by older people from public agencies, either in terms of residential or home based care. The findings illustrate the importance of examining the impact of concentrating resources on those considered '*most in need*', and the changing pattern of those '*losing out*'. Concentrating domiciliary services on the dependent, in practice, meant targeting those who were most disabled living alone (with the exception of those suffering from dementia who were *less* likely to receive home help support at similar levels of disability). Those who were married or had access to informal care experienced the highest levels of reduction in service over the two time periods.

The Mixed Economy of Home Care: Patterns of Provision

As seen in Chapter 1, a fundamental thrust of the community care reforms was to promote the diversity of supply particularly in respect of domiciliary care and this in an area where public provision dominated. In 1992, some 98% of the total volume of home care funded by social services departments was provided by in-house services.

Contemporaneous reviews (for example Leat 1995; Sawyer 1993) were sceptical of the possibilities for increasing market share in the independent sector. This partly reflected the underdeveloped nature of independent domiciliary care provision and, partly, was due to the fact that, unlike residential and nursing home care, it was not subject to any regulatory mechanisms. The Department of Health initiative *Caring for People who Live at Home*, fuelled scepticism about such developments. In their overall assessment of the initiative, Perkins and Allen (1997) concluded that in terms of its explicit aim, namely, to stimulate the market in domiciliary care, it had mixed results. First, the majority of providers were not new entrants, but preexisting providers who were extending their services or moving into

new areas. Second, many of the services ceased to function prior to the end of the initiative; whilst others ended when special funding was withdrawn or did not continue a year after the initiative finally ended. They therefore concluded that stimulation of the market was not an easy task even with the help of special funding and dedicated project staff.

Despite the gloomy prognostications, doubtless fuelled by the imperative that 85% of community care expenditure had to be in the independent sector, there has, since 1992, been a dramatic shift toward a mixed economy of home care provision, (see Chapter 1). Whereas in that year, the independent sector provided some 2% of the total volume of home care funded by social services departments, this had increased to 46% in 1998, and the trends show a year on year increase. The biggest proportionate increase occurred between 1993 and 1994 (nearly a fivefold increase) and between 1994 and 1995 (by nearly a factor of 2). In subsequent years the rate has slowed down and in 1998 there was only a small increase (4%) (Government Statistical Service: Community Care Statistics).

The impact of this shift on service users has not been systematically studied.

There is a small number of studies that have focused on local markets. Kestenbaum (1993), for example, examined domiciliary care in the East Midlands from the perspective of users' experience of independent agency care and the nature of the local market. It is limited in that it focused on people who were in receipt of awards from the Independent Living Fund and who purchased all or part of their care from an independent agency. In line with the eligibility criteria for receiving awards, ILF users were severely disabled. Moreover, whilst the Fund has enabled some 23,000 people with severe disabilities living at home to purchase the personal and domestic services they need, this represents a very small proportion of all those receiving such care contracted for by Social Services Departments. At the same time, the combination of qualitative interviews with users within a delimited area, and the picture of the market built up from a range of sources including users' experience of agencies, permits us to draw a fairly comprehensive picture of one local market from a user and provider perspective.

From interviews with 38 ILF clients, Kestenbaum found that people used a large number of agencies, mostly in the private sector. However, the choice of agency for individual users was perceived as very limited. Further, nearly a third had at some point changed this agency – either because the first one had gone out of business or because they were dissatisfied with the service. Aspects of agency care seen as satisfactory included: personal contact with a supervisor; the quality of care (efficiency and reliability) and continuity offered by care assistants; flexibility and responsiveness to *what* the users wanted and *how* they wanted it provided. Unsatisfactory agency care related to the absence of these attributes and to the cost of care and agency charging policies. Particular problems arose in respect of travel expenses, the charging of higher rates for short visits, or charging a minimum rate – which might be two hours in respect of tasks likely to take less than an hour.

The structure and composition of the independent sector market revealed in the study was one of fluidity. There appeared to be a very high turnover among the smaller agencies. At the same time, for many agencies their main business was in the supply of staff to hospitals and residential care homes, and care services for individuals in their own homes was only an emerging part of their business. It was only in the voluntary sector that training and supervision was carried out as a formal part of the agency role.

As this study was undertaken before the big explosion in independent domiciliary care provision noted above, it is likely that the size of the local market in the area has altered.

Another small-scale qualitative study on users' experience of the home care market, was carried out a little later than the Kestenbaum study by Young *et al* (1997). This was part of the broader Mixed Economy of Care Research Programme. 24 users of local authority and independent domiciliary care services across four local authorities were interviewed. In terms of the market, the key findings indicated that none of the users had been offered a choice between the local authority or independent sector services or between individual providers. Most however were willing to rely on their care managers because of their lack of information to make an informed choice. Perhaps, more importantly, across all providers, few people were offered a choice about the care worker or the composition and timing of care services.

The picture presented in the Kestenbaum study of fluidity and change in the home care market is a characteristic feature of the emerging and growing market in domiciliary care, as revealed in the findings of a number of annual surveys commissioned by the UKHCA (Hardy 1998; Young & Wistow 1995; Young & Wistow 1996). Whilst limited to members of the UKHCA, it appears that nearly half of the providers had been established only since 1993; a quarter had been in business for two years or less and only 11% had been in existence for 10 years or more (Hardy 1998). Further, most were small private businesses. Thus, just over a third were delivering 500–2000 hours service a month and almost a quarter under 500 hours a month. Given that the private sector provides an average of 8 hours weekly care per household, this suggests that a quarter of agencies were supporting fewer than 14 clients a month and a third between 14 and 60 clients. In addition to being relatively newly established and small scale, most private agencies were also heavily dependent on local authorities for business. Thus, just over half (58%) were dependent on social services departments for 'all' or 'most' of their income in 1996. This had increased to 70% in the 1997 survey (Hardy 1998).

A major area for criticism by independent providers was the overwhelming dominance of 'spot contracts', and the related instability of purchasing patterns. Indeed, Hardy (1998) shows that there has been a steady increase in the proportion of providers solely in receipt of such contracts from local authority purchasers, rising from 63% in 1995 to 69% in 1997. From the provider perspective, this indicated a failure on the part of local authorities to provide them with sufficient financial security to invest in high

quality services or maintain standards of care. A further area of concern was the tendency to purchase care in smaller and smaller units. For example, half had been asked to provide services for 15 minutes or less (!)

