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Developments in domiciliary care for the elderly

ANN V SALVAGE

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1 INTRODUCTION

In recent years, the issue of 'community care' has occupied a large number of writers, and a group which has served as a focus for debate, discussion and action has been one whose service needs have changed significantly and dramatically – the elderly. 'It has become clear', write Challis and Davies, 'that we shall not be able to cope with the increasing and changing needs of the elderly using the same mix of services we have during the early 1970s.'[1] No less than a technical breakthrough, they suggest, is required in our methods of coping with these needs, and in particular with the problem of those frail elderly people who, in the early 1970s, would have been likely to be admitted to a residential home or hospital.

This paper aims to present two main types of information. Firstly, it aims to identify the various factors – demographic, economic and ideological – which have come together to create an unprecedented crisis for those involved in the provision of health and social services to the elderly population. It will be demonstrated that, in combination, these factors are imposing a strain upon these services which, more than ever before, demands a rigorous analysis of the costs and benefits of various types of service provision, as well as serious consideration of the social consequences of such provision. Secondly, it aims to present information on some of the special schemes devised in response to the 'crisis of the elderly'. These schemes, frequently conceived and financed jointly by health authorities and social services departments, are proliferating to such an extent that it would be quite impossible to include information on all that are currently known to exist. Instead, general characteristics of a number of schemes are discussed, and considerable attention paid to their assessed costs and benefits. Special attention is paid to the format of the Kent Community Care Project, replications of which have been

conducted in numerous locations incorporating rigorous evaluative frameworks. A small number of schemes administered by health authorities alone are also discussed.

It is hoped that this information will prove useful to policy makers concerned with the development of special domiciliary care schemes for the elderly, and a list of literature recommended for further reading is provided.

2 THE CRISIS IN CARE FOR THE ELDERLY

Britain faces a crisis in the care of the elderly which has been brought about by three main factors. Firstly, demographic changes, including an increase in the proportion of elderly people in the population, smaller families, and geographical mobility, have had profound implications for the provision of care. Secondly, these demographic changes have coincided with a period of severe financial constraint, cuts in government spending, and curtailment of building programmes for residential care establishments. Thirdly, government policy has moved explicitly from the provision of residential care to the ideology of 'community care', as evidenced by a large number of policy documents in recent years.

Demographic changes

Changes in the structure of the population have been a cause for increasing concern among social scientists and planners; thus Wicks argues: 'The ageing of the population in general, and the rapidly increasing numbers of the elderly in particular, represent major social challenges and present the biggest test yet to concepts of community care.'[2] The trend for elderly people to live longer and to continue living independently has been widely reported, and even though the rapid rise in numbers of the elderly is projected to level off, a fall in the numbers of the 65–74 cohort is likely to be balanced by a future increase in the 75-plus group.[3] It is the least dependent group (those aged 65–74) whose proportion is decreasing, whilst the proportion of those aged 75 and over is increasing. Between 1901 and 1981, the numbers of those aged 75 and over increased by 621 per cent, from 396,000 in 1901 to 2,856,000 in 1981, and their numbers will increase to an estimated 3,314,000 in 2001. In 1901, those over 75 represented approxi-

mately 26 per cent of the group aged 65 and over; by 1981 this proportion had risen to 39 per cent and by 2001 it will have increased to almost 46 per cent.[2]

Alongside these changes in the age structure of the population, Bebbington notes that the proportion of the very old who are living alone has increased.[4] McKay et al estimate that 29 per cent of elderly people in Britain live alone[5] and Mitchell et al, reporting that 52 per cent of those aged 75 and over in the borough of Hammersmith and Fulham live alone, argue that 'needs on this scale pose severe problems for the statutory and voluntary services.'[6] The incidence of illness and dependency has been found to increase dramatically with age, and it is known that the very elderly probably use seven times more help from health and social services than other groups. As a DHSS report states, the higher the level of dependency, the more services are required, and the greater the costs.[7]

'Clearly', comment Challis et al, 'more fragile people will remain in their own homes and need domicilary assistance, and equally clearly the existing pattern of services must be altered if they are not to be overwhelmed by the demand.'[8] Particular attention is drawn by Levin et al to the increasing number of elderly people with dementia who, they note, make especially heavy use of places in institutions, and also of domiciliary social services.[9]

Demographic changes are also reflected in family structure; no longer do the majority of families comprise large numbers of children and, as Wicks notes, fewer children mean fewer potential carers.[2] David Eversley has estimated that a 75-year-old in the early 1980s may have 15 close female relatives, but by the beginning of the next century, this number may well be halved, with a higher proportion in full-time education or full-time work.[10] An increasing divorce rate will inevitably lead to more complicated family patterns – remarriage may bring more kin into the picture, but how close their ties will be and how strong their familial responsibility for the elderly is by no means certain.

Changes in employment patterns have led to increased geo-

graphical mobility which has contributed to the erosion of extended family networks. Alongside increases in unemployment generally, there has been an increase in recent years in the number of women (still the major source of care for elderly people living in the community) seeking paid employment outside the home.

Thus, at a time when the number of elderly people in the population is becoming a heavier burden, it seems likely that family support for those who live in the community (by far the largest proportion of those aged over 65) is likely to be weakening rather than strengthening. 'The fact is', argues Allen, 'that a major social challenge is on the way. An increase of a quarter of a million over-85 year-olds in the next 20 years must have considerable implications for policy and care.'[11]

Economic changes

Walker draws attention to the fact that, at a time when the number of very old people is increasing rapidly, financial resources are being severely constrained.[12] Pressures on local authorities to cut back on expenditure have been tightened, with increasingly severe penalties on over-spending, and in the face of increasing need for domiciliary services and the expectations of clients and service providers encouraged by official proclamations, the government has 'starved local authorities of resources to meet even existing needs.'[13] While social services' expenditure on the elderly increased by about 10 per cent in real terms between 1976/1977 and 1981/82, it fell short of the increase in the population aged over 75, thereby reversing the trend towards improved services established in the previous century.[12]

One corollary of these economic restrictions has been the failure of building plans for residential care to keep pace with increasing need. According to Davies and Challis, the DHSS in the mid-1970s[15] was planning to increase the supply of places in residential care at a rate one-fifth *lower* than would have been necessary to keep pace with the increase in the population aged 65 and over.[14] 'Nevertheless, data about local authorities' plans show that these

levels of increase in provision are not being attained'.[1] The contribution of the residential home must therefore be expected to fall dramatically during the next few years, placing far greater strain on domiciliary support than in the past. Grundy and Arie estimate that between 1976 and 1982 there was an effective fall in the rate of provision of some 9,000 places, equivalent to 180 residential homes of 50 places each, and they suggest that prospects for the future are even gloomier. Public spending cuts and local authority priorities suggest a continuing fall in the rate of provision that can be expected to have a profound effect on the National Health Service, on the burden on families, and on the condition in which old people are obliged to remain in the community.[16] Effects upon the National Health Service are all too evident. At a seminar in Bradford on a proposed domiciliary care scheme, it was noted that at the beginning of October 1980 there were 69 patients in hospitals throughout the two local health districts awaiting admission to local authority residential accomodation. These patients had to compete with people living in the community, with the result that hospital beds were 'blocked', often for up to twelve months, 'leading to costly and inappropriate use of medical and nursing resources.'[17]

The provision of residential care for the elderly population represents a very substantial proportion of the social services budget yet, as Challis comments, it only benefits a very small percentage of the elderly.[18] On average, almost a quarter of social services departments' revenue budget is devoted to residential care for the elderly and more than one-tenth to home care and support.[14] A report from Essex suggests that the elderly absorb nearly 50 per cent of the budget of the Essex Social Services Department and notes that one of the biggest operational allocation decisions to be made is whether to put someone forward for care in a residential home.[19]

Cuts in expenditure have meant that domiciliary services, where they *are* provided, are frequently inadequate and Allibone and Coles argue that, while it is not difficult to explain the Govern-

ment's enthusiasm for community care, 'what remains in doubt is the extent to which they are prepared to support that commitment with cash and decree.'[20] Other writers have drawn attention to wide variations in the provision of services within and between authorities[21,22,23] and it is perhaps not surprising that a number have drawn attention to the urgent need for a search for efficiency and effectivness in the provision of health and social services for the elderly. Salmon, while accepting that the current round of expenditure cuts has brought many problems, suggests that it has nevertheless forced many authorities to look more carefully at the effective use of their resources,[24] and Williamson argues that 'all aspects of care for the elderly must come under scrutiny both to see that inefficiencies are reduced and that the most effective forms of care are identified and fostered.'[25]

Changes in government policy

Adding to the pressures on social services departments has been a marked shift in government policy away from institutional care towards care in the community. In 1976, the consultative document *Priorities for Health and Personal Social Services in England* affirmed the state's explicit commitment to community care. In relation to the elderly, the report stated: 'The general aim of policy is to help [them] maintain independent lives in their own homes for as long as possible. The main emphasis is then on the development of domiciliary services.'[15] Another report, published a year later, announced that £6 million of capital revenue in 1977-78 would be diverted to domiciliary services in response to comments on the previous document. In addition, hope was expressed for a slightly higher rate of growth in such services for the elderly than was envisaged in 1976.[26]

A Happier Old Age, published in 1978, again stated that a main aim of central and local policies should be to preserve or restore the independence of elderly people and noted that their position 'is special because a number of factors combine to make them feel that they are receivers rather than givers' (including the cessation

of employment and reliance on state income).[27] The policy of 'community care' was once again reiterated in a White Paper, *Growing Older*, published in 1981. This document acknowledged the aim to promote care 'by the community' (that is by relatives, neighbours and informal support networks) alongside care 'in the community' (by public sector and voluntary agencies). 'Whatever level of public expenditure proves practicable and however it is distributed, the primary sources of support and care for elderly people are informal and voluntary. ... It is the role of public authorities to sustain and, where necessary, develop – but never to displace – such support and care.'[28]

Another DHSS publication in 1981, *Care in Action*, marked the shift in emphasis away from the concept of the state as provider[29], while *Report of a Study on Community Care* noted that the higher the level of dependency, the more services are required and the greater the costs.[30]

Yet another paper published in 1981 (a consultative document on moving resources for care in England), drew attention to the potential energy and resources that lay in the voluntary sector.[31]

These documents appear to advocate community-based care as a policy preferred by clients or patients, and often by their carers. They do not question its philosophy, but neither do they regard community care as a universal solution or as always appropriate to the needs of individuals.[20]