Linked with financial instability was the finding reported in the 1996 UKHCA survey of the difficulty providers experienced in securing a trained and permanent workforce. As workloads varied from week to week, it was problematic to offer staff a guaranteed number of hours and therefore income. At the same time, the provision of training was not seen as cost effective in the context of a rapidly changing workforce.

Hardy and Wistow (1998), on the basis of their research on the mixed economy of care, delineated five aspects of the purchaser/provider relationship in domiciliary care that was giving rise to concern about its ability to deliver quality care. These are:

- > duplication and laxity of provider accreditation;
- > inflexibility of contracts;
- > inappropriate contract types;
- > multiplicity of providers and carers;
- > inadequate monitoring and review systems.

However, whilst the research located described the main features of the evolving market in domiciliary care, there was a dearth of studies examining the impact of these market changes on user outcomes or user satisfaction with the service.

Charging Policies for Home Care

Charging for domiciliary social care services has become one of the major policy issues of the last decade. However, the question of charging users of social care services is not new. Rather its origins lie within the 1946 National Health Service Act, and the 1948 National Assistance Act. During the passage of the former, a fundamental distinction was made between health care services that were to be free at the point of delivery and social care services, for which a charge might be made. Whilst the terms of the 1948 National Assistance Act required those entering residential care to contribute to the costs of that care, charges for domiciliary services were left to local discretion. In subsequent decades, whilst the shape, scope and the users targeted for domiciliary care services have changed considerably, charging policies have remained at the discretion of local authorities. This has resulted in considerable variation between authorities on policies, levels of payment, and approaches to the calculation of financial liability.

However, the community care reforms, presaged in the Griffiths Report (1988) and the White Paper *Caring for People* (1989) and enshrined within the NHS and Community Care Act 1990, involved important shifts in respect of normative expectations around payments. At the same time, the reforms increased the financial pressures on local authorities to extend and increase charges for domiciliary care services.

In reviewing the research on charging, different types of evidence have been

drawn upon. First, there are those studies that examine variation in policy and practice in charging for domiciliary care. Thus, there are a number of cross sectional surveys carried out across all local authorities that examine trends over time and variation across authorities (Association of Metropolitan Authorities 1994 and 1995; and the National Consumer Council 1995). Additionally, a number of detailed case studies have been undertaken on policy and implementation issues within a small number of selected authorities (Baldwin & Lunt 1996 or linked with welfare rights campaigns, as in Alcock & Vaux 1997).

Second, there are those studies that have sought to examine the impact of charging on service users. Despite the policy significance of the issue very few studies were located that examined the user perspective on, or user outcomes of, charging. Moreover, these were variable in scope and quality. Chetwynd *et al* (1996) carried out a qualitative study involving interviews with 36 disabled people in five local authorities with different charging policies; Southwark Community Care Forum (SCCF 1998) commissioned a survey of 200 home care users in the Borough with comparative samples from three other London boroughs (not only regarding home care but for all services, including day care and respite); Devon Social Services Department examined the reasons for termination or refusal of home care services assessed as needed, from the perspective of service users and care managers (Lankshear & Giarchi 1994).

The findings of the studies are now considered in detail.

Scale and Pattern of Charging Policies in Home Care

The dominant picture emerging from successive national surveys carried out by the Association of Metropolitan Authorities (AMA 1992; AMA, 1994; AMA/LGAPU 1995) is one of expansion of charging schemes and increased charges to service users. At the same time, there also persists considerable variation in policies and practice across local authorities. The more recent surveys indicate that full implementation of the community care reforms from 1993 were accompanied by major changes in respect of charging for services and it is not clear yet whether this flux is subsiding. Similar findings were noted from the other studies included here. Thus, Baldwin & Lunt (1996) from their study in six local authorities, found that all of them had reviewed or changed their policies since the community care legislation, and that there had been a further flurry of activity following full implementation in 1993. Even so, further changes were seen as likely when fieldwork took place in 1995. Similarly, Chetwynd *et al* (1996) noted that all of the local authorities in their study had changed their charging policies at least once in the previous three years.

The findings from the AMA surveys offer a broad brush, representative overview of charging policy, given that the response rate was very high (around 70%). With regard to home care, the findings indicate that between 1992 and 1995, the proportion of authorities imposing charges increased from 72% to 87%. There was also a shift away from flat rate systems to a means tested approach.

Detailed studies of policy and its implementation in specific local authorities (Baldwin & Lunt, 1996; Alcock & Vaux 1997) indicate that within this broad trend, there is enormous variation in policy and practice. Baldwin and Lunt (1996) for example, focused on what they regarded as key elements of charging policy, extending the simple distinction of a *no charge/flat rate/means test* to include the following dimensions:

- > whether charges were assessed for services individually or one, overall charge was levied;
- > the nature of the means test used;
- > whether the charge bore any relationship to the hours of service used;
- > whether it reflected the real cost of providing the service or was purely notional;
- > what assumptions were made about income from capital.

Whilst the study was not intended to examine the impact of different charging policies, the authors sought to evaluate whether they were *reasonable*. This is the criterion employed in the 1983 Health and Social Services and Social Security Adjudications Act (HASSASSA), where the notion of reasonableness is considered both from the perspective of the local authority and the service-users' ability to pay.

Whilst recognising the contestability of what is '*reasonable*', Baldwin and Lunt (1996) applied the following criteria:

- > whether they reflected an individual's real capacity to contribute to the cost of services received, i.e., did the policies make appropriate assumptions about users' incomes and any unavoidable demands on those incomes, recognising users' rights to a reasonable quality of life and participation in social and leisure activities;
- > the underpinning assumptions made about how much of peoples' savings they should be allowed to retain;
- > the basis on which charges were set – i.e., some nominal level or related to the actual cost of provision, given that people already contributed to services via national and local taxes.

They concluded that whilst the charging policies in all of the authorities they studied varied considerably, they fell short of what they construed as reasonable at many different levels. Thus:

- > Most authorities employed a minimum flat rate charge for home care services which meant that users' incomes would be below income support level on payment of the charge.
- > When assessing ability to pay for means tested services, the common cut off point was income support levels with additional premiums. Yet this was generally considered to be too low to sustain a reasonable standard of life and social participation.