Similar commitments to care in the community may be found in local authority policy documents. Thus a social services strategy paper for the London borough of Hammersmith and Fulham set out as overall policy aims: (a) the encouragement of elderly people to maintain independence and control over their own lives for as long as possible and to develop means of rehabilitating or preventing deterioration in mental and physical capabilities; and (b) the provision of more support to those caring for elderly people at home.[32]

While it has been argued that the shift in emphasis from institutional care to care in the community merely reflects central

government's rejection of financial responsibility for the care of the elderly, there can be no doubt that other factors have been instrumental in influencing government policy. Among the factors identified by Johnson and Challis in the impetus towards 'community care' is an ideology of 'anti-institutionalisation'.[22] Disillusionment with formal residential provision was generated by the work of Goffman in the 1960s,[33] while the Ely and Whittingham Hospital inquiries cast further doubt on its desirability.[34] Barbara Robb's *Sans Everything*, published in 1967, suggested that residential care should be avoided at all costs,[35] and Townsend's *The Last Refuge* concluded that residential institutions for the elderly failed to meet the physical, psychological and social needs of the residents and argued that alternative services and living arrangements should take their place.[36]

At the same time, evidence has been accumulating to suggest that, given the choice, elderly people prefer to remain in their own homes wherever possible. Luckett proposes that 'a high proportion of those entering homes do so reluctantly, perceiving it to be the only practical option open to them',[37] while Mitchell and Earwicker demonstrated in their Hammersmith and Fulham study 'the aversion of the great majority of elderly people (95 per cent) to the prospect of residential care.'[38] A study in East Sussex indicated that 'old people wished to remain in their own homes as long as possible'[39] and a report by Surrey County Council that 'many elderly people wish to cling to their homes despite the risks involved and their dependence on others to assist them.'[40] Wicks asserts that 'most elderly people cherish their independence, which often involves living alone', and argues that a key task for social policy-makers, practitioners and families, will therefore be to allow individuals to live independently. For once, he notes, economic as well as other factors point in the direction indicated by people's preferences.[2]

Some implications for carers

It can be seen that changes in the size and structure of the

elderly population, along with other demographic changes affecting the family and a climate of severe financial restraint, have coincided with renewed expressions of government commitment to community care. While this situation has obvious implications for the provision of services to our growing population of elderly people, it must be remembered that most social care 'is provided neither by statutory services, nor by voluntary organisations, but by informal carers.'[5] Recent attempts by professionals to provide services to the elderly to enable them to remain at home has placed considerable strains on the relatives caring for them, and any consideration of service provision must bear very much in mind the needs of the individuals who care for the elderly as well as elderly people themselves.

Recently, there has been an upsurge of interest in what the Equal Opportunities Commission has defined as 'those caring for dependents on an unpaid basis.'[41] Levin et al comment that emotional and psychological costs to carers vary tremendously, but note that there is ample evidence of the great stress under which many carers operate, especially when subjected to personality changes and behavioural problems in beloved relatives.[9] Likewise, Sinclair et al found in a study of supporters that many were under 'severe strain',[42] and McKay et al found that 54 per cent of primary carers in their study were above the threshold point for clinical disturbance on an assessment of general health.[5] Particular attention has been drawn to financial costs to carers, their social isolation, lack of relief,[11] disruption of family life and erosion of privacy.[43]

Consideration of the strains imposed upon those who care for the elderly at home is particularly relevant if it is recognised that the inability or unwillingness of a carer to continue coping is a frequent factor underlying admission to residential care. There is much evidence to suggest that admissions to institutions are often a consequence of collapse of family or informal support, rather than a marked deterioration in the individual.[44] Mitchell and Earwicker found that one prominent reason underlying applica-

tions for residential care in Hammersmith and Fulham was 'stress on supporters' – the most frequently assessed single problem underlying application being emotional stress.[38] A study in Avon revealed that 30 per cent of admissions to old people's homes were primarily due to stress on relatives, and in 87 per cent of the cases where stress was ranked first in importance, emotional stress was a primary problem.[45]

Stress on supporters is also an important factor in hospital admissions. Sanford found that 12 per cent of geriatric admissions in his study were for patients whose relatives or friends could no longer cope with them,[46] while McKay et al found that in two hospitals 21 per cent of admissions were due to 'breakdown of home care.'[5]

The strain on carers is especially severe when elderly people are afflicted by dementia. Levin et al comment that dementia has been characterised as 'the quiet epidemic', and the discussions they had with families '... left the research team in no doubt about the distressing effects of dementing illnesses, and their key role in keeping these confused elderly people at home.'[9] The number of elderly people with dementia is increasing; at the 1978 annual general meeting of Leicestershire Age Concern, anxiety was expressed at the problem of the 'escalating dementia epidemic',[47] and surveys have shown that between 13 and 44 per cent of the population aged over 65 appear to have at least some degree of psychiatric abnormality, with about 8 per cent having significant impairment.[48] The strain on carers imposed by dementing illness is exacerbated by the fact that general practitioners are frequently aware only of a small proportion of existing cases. Levin et al found that 48 per cent of those with severe dementia had not seen their GP in the three months prior to their study, and that 60 per cent of those with severe dementia had not seen a psychiatrist.[9] The lack of contact with general practitioners, they suggest, gives particular cause for concern since these individuals may be seen as the 'main gatekeepers' to services and the key to early identification.