- > In determining income, authorities tended to assume that some part of Attendance Allowance or Disablement Living Allowance was available to pay for care, yet none of the authorities sought to examine outgoings or the actual disability related expenditure people incurred.
- > All authorities took savings into account in assessing the level of charges, commonly applying the same cut off points as in respect of people entering residential and nursing home care. However, this was considered unreasonable in that those continuing to live in their own homes would likely have additional ongoing costs around for example home maintenance.

It was notable too that authorities did not routinely collect information on the impact of the charging policies on users.

A key problem identified by Baldwin and Lunt was that for most people using social services help, their main source of income was likely to be welfare benefits. This is illustrated in Alcock and Vaux's study of home care users specifically. This reports the outcome of a welfare rights campaign carried out in Sheffield in the context of the introduction of a flat rate charge of £5, except for those only receiving Income Support. All existing users and new applicants were offered a benefits check. At the time of the study, around a third had had a benefits assessment. Of these, most (nearly three quarters) resulted in successful claims leading to an increased income for these users. The two main types of successful claims were in respect of Income Support and Attendance Allowance. Apart from the gains for individual users, the campaign resulted in increased income for the Local Authority in that the increased numbers of people claiming Attendance Allowance made them liable for charges for which they had previously been exempt. However, the likely impact of charging on anti-poverty strategies is revealed in the fact that a fifth of the users who were incurring charges had incomes of less than £10 above Income Support levels. Thus, the imposition of a flat rate charge of £5 per week for home care would put them below or just above Income Support levels.

Impact of Charging on Service Users

It was noted above that local authorities do not tend to collate information about the impact of charging policies on users. One local study (Lankshear & Giarchi 1994) carried out in Devon SSD, sought to explore the reasons why people assessed as needing home care had either ended or reduced the service received during a four month period. The service adopted a complex, multi-level charging system, whereby everyone paid a minimum amount including those on Income Support, although this was on a sliding scale depending on the rate of Attendance Allowance or Disabled Living Allowance received. In addition, people not in receipt of income support paid an hourly rate up to a weekly maximum; for those with savings of more than £8000, an hourly rate was payable for each service with no maximum charge. Thus, with the charge, people in receipt of Income Support (IS) only, ended up with an income below IS levels.

A major difficulty encountered in this research from the outset was in identifying their potential service-user population. Three different sources were used: the computerised database, team managers, and home care managers in the provider services. The lists obtained from these different sources did not correspond. The sample was then selected by sending out the computerised list to team managers and asking them to identify the reasons why people had terminated or reduced their service.

This study is problematic on methodological grounds. First, there were the acknowledged difficulties in identifying the population of users. Second, information about how the eventual sample was selected is not provided, though it appears that those selected were twice as likely to refuse on cost grounds as those not included. Third, for a third of users the information on termination was not obtained directly. Instead, in most of these cases, the care managers or other social services staff member provided the information. Thus caution needs to be exercised in drawing conclusions about its generalisability. At the same time, the particular context for the findings needs to be located within the framework of the charging policies pursued.

Even so, one can deduce that for between a quarter and nearly half those terminating or reducing services, the reason was ascribed to the cost of provision. Among those in the study, the level of help assessed as needed among those refusing the service was low, being one to two hours of help. In many cases, having withdrawn from the service, people were left to manage on their own. Thus, cost appeared a major factor in reducing or terminating the service, especially for those requiring a relatively low level of home care: 'a little bit of help'.

Another locally based study was carried out in the London Borough of Southwark (SCCF 1998). A random sample of users of non-residential community services currently being charged, were interviewed. This comprised 200 people stratified to include 100 older people and 100 with physical, sensory, or learning disabilities or living with HIV/AIDS. Black and minority ethnic users comprised 15% of the sample as a whole, though they constituted only 7% of the older people. Around 3% of respondents indicated they were no longer receiving services because of the charges. However, a higher proportion said they had stopped receiving some services because of worries about charges. Older people in particular were more likely to reduce services than people with disabilities.

It is impossible to contextualise these findings as there is no information given on the nature of the charging policy in place. Second, it reflects all non residential services although the majority of people (57%) were only receiving home care. Clearly it would have both policy and practice significance if there was a relationship between the type of charging policy in place and its impact on reduction or withdrawal of service.

Chetwynd *et al* (1996) also examined the impact of charging policies on service users. Their focus was disabled people in five different local

authorities, assessed as liable for home care charges. Most (33 of 36 people interviewed) were current home care users and nearly two thirds were receiving more than five hours a week service. Being based on qualitative indepth interviews, the study offers insight into the meaning and experience of charging for these users. The study revealed that the most common response to the charges imposed was *resigned acceptance*. Given the service provided was perceived as central to their needs; that many were also purchasing private domestic help and that informal care where available was being drawn upon, users considered there was no option but to pay. At the same time, an overriding concern was the anxiety the charges created about the future. This applied particularly to people who had a degenerative condition as well as those for whom their existing package did not adequately meet their needs. Thus, users were reluctant to request further services for fear of being unable to pay. They were also reluctant to request a review of their services particularly in view of the extra costs that might be incurred. There was no sense either that payment increased their perceived control over the service; whilst the charging process itself engendered confusion and uncertainty. This applied to how charges were calculated; lack of awareness of an appeals procedure and the variability of the information received about the charging system. There were also mixed views on the principle of being charged. Some considered it a charge for being disabled and therefore as discriminatory and inequitable. Others felt that disability benefits were intended to cover costs of care and reluctantly accepted the charges. Yet others considered that the costs of being disabled were not recognised in current charging policies but they were generally resigned to paying nonetheless.

Interface between Health and Social Care in Home Care Provision

There were no studies located that specifically examined the issue of the respective roles and tasks of health and social services in home care provision. From the studies that examined tasks and service use (Chetwynd *et al* 1996; Cooney 1998; 1999; Davies *et al* 1998; Herbert *et al* 2000) however, one can deduce the following:

First, the shift to home care has increasingly involved home care staff in such tasks as supervision of medication and bathing. At the same time, community nursing services, have adopted a more explicit definition of what are specialist nursing tasks and therefore within their purview.

Second, from the limited evidence on the impact of charging policies on users (Chetwynd *et al* 1996), a significant issue of concern was the fact that whereas previously they might have received a service through health care providers (bathing or respite), they were now receiving the same service through local authority funded home care. The difference however, was that whereas for the former there was no charge at the point of use; for the latter, there was a charge. Thus the issue of who provides and whether the service is construed as meeting medical or social needs, is intimately bound up with charging policies.

It is likely that with the development of community based rehabilitation

services, the interface between health and social care will become a site of increasing conflict and dispute, precisely because of the extension of the scope and level of charging for social care services on the one hand and the concept of a free NHS at the point of use, on the other.

Summary In the three areas of targeting, the penetration of the market and charging policies for care, enormous changes have occurred in the home care service, since the implementation of the community care reforms. Moreover, there is considerable variation between local authorities and across different parts of the UK, in policy and practice. The impact of these changes on service users has not yet been subject to systematic research endeavour.

From the small number of studies that exist the following points emerge.

Targeting

- > Whilst overall the trend has been for a more intensive service targeted at users with high dependency need, there still exists considerable variation in the content and amount of home care packages between local authorities and across different part of the UK.
- > For some local authorities, targeting relates not only to the needs of users but to the prioritisation of certain tasks over others. Here, practical support in respect of housework is no longer perceived as a component of domiciliary care support provided or commissioned by the local authority, even for those with high dependency needs.
- > Domiciliary care remains focused on those living alone.

Mixed economy

- > The domiciliary care market is characterised by considerable heterogeneity. Whilst there has been an enormous shift in the level of independent sector provision, the industry is marked by a high degree of instability and organisational mortality.
- > Few studies have examined the impact of the market on user experiences and outcomes of care. What does appear to emerge however is that diversity of providers does not in itself increase choice for individual users.
- > Some features of the market as it has developed (casualised workforce, dominance of spot contracts, purchase of care in smaller units of time) are likely to result in service delivery processes that conflict with, or are in opposition to, user conceptions of service quality (e.g., continuity, relationship, competence).

Charging

- In the period since the community care reforms, charges have both widened and increased for domiciliary care users. Whilst the evidence base is small, and problematic in certain aspects, it does appear that the main impact in terms of withdrawing from services is felt by users with less intensive needs.
- For those with higher levels of need, the impact of charging on users is one of resigned acceptance, although even here, some people appear reluctant to have their needs re-assessed or to ask for further help for fear of being unable to pay the resulting increased charges.
- The withdrawal from service for those with low intensity needs poses both equity and policy questions. With regard to equity, it means that the likelihood of certain needs being met will depend on ability to pay for services in the private market. From a policy perspective, it places into question access to preventive services for some potential users with limited means.

Research and Service Development Implications

Introduction

This review has concentrated on the effectiveness and outcomes of home care services. We have addressed the different ways in which home care has been conceptualised, the nature and quality of the evidence base as well as on the key findings from the extant research we have found, and extensively screened and evaluated. Here, we focus on the research and policy implications arising from these review findings.

Issues Arising from the Review

Research Implications

Generally, the evidence base within this topic area was of variable quality. On the one hand, the studies on effectiveness were relatively old and focused on outcome criteria and measures related to such factors as admission to long stay residential and nursing home care; rates of admission to, and length of acute hospital; health and social functioning. However as indicated in Chapter 3, it is extremely difficult to draw meaningful conclusions about the impact of home care on institutionalisation either at a population level or at the level of outcomes for individual users. In part this reflects the fact that entry to long term care is not only related to level of dependency and /or availability of informal care but also reflects motivational factors, the meaning attached to independence, normative obligations around care-giving, the relationship between carer and cared for, and the effectiveness of the coping strategies employed to manage both impairments and dependency. Most of the studies on effectiveness whilst targeting users with high dependency needs did not focus on those assessed as being at risk of institutional admission.

The question of the impact of home care on acute hospital use is even more complex. Attempts to maintain people at home when the supply of home care is restricted (e.g., where 24 hour care is not available) may actually increase the use of hospitals for crisis relief.

The process of becoming a user

A key problem in assessing effectiveness in this area is the fact that many people with similar dependency needs as users, do not access services. Further, among those receiving home care, their care trajectory may involve movement between different levels and types of care for reasons to do with the natural progression of illness or disability. In order to understand the impact of home care provision therefore, longitudinal studies are required that focus on the process of becoming a user. This would explore not only the impact of loss of functioning but also the *events* that give rise to the demands for care; the need situation of informal caregivers; the supply and structure of services; the allocation procedures and practice of service organisations. A longitudinal design moreover would enable examination of the factors involved in the transition between different sorts of care.

Quality of life outcomes

There is a need for research that explores the effectiveness of home care not only in terms of pre-set service outcomes (such as impact on institutionalisation) but that also addresses user and caregiver conceptions of what constitutes a good-quality service, both in terms of process and effects. Thus, quality of life needs to be conceptualised and measured, not simply in respect of physical functioning but in terms of enabling people to maintain a valued lifestyle. Such a programme moreover should address impacts across a range of need, i.e., not only those with high dependency needs but those whose needs encompass practical support.

Focus on the nature of the intervention employed

A key problem identified in the review was the variation in the content of programmes under the broad rubric of home care. At the same time, there was often a lack of detail in the studies on the nature, frequency and intensity of the range of inputs provided. Within any complex intervention the research methodology needs to address not simply the outcomes produced but the specific components and processes that can plausibly be said to produce particular outcomes for particular kinds of service-users.

As home care support has increasingly been targeted on people with high intensity needs and is therefore one element of a package of care that may encompass day care, respite, and rehabilitation as well as informal care, there are enormous conceptual and methodological challenges for research in gaining understanding of the outcomes of such complex interventions. The question that is posed is not simply does this work. Rather the issue is what specific mix of services and interventions produces best outcomes for which users in what kinds of settings?

Heterogeneity of the user population

There has also been little consideration of the impact of variation in the populations served by home care. Although most of the research on effectiveness to date has concentrated on older people, we do not know for example whether outcomes differ as between frail elders and those suffering from a cognitive impairment such as dementia. For instance many of the studies on effectiveness excluded people with dementia from the research.

Yet there are some tantalising suggestions from the existing evidence on targeting for example that the pattern of home care provision may be biased against older people with dementia. Another area of research interest posed in respect of targeting is the need for a clearer understanding of its impact in respect of different types of carer relationships. The focus of research thus far has been on informal carers *per se*. What is less clear is the impact on, and outcomes of, allocation patterns and provision of specific home care services, on those with different relationships to users, for example spouse carers, adult children and those providing care within and out with the vulnerable person's household.