If 'community care' has frequently meant 'family care' there can be little doubt that 'family care' has usually meant 'female care'.[49] Nissel and Bonnerjea found that women were responsible for the vast bulk of caring for the elderly people in their study[43] and the paucity of assistance offered by husbands or other relatives has been documented by Levin et al.[9] Nissel and Bonnerjea draw attention to the high incidence of emotional strain, feelings of isolation and physical and mental frustration suffered by women carers, and note that about half of those questioned spontaneously reported deterioration in their marital relationships.[43] At a time when an increasing proportion of women are seeking work outside the home,[11] the strain imposed by caring for elderly relatives often means that women either have to give up work altogether or reduce the number of hours worked. A study by the Equal Opportunities Commission found that the income and work opportunities of women carers were clearly restricted by their domestic responsibilities.[50] Nissel and Bonnerjea found that many of their respondents regretted the impossibility of taking paid employment whilst caring for a dependent relative, and note that nine out of the 22 wives had given up employment because it was incompatible with the elderly person's needs.[43]

At a time of high unemployment, special consideration must be given to the extra burdens placed upon the family, and particularly upon its female members, by commitment to a policy of community care, and the 'opportunity cost' of care for the elderly relatives must be realistically calculated. If community care is here to stay, then very serious consideration must be given to the support of those who bear the main burden of the caring which that policy involves.

3 COMMUNITY CARE SCHEMES – SOME INTRODUCTORY COMMENTS

The need for innovation in the organisation of services for the elderly is eloquently expressed by Davies and Ferlie. 'Given the problems of an explosion in the quantity and intractability of need, of tightening financial pressure and the need to develop new, targeted services for specific subgroups,' they argue, 'agencies will have to go beyond expanding conventional provision to utilise innovation as a way of making major contributions to greater effectiveness and efficiency.'[51]

There is much evidence to suggest that many admissions to institutional care could be prevented if sufficient domiciliary care were provided. In the Avon study, for instance, one-third of all those admitted to residential homes were assessed by social workers as being willing to live in the community, and capable of doing so, if increased domiciliary services were available.[45] The cost would be lower than care in residential homes. Currie et al estimated that between 30 and 40 per cent of elderly patients in their study who were admitted to acute medical wards received a type of medical and nursing care that could have been provided at home. The non-medical factors which precipitated admission were commonly 'social' in that 'family support for the acutely ill was either inadequate or absent, or appropriate nursing care was unavailable, or simply that a few nights' supervision could not be provided.'[53]

It appears that, in many cases, the traumatic effects and high costs of institutionalisation could be avoided if only there were sufficient domiciliary services and support, and Davies and Challis argue that social services' support of the frail elderly 'has been less effective than it should in improving their quality of life and preventing their needless institutionalisation.'[53] The same authors

in another paper argue that there are four main factors which make for ineffective case management by social services departments. Firstly, there is a failure of services (especially home help) to match resources to the variety of client needs. Secondly, there is a failure to interweave services with inputs from informal networks of support. Thirdly, the prevailing attitude towards work with the elderly has restricted the number of social workers willing to undertake it. Finally, there is an absence of devices to secure accountability while maintaining workers' ability to respond to clients' circumstances.[54] A further specific criticism has been the failure of the home help service (acknowledged by many as the mainstay of support for elderly people who live alone) to provide support early in the morning, late at night and at weekends.[14]

In responding to changes in the structure of the elderly population and in government policy towards community care, social services departments have frequently been hindered by a lack of systematic evidence about the costs and benefits of particular services, and about the most appropriate methods of implementation. Little information has been made available on the amount of benefit derived from particular services, on the marginal benefit of increased provisions, or on the impact on clients of different provision strategies.[12] However, Ferlie draws attention to the proliferation of innovatory care schemes 'going beyond the expansion of existing services to encompass new tasks, roles and forms of co-ordination' in social services departments, the NHS, housing departments and voluntary organisations.[3] The largest number of schemes reported in his *Sourcebook of Innovations* appears under the social services department (SSD) category (122 out of a total of 229 schemes), and the largest sub-category of all – SSD-sponsored extra domiciliary care – accounts for nearly 17 per cent of all entries and 31 per cent of SSD entries.

Many schemes devised to meet the needs of the elderly people in the community have been constructed with a built-in system of evaluation and many involve careful comparison with control

groups of individuals not receiving special services. In the next chapter, the main features of some of these schemes (frequently organised through joint planning) are discussed.

4 COMMUNITY CARE SCHEMES – COMMON CHARACTERISTICS

'Community care' has been defined by Challis et al as 'any reasonable service or services needed by an individual client which may be provided by suitable members of the local community and which are likely to postpone or obviate the need for residential care where this is considered to be a desirable objective.'[8] Thornton suggests that the term embraces two distinctive but limited concepts: firstly, the care of patients *in* the community (rather than in an institution), and secondly care *by* the community – a much, more nebulous concept which implies that individuals or groups such as neighbours, volunteers, voluntary organisations, and formal and informal local support networks, assume major, or even total responsibility for many kinds of care and assistance which would otherwise be performed by the statutory services, or would not be performed at all.[55] All the schemes discussed in this chapter have been conceived in response to the changing needs of the elderly brought about by the factors discussed in chapter 2. All are run by social services departments, many in conjunction with local health authorities and some in collaboration with voluntary organisations. Most are either extensions of, or additions to, the existing home help service and involve the employment of individuals who fulfil roles which are similar to those of conventional home helps, but extended to include more personal and, in some cases, basic nursing tasks. These workers are referred to variously as 'Home Care Aides', 'Home Care Assistants', and 'Domiciliary Aides'. Many of the schemes have built-in evaluative frameworks, which will be discussed, together with reported costs and benefits, in chapters 6 and 7.