Impact of commissioning and purchasing arrangements

The review has indicated that as a result of the community care reforms, large-scale changes have occurred in the nature, scope, pattern and targeting of home care services. The research thus far has focused on documenting these changes and there have, not surprisingly, but regrettably, been few studies that have examined the impact on service users and caregivers. For example, home care services have become increasingly targeted on those who are considered '*most in need*', which, in practice, has meant those in need of personal care support. Even so, there is variation in the extent to which targeting has been pursued. It has also been interpreted in different ways. On the one hand, some local authorities have seen it as meaning a withdrawal from providing domestic assistance, even to those with high dependency needs. On the other hand, it has meant targeting users with high dependency needs to offer them a range of help including domestic assistance. The impact of different targeting policies has not been subject to systematic research endeavour.

Implicit within the targeting policy is the view that focusing on those with high dependency needs, particularly people requiring personal care support, will reduce reliance on residential/nursing home admission. As indicated above factors around admission are considerably more complex than the level of disability *per se*. There is no simple equation between high dependency need and risk of institutional admission. At the same time, the hierarchical notion of dependency used to target services and assess need requires sustained empirical examination. It appears from what little evidence is available that people with disabilities may value retaining control over some aspects of living much more highly than others and that continued independence in these activities is imbued with symbolic significance.

Service Development Implications

The penetration of the market in home care has been one of the most dramatic changes that have occurred as a result of the community care reforms. Whilst the first phase of the reforms has placed emphasis on the diversification of providers, attention needs to be focused on how and whether such diversity increases user choice and perceived quality of care.

It is evident that the process of commissioning and purchasing services has potentially negative consequences for the organisation and delivery of

quality provision. It was notable for example that in framing their conceptions of a quality service, users emphasised the relationship with the home carer, the continuity of care offered and the reliability and flexibility of the service response. It is difficult to see how a pattern of provision marked by a multiplicity of providers, carrying out discrete and personal care tasks, in an increasingly impersonal way, can achieve the quality of care that users require to enhance their independence. A key issue for commissioners therefore is how to achieve a home care service that has as its centre the delivery of quality care from a user perspective.

The White Paper '*Modernising Social Services*' (DoH 1998) has proposed the introduction of a statutory regulatory framework for domiciliary care as well as the extension of direct payments to those over 65 years, to be effective by 2002. With regard to the former, it is the organisations providing domiciliary care, rather than individual carers, who will be registered. Further, registration will only be applied to organisation providing personal care to people in their own homes and not those offering housekeeping services. Both these provisions raise questions about quality assurance systems. First, how are regulatory bodies going to define quality standards for organisations that relate to the care provided by individual carers to vulnerable people in the privacy of their own homes? Second, and particularly in the context of a focus on prevention, should agencies providing domestic assistance, be excluded from the regulatory mechanisms?

The focus on home care as an alternative to institutional admission has had a major impact on who gets home care and on the nature of the support received. *First*, not only have users with particular kinds of needs been targeted, but services have also prioritised particular kinds of tasks over others. *Second*, such targeting strategies are likely to impact on informal carers in unintended ways. Thus, whilst there is a relative paucity of research in this area, what exists tends to suggest that what informal carers are seeking from home care is help with such tasks as heavy lifting, cleaning and other kinds of practical help as well as emotional support. Local authorities therefore need to monitor the impact of their targeting policies in relation to other policy objectives, such as providing support to informal carers. Consideration needs to be given to both unintended as well as intended policy consequences. Similarly, issues of access, including charging policies, need to be examined in the context of achieving equity.

Commissioners need to consider how the organisation and delivery of home care provision is integrated with policy objectives such as preventing dependence, and placing greater emphasis on rehabilitation. This will have implications not only on the kinds of tasks undertaken by home carers but the objectives of support. Thus, in the context of home care input in community centred rehabilitation services, the traditional emphasis on substitution may not be appropriate. Rather the emphasis may be more appropriately placed on enabling people to develop strategies for managing the tasks of daily living themselves. It may also involve support in those areas that are perceived to be less central toward maintaining independence,

thereby facilitating people expending their energy on more valued activities. However, envisaging a role for home care within a rehabilitation strategy raises some difficult problems, not least being the charges incurred for what are deemed to be *social care* services. Increasingly, the issue for users in terms of seamless care is not solely the coordination of health and social care inputs, but the differences between health services that are free at the point of use and social services for which charges are increasingly imposed.

We have presented here, we hope in a user-friendly way, our findings from a systematic review of research on the effectiveness of home care. We hope that our deliberations and conclusions will be of use to practitioners, managers, policy makers, and service-users and carers. However, our commitment does not end here, in that reviews commissioned by the Centre for Evidence-Based Social Services are not only sent out in large numbers to key stakeholders, but are also the subject of regional dissemination and training events. We look forward to participating in these and receiving feedback on this study from all those concerned with making home care work in practical terms for those on the receiving end of our collective good intentions.

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An Example of a Search Strategy

Database: Sociofile

| | |
|----|--------------------------|
| 1 | exact{HOME-HEALTH-CARE} |
| 2 | home |
| 3 | care |
| 4 | home care in DE |
| 5 | home |
| 6 | care |
| 7 | home care in TI,AB |
| 8 | homecare |
| 9 | homecare in TI,AB |
| 10 | #4 or #7 or #9 |
| 11 | home |
| 12 | help |
| 13 | home help in DE |
| 14 | home |
| 15 | help |
| 16 | home help in TI,AB |
| 17 | homehelp |
| 18 | homehelp in TI,AB |
| 19 | #1 or #10 or #16 |
| 20 | PY = 1980-1999 |
| 21 | #19 and (PY = 1980-1999) |
| 22 | LA = "ENGLISH" |
| 23 | #21 and (LA = "ENGLISH") |

Items 1–18 retrieve materials relating to home care and home help services, and are combined in item 19

Item 20 retrieves materials published between 1980 and 1999, and is combined with item 19 (home care) in item 21

Item 22 retrieves materials published in English language, and is combined with item 21 (home care materials published between 1980 and 1999) in item 23

Inclusion and Exclusion Criteria

Inclusion Criteria

Study Type: Qualitative or quantitative evaluative studies. Literature or systematic reviews in which explicit search strategies were provided, and in which at least one study met the inclusion criteria for this review.

Intervention: Any intervention provided within the home which encompassed personal care support and/or domestic support and/or home maintenance services. Studies of packages of care were included only where these services were the main component.

User Group: Those who required support to be able to live in their home environment, and who did not require acute medical or terminal care.

Setting: Where the main component of the intervention was provided within the home.

Studies which evaluated the effectiveness of home care published between 1 January 1980 and 30 December 1999.

Studies which addressed issues around the organisation of home care services published between 1 January 1990 and 30 December 1999.

Exclusion Criteria

Study Types: Purely descriptive texts.

Intervention: Home-based care with a primary focus on acute or terminal care or where within a package of care there was little focus on the provision of domiciliary support schemes.

Setting: Studies that only evaluated support services provided outside of the home.

Cultural: If the study was undertaken in a country where cultural characteristics were substantively different from the UK.

Non-English language references.

Nature of Reference: Documents which were a commentary, book review, thesis, conference report, conference paper, or abstract.

(a) Evaluative Tool for Quantitative Research Studies

| Review Area | Key Questions |
|---|--|
| (1) STUDY OVERVIEW | |
| Bibliographic Details | <ul style="list-style-type: none"> Author, title, source (publisher and place of publication), year |
| Purpose | <ul style="list-style-type: none"> What are the aims of the study? What are the aims of this paper? |
| Key Findings | <ul style="list-style-type: none"> What are the key findings of the study? |
| Evaluative Summary | <ul style="list-style-type: none"> Could the observed results have been brought about by something other than the intervention/care process? (Draw together evaluative comments on the study as a whole – strengths and weaknesses – and indicate further research work required, as appropriate, and possible theory, policy and practice implications) |
| (2) STUDY, SETTING SAMPLE AND ETHICS | |
| The Study | <ul style="list-style-type: none"> What type of study is this? What was the intervention? What was the comparison intervention? Is there sufficient detail given of the nature of the intervention and the comparison intervention? What is the relationship of the study to the area of the topic review? |
| Setting | <ul style="list-style-type: none"> Within what geographical and care setting was the study carried out? |
| Sample | <ul style="list-style-type: none"> What was the source population? What were the inclusion criteria? What were the exclusion criteria? How was the sample selected? If more than one group of subjects, how many groups were there, and how many people were in each group? How were subjects allocated to the groups? What was the size of the study sample? Is the final sample of sufficient size to warrant the conclusions drawn? Is information provided on loss to follow up? Is the sample appropriate to the aims of the study? What are the key sample characteristics? (i.e. in relation to the topic area being reviewed) |
| Ethics | <ul style="list-style-type: none"> Was Ethical Committee approval obtained? Was informed consent obtained from participants of the study? Have ethical issues been adequately addressed? |

(a) Evaluative Tool for Quantitative Research Studies continued

| Review Area | Key Questions |
|--|---|
| (3) GROUP COMPARABILITY AND OUTCOME MEASUREMENT | |
| Comparable Groups | <ul style="list-style-type: none"> • If more than one group was analysed, were the groups comparable before the intervention? In what respects were they comparable and in what were they not? • How were important confounding variables controlled (e.g. matching, randomisation, in the analysis stage)? • Was this control adequate to justify the author’s conclusions? • Were there other important confounding variables controlled for in the study design or analyses and what were they? • Did the authors take these into account in their interpretation of the findings? |
| Outcome Measurement | <ul style="list-style-type: none"> • What outcome criteria were used in the study? • What are the outcome measures used in the study? • Are the measures appropriate, given the outcome criteria? • What other (e.g. process, cost) measures are used in the study? • Are the measures well validated? • Are the measures of known responsiveness to change? • Whose perspective do the outcome measures address (professional, service user, carer?) • Is there sufficient breadth of perspective adopted in the outcome measures? • Are the outcome criteria useful/appropriate within routine practice? • Are the outcome measures useful/appropriate within routine practice? |
| Time Scale | <ul style="list-style-type: none"> • What was the length of follow-up? When was the data on the outcome measures collected? • Is this period of follow-up sufficiently long to warrant the conclusions drawn or to see the desired effects? |
| (4) POLICY AND PRACTICE IMPLICATIONS | |
| Implications | <ul style="list-style-type: none"> • To what setting are the study findings generalisable? (Indicate if: the setting is typical or representative of care settings and in what respects; and if the setting is atypical, is this likely to present a stronger or weaker test of the hypothesis?) • To what population are the study’s findings generalisable? • Is the conclusion justified given the conduct of the study (e.g. sampling procedure; measures of outcome used and results achieved?) • What are the implications for policy? • What are the implications for service practice? |
| Other Comments | <ul style="list-style-type: none"> • What were the total number of references used in the study? • Are there any other noteworthy features of the study? • List other study references |
| Reviewer | <ul style="list-style-type: none"> • Name of reviewer • Review date |

APPENDIX 3 (b) Evaluative Tool for Qualitative Research Studies

| Review Area | Key Questions |
|--|---|
| (1) STUDY OVERVIEW | |
| Bibliographic Details | <ul style="list-style-type: none"> · Author, title, source (publisher and place of publication), year |
| Purpose | <ul style="list-style-type: none"> · What are the aims of the study? · What are the aims of this paper? |
| Key Findings | <ul style="list-style-type: none"> · What are the key findings of the study? |
| Evaluative Summary | <ul style="list-style-type: none"> · Could the observed results have been brought about by something other than the intervention/care process? (Draw together evaluative comments on the study as a whole – strengths and weaknesses – and indicate further research work required, as appropriate, and possible theory, policy and practice implications) |
| (2) STUDY, SETTING, SAMPLE AND ETHICS | |
| The Study | <ul style="list-style-type: none"> · What type of study is this? · What is the intervention? · What, if any, is the comparison intervention? · Is there sufficient detail given of the nature of the: (i) intervention; and (ii) comparison intervention? · What outcome criteria are used in the study? · Whose perspective do they address (professional, service user, carer)? · Is sufficient breadth in perspective adopted? |
| Setting | <ul style="list-style-type: none"> · Within what geographical and care setting is the study carried out? · What is the rationale and appropriateness for choosing this setting? · Is sufficient detail given about the setting? · Over what time period is the study conducted? |
| Sample | <ul style="list-style-type: none"> · Who is included in the study (inclusion criteria)? · Who is excluded from the study (exclusion criteria)? · How is the sample (informants, settings, events) selected? · What is the size of the study sample and groups forming the study? · Is the sample appropriate in terms of depth (intensity of data collection – individuals, settings and events) and width across time, settings and events (does it capture key persons and events)? · Is the sample in terms of informants, settings and events appropriate to the aims of the study? |
| Ethics | <ul style="list-style-type: none"> · Was Ethical Committee approval obtained? · Was informed consent obtained from participants of the study? · Have ethical issues been adequately addressed? |