Aims

Where the aims of community care schemes are made explicit, they frequently include the attempt to avoid or postpone admission to residential care. Thus in the Essex scheme 'the reason for commencing service in all cases was the deferment of an avoidable Part III admission',[19] while a stated aim of the Kingston scheme was 'to endeavour to avoid or postpone admission to long-term residential or hospital care'.[44] Some schemes aim not only to prevent or delay admission to institutional care, but to bring about rehabilitation; the Oxford scheme aims to enable, where appropriate, elderly people at present in Part III accommodation or in hospital on an indefinite basis, to live in their own homes, lodgings, or sheltered accommodation.[56]

Some schemes aim particularly to relieve pressure on carers. The Hammersmith scheme was set up in May 1978 to maintain the handicapped, frail elderly and infirm in their own homes by directly helping those living alone and by relieving relatives and friends of some of the burden of caring.[57] The Association of Crossroads Care Attendant Schemes, based in Rugby and largely funded by the DHSS, aims to relieve stress in families or persons responsible for the care of disabled persons (including a large number of elderly people) and works closely with health and social services departments to set up schemes all over the country. It is not the policy of the Association to initiate interest in a given area, but rather to help and encourage groups which have recognised their own local needs. The Association has the expertise and the experience to assist new groups in forming a steering committee to assess local need, and works at local level from the formation of the committee through to helping with applications for statutory authority funding (it is a policy of the Association to have at least two years, realistic funding from statutory sources before starting a scheme). By February 1984, Crossroads schemes existed in 65 areas (see Appendix), and it is likely that a considerable number of new schemes have been initiated since then.

Some schemes embrace the aim of enhancing the quality of life

for elderly people,[58] while others aim to maintain independence in old age.[59]

Finance

As Ferlie comments, 'the interaction between social and medical problems is nowhere felt more sharply than in the care of the elderly.'[3] Since 1973, SSDs and AHAs have been required to appoint joint consultative committees, and since 1977 they have been further required to appoint new joint care planning teams to develop joint plans and utilise the new joint finance.[60] Forty-five of the SSD-based schemes detailed in Ferlie's *Sourcebook* are funded by joint finance,[3] including Bolton,[61] Cleveland,[62] East Sussex,[39] Bromley[63] and Wiltshire.[64]

In some schemes, charities and voluntary organisations work alongside health authorities and social services departments using joint funding – for instance a project in Liverpool to provide intensive domiciliary care for the elderly mentally ill is run jointly by Liverpool Age Concern, Liverpool Health Authority and Liverpool Social Services Department.[65] There an Age Concern co-ordinator with experience of running a Good Neighbour scheme supervises domiciliary aides in conjunction with a psychiatric community nurse (the project being accountable to an advisory group consisting of medical and social services personnel). Schemes which are conceived as a direct extension of the Home Help Service are frequently funded directly by the local authority; thus the Coventry Home Help Project was made possible by an increase in expenditure on the Home Help Service in the Wyken area.[66]

Given the commonality of interests between social services departments and health authorities and their complementary functions in the care of the elderly, it would appear that the new joint finance should be utilised to its fullest extent and it is hoped that the necessary interaction and cooperation will lead not only to greater cost-effectiveness but to an enhanced quality of life for the elderly and greater inter-professional understanding and awareness.

Relationships with existing support networks

Perhaps one of the most distinctive features of the new domiciliary care schemes is the extent to which they seek to build upon existing community support networks. Thornton comments that one feature of alternative schemes of care for the elderly 'is the degree to which they build upon the effort and conscientiousness of ordinary people – the carers and, often, their families.'[55] Challis et al note that such schemes are especially concerned to uncover the potential resources available in the client's community which, in conjünction with more usual departmental services, can make it possible for the client to continue living in the community; they attempt to consolidate informal care rather than undermine it.[67] Commenting on the Coventry project, Latto notes the extent to which attempts were made to employ home helps in the areas in which they lived – the sense of shared community helped the development of an easy relationship between client and care staff.[69]

Many of these projects extend the principle of 'interweaving' discussed by Bayley.[68] The worker is used to complement relatives and other informal carers and to interweave with, rather than replace, existing statutory help.

Flexibility

Ferlie notes that the bulk of responses to his request for information on community care schemes emphasises the reduction of traditional long-term institutional care through the provision of more flexible and intensive community-based alternatives and through supporting and interweaving with other forms of care.[3] Indeed 'flexibility' would appear to be the ideal of many of these schemes.