| Review Area | Key Questions |
|--|--|
| (3) DATA COLLECTION, ANALYSIS AND POTENTIAL RESEARCHER BIAS | |
| Data Collection | <ul style="list-style-type: none"> What data collection methods are used to obtain and record the data? (Provide insight into: data collected; appropriateness; data availability for inspection / independent analysis) What role does the researcher adopt within the setting? Is the process of fieldwork adequately described? (e.g. account of how the data were elicited; type and range of questions; interview guide; length and timing of observation work; note taking) |
| Data Analysis | <ul style="list-style-type: none"> How are the data analysed? How adequate is the description of the data analysis? (e.g. to allow reproduction; steps taken to guard against selectivity) Is adequate evidence provided to support the analysis? (e.g. includes original / raw data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity – searching for negative evidence, use of multiple sources, data triangulation); reliability / consistency (over researchers, time and settings; checking back with informants over interpretation) Is the study set in a broader context, in terms of findings and relevant theory? |
| Researcher's Potential | <ul style="list-style-type: none"> Are the researcher's own position, Bias assumptions and possible biases outlined? (Indicate how these could affect the study, in particular, the analysis and interpretation of the data) |
| (4) POLICY AND PRACTICE IMPLICATIONS | |
| Implications | <ul style="list-style-type: none"> To what setting are the study findings generalisable? (Indicate if: the setting is typical or representative of care settings and in what respects; and if the setting is atypical, is this likely to present a stronger or weaker test of the hypothesis?) To what population are the study's findings generalisable? Is the conclusion justified given the conduct of the study (e.g. sampling procedure; measures of outcome used and results achieved?) What are the implications for policy? What are the implications for service practice? |
| Other Comments | <ul style="list-style-type: none"> What were the total number of references used in the study? Are there any other noteworthy features of the study? List other study references |
| Reviewer | <ul style="list-style-type: none"> Name of reviewer Review date |

Description of Homemaker programmes

| Programme | Follow-up | Allocation | Aim | Targeting (% of control group) | Sample Size | Sample characteristics | Services |
|--|-----------------------|-------------------|--|---|--|---|---|
| Homemaker (Weissert et al 1980) | 12 months | Randomisation | To provide homemaker services to a chronically ill population | % of users who were admitted to nursing home = 18%. Average number of total days per capita spent in nursing homes = 4 days. % of users admitted to hospital = 73%. Average total days in hospital = 16 days | 630 Intervention = 307 Control = 323 | Discharged from hospital. Needed home care services, but not 24 hour supervision, to restore or maintain functional ability and not merely custodial care. The majority were severely dependent. | Homemaker services including chore, personal care, shopping and escort. Both groups also had access to Medicare covered services including in-patient care, skilled nursing, outpatient services. |
| BRH Home aide (Weissert et al 1988, Hughes **) | 12 months | Randomisation | To provide home health aide services to those leaving hospital not already receiving them. | % of users admitted to nursing home = 28%. Average number of total days per capita spent in nursing homes = 53.1 days. Average number of total days per capita spent in hospital = 11.4 days. | 100 50 in each group | Those discharged from geriatric rehabilitation hospital to a noninstitutional setting, and those not already receiving organised home aide, homemaker services from a community agency. | Home aide services, escort, health care, housekeeping. Leisure and personal care services. |
| Chicago Five Hospital Homebound Programme (Hughes et al 1984) | 9 and 48 months | Non randomisation | Long-term comprehensive maintenance care. | % of users admitted to nursing home = 30.3%. Average total days per capita in nursing home = 33.4 days. % of users admitted to hospital = 63.5%. Average total days spent in hospital per capita = 14 days. | 245 Intervention = 122 Control = 123 | Chronically impaired older persons requiring maintenance care. Homebound, impaired in ADLs, not in need of 24 hour supervision. Did not have to be admitted to hospital. | In-home visits by physicians, nurses, social workers, and home health aides providing personal care, shopping, cleaning and other services such as telephone reassurance and volunteer friendly visiting. 1 nurse visit per month and 1 social worker visit per 6 weeks considered not intensive. |
| Chronic Disease (Weissert et al 1988, Hughes et al 1984) | 6 months 12 months | Randomisation | Home health aide service for those in need of lowintensity home care assistance. | Average total days per capita in nursing home = 14.5 days. Average total days per capita in hospital = 11.6 days. | 874 Intervention = 438 Control = 436 | Persons 45 and over. Either receiving care from ambulatory care facilities or about to be discharged from hospital at baseline. 66% impaired in 1 or more ADL function. Discharged to or living in noninstitutional setting. In need of assistance for at least 3 months with respect to bathing, dressing, walking, or cardiopulmonary care. Not in need of 24 hour supervision. | Health assistant, physician, nurse, social worker, therapeutic exercises, and light housekeeping. Average length of service less than 2 months. |

Outcomes of homemaker/home care programmes

| Programme | Service outcomes | | Health and physical functioning | | | | Subjective well-being | Quality of care | Carers | Cost |
|------------------|------------------|-----------|---------------------------------|-----------------|-----------------------|-----------|-----------------------|-----------------|------------------|------|
| | Hospital home | Nursing | ADL | Self-perception | Cognitive functioning | Survival | | | | |
| Homemaker | NS | + NS | + sig. | | + sig. | + sig. | + sig. | | Household stress | - |
| BRH Home Aide | NS | + sig. | - NS | | + NS | - NS | + sig. | + NS | NS | |
| Chicago | NS | + sig. | - sig. | + sig. | + sig. | + sig. | | + sig. | | - |
| Chronic Disease | NS | | | | NS | | NS | | | + |

Where + = favourable/positive outcome. NS = non-significant difference and sig. = significant difference between the intervention and control groups.

Description of Short-term Care Programmes

| Programme | Follow-up | Allocation | Aim | Targeting (% of control group) | Sample Size | Sample characteristics | Services |
|--|------------------------|----------------------|--|-----------------------------------|------------------|--|---|
| Rhondda Special Care Scheme (Victor <i>et al</i> 1986) | 6 weeks and 6 months | Matched case control | To unblock hospital beds and provide support at home to those at risk of delayed discharge | | 66 matched pairs | Disabled and very elderly. Mobility was assessed as presenting the greatest potential difficulty. | Provided care for a maximum of 10 weeks after discharge for up to 15 hours a week. Provided additional home help and night sitters. |
| Care Attendants Scheme (Townsend <i>et al</i> 1988) | 3 months and 18 months | RCT | To provide support after discharge, to return recipients to maximal independence by leaving them adequately supported. | | 903 | Mean age was 82 years, 25% were aged over 85 years. 64 were female, and 43% were living alone. | Support from care attendants for up to 12 hours a week for two weeks after discharge. Support comprised practical care, help with rehabilitation and organisation of social help. |
| Hospital from Home Scheme (Waddington and Henwood 1996) | | Survey | To ensure the smooth transition of persons from hospital to home, and to provide support during the immediate post-discharge period. | | 33 | 2/3 were female, mean age of 73 years. 73% were widowed. 79% lived alone. 48% lived in rural or village areas. Only 9% considered that they lived in an inner-city area. | |

Outcomes of short-term care programmes at 12 months

| Programme | Service outcomes | | Health and physical functioning | | | | | | Subjective well-being | | Quality of care | Carers | Cost |
|-----------------------------|------------------|--------------|---------------------------------|---------------------|-----------------------|------------------------|----------|-------|-----------------------|----|-----------------|-------------------|------|
| | Hospital | Nursing home | ADL | Level of disability | Cognitive functioning | Anxiety and depression | Survival | Moral | Quality of life | | | | |
| Care Attendants Scheme | + | (sig.) | NS | NS | NS | NS | NS | NS | NS | NS | Unmet need | Carers distress | + |
| Rhondda Special Care Scheme | NS | NS | NS | NS | NS | NS | NS | NS | NS | NS | | NS | - |
| Hospital from Home Scheme | | | | | | | | | | | + | (user perception) | |

Where + = favourable/positive outcome. NS = non-significant difference and sig. = significant difference between the intervention and control groups.

Descriptions of Case-managed programmes

| Programme | Follow-up | Allocation | Aim | Targeting (% of control group) | Sample Size | Sample characteristics | Services |
|---|-----------|--------------|--|---|---|---|---|
| Darlington (Challis <i>et al</i> 1989) | 12 months | Quasi-random | To provide care at home as an alternative to patients receiving long-stay hospital care. | 46% of control group in hospital at 12 months, 71% at 6 months. 10% in nursing home at 12 months. | 214 101 = intervention group | Frail elderly hospital patients. Most of whom had been recently admitted. Average age = 80 years. Severe mobility and self-care problems. Physically handicapped but mentally alert. | Multipurpose carers deployed by case managers. Instructed and used by a variety of professionals. Personal care, toileting, transfer, management of medication, housework, cooking and laundry. Core tasks of case management. Joint health and social care agency model. Decentralised budget. Comparison was long stay geriatric wards. |
| Gateshead (Challis <i>et al</i> 1990) | 12 months | Quasi-random | To provide alternative care to residential and long-term hospital care for frail older persons. | 39% in residential home at 12 months 4% in hospital care. | 180 90 matched pairs | Frail elderly whose needs placed them on the margin of institutional care. Average age 81 years; 87% female; over two-thirds had an informal carer. | Case management. Single agency social care scheme. Helpers employed to work flexibly. Work ensuring adequate diet, personal care, help to manage incontinence, social support, housework, help with daily living skills. Comparison usual range of services. |
| Gateshead (b. 4 years later) (Challis <i>et al</i> 1990) | 12 months | Quasi-random | To extend the above programme to include health professionals. | After 12 months 50% in residential care. | 28 matched pairs | Older people with health and social care needs. More dependent than above. Average age - 81 years. 70% living alone. | Health and social care pilot project. Funding provided for additional support of full-time senior nurse, parttime registrar, and physiotherapist. |
| Kent (Challis <i>et al</i> 1986) | 4 years | Quasi-random | To make care at home more effective, achieve an appropriate use of resources, and delay or obviate the need for unnecessary admission to nursing home. | 12 months: 27% in residential care. 5% in hospital care. 24 months: 34% in residential care and 3% in hospital care. | 74 matched pairs | Frail older persons whose needs placed them at the margin of admission to nursing home. | Case management. Use of local people as helpers. Performed tasks such as practical help with daily living, social and therapeutic help. Budgeted. |
| New York (Brill and Horowitz 1983) (Weissert <i>et al</i> 1988) | 12 months | Quasi-random | To prevent or defer unnecessary institutionalisation | 7.1% in nursing home at 12 months and 42% in hospital. | 504 project clients 200 matched comparison | Home-bound chronically ill older persons who needed help with leaving the house, walking stairs, dressing or bathing. 60% female, 68% over 75 years. Extremely disabled. Target population was the underserved or unserved community residents. | Case management and 820 hours per week of home/maker/personal care, non-emergency transport and organised social activities. |

Outcomes of case-managed programmes at 12 months.

| Programme | Service outcomes | | Health and physical functioning | | | | | Subjective well-being | | | Quality of care | | Social Activity | | Carers | | Cost |
|-----------------------|------------------|----------|---------------------------------|-------------------|---------------------------|----------|-----------------------|-----------------------|-------------------|------------|-----------------|--|-----------------|---------------------|----------|--|------|
| | Hospital | Nursing | Physical home | Apathy disability | Survival | ADL | Cognitive Functioning | Moral | Life Satisfaction | Depression | Unmet need | | | Tasks undertaken | Distress | | |
| East Kent | | + (sig.) | - (NS) | | + | | | + (sig.) | | + (sig.) | + (sig.) | | | | | | + |
| Gateshead 'Stage One' | | + (sig.) | | | NS | | | + (NS) | + (sig.) | + (sig.) | + (sig.) | | | + (NS) | + (sig.) | | NS |
| Gateshead 'Stage two' | | + (sig.) | | | | | | | | | | | | | | | NS |
| Darlington | | + (sig.) | | | - (NS) (sig. At 6 months) | | | + (sig.1*) | + (NS) | | + (sig.) | | | + (sig. At 2 weeks) | + (sig.) | | + |
| New York | | + (NS) | - (NS) | | + (NS) | - (sig.) | + (NS) | | + (sig.) | | + (sig.) | | | | + (sig.) | | |

¹where + = favourable/positive outcome. NS = non-significant difference. Sig. = significant difference between intervention and control groups.



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