The report on the Coventry project comments that it was characterised by a 'wider range and more flexible services, in terms of hours, visits and duties'; it was in its ability to provide a greater variety of services that the project differed most markedly from conventional provision.[66] A discussion paper on the Bolton

scheme states explicitly that 'the essential feature of home care is flexibility',[61] while the Bradford report argues that 'most of the inflexibility of the present service stems from the rigid way in which people have been employed to work in the Home Help Service.'[17]

The report on services in Bradford points out that home helps normally work only part-time and only on weekdays and argues that 'we cannot hope to meet the needs of old people by such inflexible employment patterns. This fact has been recognised and decisions taken to appoint staff in a much more flexible way.'[17] The Bolton scheme took as a central tenet that care would often be necessary well outside normal working hours and at weekends, and the report on the scheme argues: 'Home care must break with the traditional Home Help Service by becoming a task-related service rather than time-limited.'[61]

Flexibility may be conceived not only in terms of hours and duties, but in terms of control over the deployment of resources. The Kent Community Care Project is virtually unique in this respect. There the possession of a 'budget' by social workers enables them to provide individually tailored packages of care for clients.[1]

Relationships with other services

The extent to which community care schemes are seen as a substitute for, or an addition to, existing health and social services varies; some reports indicate decreased use of services while others suggest an increase in demand. One example is in the use of Meals-on-Wheels. Some schemes utilise home care staff to prepare meals in order to free the mobile meal service for other clients, as in Liverpool where it was agreed that the service provided would take the place of Home Help, Meals-on-Wheels and Good Neighbour services.[65] Other schemes continue to provide Meals-on-Wheels, preferring to utilise home care assistants for other tasks. The Bexley scheme provides Meals-on-Wheels to avoid the home help having to prepare the main meal;[58] the same applies in Coventry.

In some schemes, day-care facilities continued to be used (for

example Bolton[61] and Sutton[70]) while in others, day-care was either entirely precluded (Cleveland[62]) or limited (Liverpool[71]). While some schemes entirely replaced conventional home help staff with home care staff (Liverpool[71]), others did not (Cleveland[62]).

In Bradford it was necessary to develop a special night-care scheme alongside the Home Care Aide Service, and this was introduced at the same time.[17] In Bexley, physiotherapists and occupational therapists were coopted onto the scheme.[58]

Perhaps the most interesting area of intersection is that which occurs at the domiciliary care/nursing interface. In Bexley, community nurses have been used for both day and twilight services anduseful links forged with the Home Help Service (for example a client who otherwise would not have allowed the district nurse to bath her at home, was bathed at a day hospital when accompanied by the Home Help).[58] The Bradford scheme likewise works closely with the community nursing services, joint care and support being provided for many elderly people.[17] A report on the Sutton scheme comments that the management of community support team clients has been greatly eased by the involvement of other agencies such as community nursing services, day hospitals and day centres.[70]

The degree to which home care staff can take over tasks previously performed by community nurses will obviously affect the balance of care between health and social services. In Surrey, it was found that although the scheme did not significantly reduce the number of visits by nurses, tasks such as preparing meals and washing-up previously undertaken by some nursing staff became the responsibility of the Home Help Service on the introduction of the scheme.[40] The report on the Coventry scheme notes that while project clients tended to make more use of local authority services than non-project clients, the level of provision of domiciliary health services was significantly lower.[66]

Client characteristics

One important question which has yet to be answered is which

specific client groups benefit from particular types and combinations of home care (the Kent Community Care Scheme and its counterparts throughout the country will hopefully provide an answer). It is clear, however, that many of the new community care schemes aim specifically to help individuals on the margin of need for residential care, and in many cases this is one criterion for acceptance as a client. The Bexley pilot project aimed 'to assist up to ten people who would otherwise require Part III or hospital care, including those who refused to leave their own homes even if offered alternative residential care',[58] while in Kingston, the level and nature of the support provided was such that 'without it [the clients] would find themselves at considerable risk or unable to cope and would have to consider residential care or hospital.'[44] In Sutton, the main criterion for acceptance to the scheme was the client's 'increasing inability to live at home with normal supportive services, and where the next move is likely to be into a home for the elderly or hospital.'[70] The Kent project[1] and the schemes in Anglesey[72a] and Thanet[54] all demand that clients be on or above the margin of need for residential care and wish to remain at home.

Information on the physical and mental functioning of home care clients is somewhat difficult to catalogue, owing to the variety of measures used, but it is clear that for most it would be impossible to continue living in their own homes without help. The Cleveland scheme aims specifically to help those with 'low physical functioning' (although those accepted are generally expected to be sufficiently stable mentally to be left for long periods without nursing or home care support),[62] and the Surrey scheme caters for clients who would probably be too infirm for acceptance to local authority residential care.[40] The report on the scheme in West Glamorgan noted that all clients had physical disabilities to some degree; 20 per cent also suffered from mental disability or confusion, and almost 50 per cent had mobility problems.[73] In Coventry, 3 per cent were found to have 'severe incapacity' (based on mobility, sight, hearing, speech, continence and mental state

scores) and in an assessment of self-care ability, 58 per cent were judged to have 'considerable difficulty'.[66]

Clients of the Hammersmith scheme had a higher level of incontinence than individuals receiving normal home help services and a large number were unable to perform many of the essential tasks of everyday living. In comparison with other care groups, it was found that more of the scheme's clients (64 per cent) were rated 'poor' in functional level than Part III residents (42 per cent), home help clients (25 per cent) or hospital in-patients (59 per cent).[57]

The Liverpool scheme provided intensive home care specifically for clients suffering dementia,[71] and Buckinghamshire has now extended its assistance to the elderly mentally infirm to cover very frail elderly people and the younger physically handicapped.[74]

Many clients lived alone; in Oxford 56 per cent[56] and in West Glamorgan, 63 per cent.[73] Not surprisingly, the majority of clients were women but the age balance appears to vary. In the Oxford scheme 83 per cent were over 75,[56] in West Glamorgan 41 per cent were over 80,[73] and in Cleveland, 83 per cent were over 75.[62]

Reports of some schemes draw attention to the number of hospital discharges among home care clients. The Bradford scheme has dealt especially with those discharged after long periods of hospitalisation,[17] and 30 per cent of the West Glamorgan clients were hospital discharges.[73] The Tower Hamlets Family Aide Service aims to help in an emergency situation such as incapacitating illness and it provides help for other age groups as well as the elderly.[75]

Number of clients served

The number of clients served by a community care scheme will depend on the level of funding, the number of employees and the level of care provided. Some care for a large number of clients; the Coventry Home Help Scheme towards the end of its second year in operation was serving 224 compared with 149 at the start.[66] The Bradford scheme in 1983 was serving 250 clients using 72 aides.[17]

At the other end of the scale, Kingston was supporting 15 clients in 1983,[44] and during the first six months of the Cleveland scheme only 24 referrals were accepted.[62] At first the weekly caseload of the West Glamorgan scheme was between 12 and 14 clients; following an expansion of the team and area, it was increased to an average of 22.[73]

In between were Hove, catering for an average of 64 clients a week,[39] and Oxford with 116 (half of those referred) between 1980 and 1982.[56]

Staffing

The administration and staffing of community care schemes varies in the extent to which interdisciplinary representation is achieved and who provides the leadership. In some schemes, a home help organiser occupies a key position. The Surrey Heath scheme (part of the Surrey Community Support Scheme) has a home help organiser with main responsibility for coordination on a day-to-day basis in collaboration with the district social work director. In another part of the same scheme (Guildford), the coordinator was an assistant district social work director; here again, the day-to-day running of the scheme was the responsibility of the home help organiser.[40]

In Cleveland, home care staff were recruited mainly from the existing home help staff and were responsible to the home help organiser at a health centre.[62] An interesting but unplanned development in the Coventry Home Help Project has integrated the organiser as a team member who has taken responsibility, together with a social worker, for assessing need for residential, domiciliary and other services.[66]

In Kingston, the area manager for services for the elderly took the role of coordinator with control of a project team including twelve part-time domiciliary welfare assistants, a part-time occupational therapist, a part-time neighbourhood counsellor, a part-time project officer, and a full-time administrative assistant/volunteers organiser.[44] The Oxford team was led by a senior social

worker and included a district nursing sister, a CPN sister, eight specially recruited and trained home care assistants and a half-time secretary.[56] In Gateshead, the team comprised a team leader, a senior social worker, two social workers, a research and monitoring officer and a clerical officer.

The intensive domiciliary care project in Hove combined a new domiciliary care service with the appointment of a social worker to carry out assessments and casework with clients and relatives.[39] In Liverpool, the project coordinator and community psychiatric nurse are supported in their work by a small group which meets monthly and draws on social work and nursing skills, and also advisors who meet about once every three months and provide an opportunity for a more general review of the progress of the project. Commenting on the Liverpool scheme, Flynn observes that 'collaboration remains the key concept and reality: the attachment of a Community Psychiatric Nurse to the project ensures the ready access to a vital health service input necessary to the success of such a scheme ....'[65]

Services provided for community care clients

The nature of services provided for community care clients varies from scheme to scheme, but in most cases tends to 'extend' the role of the conventional home help towards the kind of care provided in residential establishments. The job description of Hove's home care assistants was similar to that of the care assistants in residential homes, so they were required to undertake normal home help tasks as well as additional tasks like bathing, dressing and undressing.[39]

One feature which sets these schemes apart from conventional service provision, however, is the degree of emphasis placed upon the development of a close relationship between client and care assistant. In the Liverpool scheme, domiciliary aides combined the duties of home helps and Good Neighbours, and an essential part of their role was 'to develop a relationship with the elderly person, especially by listening to him/her.'[65] In Hammersmith,

workers were expected to befriend the client 'like a relative',[57] and in Oxford, aside from personal and domestic duties, 'considerable emphasis is placed on the need for care assistant staff to relate closely to the client and take account of his emotional well-being.'[56] Latto notes that the Coventry home helps were encouraged to see their role as providing overall care and support to the client rather than a strictly domestic function,[69] while in West Glamorgan '...it was hoped that the Intensive Home Care Assistant would establish a relationship with the client by spending some time listening and chatting with him or her.'[73]

To convey the range of duties performed by community care staff, it is probably simplest to give examples of tasks expected of them in some of the schemes. In West Glamorgan, tasks performed for all clients included companionship, preparation of meals and drinks, washing up, liaison with relatives and neighbours and paper work. Certain clients were helped with washing, dressing, toiletting and getting up or putting to bed; other tasks included hair-cutting, shaving, bathing eyes, administering medication, helping with feeding and encouraging clients to eat. Care assistants were responsible for ensuring that adequate heating, bedding and clothing were available and their domestic tasks included making beds, filling coal-buckets, emptying commodes and dealing with laundry, cleaning and sewing. They also helped with shopping, performed escort duties outside the home, collected pensions and prescriptions and paid rent and other bills on behalf of the client.[73]

Home care aides in Bradford were expected to assist with dressing, undressing, toiletting, personal hygiene and bedmaking, dealing with soiled laundry, collecting prescriptions and urgent shopping. They had to ensure adequate warmth and food, supervise medication and undertake limited household tasks, as well as to keep a record of their clients' progress or deterioration and take any action necessary in emergencies.[17]

In Anglesey, a prime instrument of administration was the 'contract' – a statement of tasks and fees and an undertaking by

the administration to support the helper in fulfilling her tasks. Types of contracts have included undertakings to prepare meals (either at the client's house or in the helper's home), prepare clients for bed (toiletting, changing, settling down and securing the house), getting up (dealing with incontinence, preparing breakfast, dressing and so on) and checking to ensure the well-being of a client while a carer is at work. The wide variety of tasks undertaken by the Anglesey workers are mainly in the nature of personal care or light housework. Many of the workers 'have undertaken tasks of a highly personal nature for their clients and have gone well beyond the bounds of their contracts to avoid seeing their clients in need or distress.'[72]

One special requirement of the Liverpool aides (who work with elderly mentally ill people) is that they 'stimulate clients mentally and behaviourally, so that the client is achieving as great a level of self-awareness and performance in activities of daily living as possible.'[71] In Leicestershire, helpers call upon mentally infirm clients several times a day to provide memory cues as well as preparing them for day-care, carrying out escort duties and shopping, emptying commodes, cooking meals and doing a variety of other practical tasks.[47]

The Wandsworth scheme focused upon the delivery of frozen pre-packed meals to people who had received mobile meals in the past. The delivery of a conventional mobile meal provides little social contact but the neighbourly aides in Wandsworth helped their clients practically, gave welfare assistance and had much greater contact with them – as well as delivering meals. It was common for a client to be visited or telephoned daily, escorted to a hospital or clinic, or for an aide to write on the client's behalf to the social services department or other welfare agencies. Aides also washed clients' curtains, collected pensions and made enquiries about the payment of bills.[59]

Special features provided by some schemes included a night-sitting service (Anglesey[72]), and 'living-in' with families to tide them over periods of crisis (Tower Hamlets[75]). In Bromley, care

workers assisted a sheltered housing scheme by relieving the warden and deputy warden when they were trying to deal with increasingly older and frailer residents. Each day the workers have briefings with the warden or deputy warden to learn which residents require help, and their work comprises 'all the personal services ranging from helping residents out of bed in the morning to aiding them with dressing, doing their hair, cutting their nails and changing clothing and bedding for incontinent people. They also prepare meals, make beds, tidy rooms and [perform] other tasks.'[63]

Aside from the emphasis on the development of close personal relationships, one feature which characterises the tasks required of community care assistants is the shift in the balance of time spent on personal and domestic tasks. Whereas the traditional home help service has provided an essentially 'domestic' service, the new schemes are providing a great deal more personal care, and thus moving closer to the health care boundary. The report on the Surrey scheme notes the high level of personal care that has been required by clients,[40] and in the Coventry scheme the amount of time devoted to personal care and other tasks directly related to the clients' health and well-being more than doubled and came to occupy nearly one-third of the home helps' time.[69]

Together, these two shifts in emphasis (towards closer client-worker relationships and the fulfilment of more personal tasks) may be seen to set a pattern for future service provision, when more and more of our elderly will continue to live in their own homes, frequently without the comfort of a close kinship network to provide their most basic needs.

Training schemes

Given the large number of personal care tasks demanded of workers in community care schemes, it is not surprising that many schemes provide extensive training programmes for their staff. A discussion paper on the Bolton scheme argues: 'If we are asking Home Care workers to change their role, to operate more flexibly,

and to provide life and social skills training to clients as rehabilitation, the Department will need to initially re-educate those workers to the new role.' Furthermore, states the paper, the department would need to give a commitment to ongoing training on a much larger scale than previously in order to continue to up-date the workers' skills.[61] The appropriate training would be in three parts. Firstly, a period of induction, providing basic information on the social services department, their contract of employment and conditions of service, and the basic principles of home care; secondly, a ten-week day-release in-service training programme (similar to that already existing for home help staff); thirdly, training every two or three years which would teach or develop new skills to meet new demands and describe changes and trends in the care of the elderly.

The Coventry scheme also accepted the need for training and designed a programme to encourage home helps to see themselves as concerned with the overall well-being of the client.[69] New home help staff spent their first four weeks entirely on training, listening to talks, taking part in discussions and visiting residential and day-care establishments. The provision of an ongoing programme of training and support for the original as well as the new home helps was considered important. Training led to increased awareness of clients' needs, the subjects discussed including welfare rights, care of elderly mentally infirm people and hypothermia.[66]

Other training courses are shorter. In Oxford, an initial two-week training was provided, with theoretical and practical in-puts and information on services. Visits were made to local hospitals for sessions on lifting techniques and giving assistance with walking and personal care. In the second week, trainees accompanied experienced staff on their rounds. Afterwards all full-time and most part-time staff attended a two hour multi-purpose meeting with all professional members of the group once a fortnight (each meeting having a training component besides allowing in-depth discussion of cases and administrative and management matters).[56]

A one week induction course was arranged in West Glamorgan

by the social services department and the health authority (topics included hypothermia, medical emergencies and administrative procedures),[73] and the Liverpool training scheme provided specific information about helping elderly mentally ill clients.[65] Initial training in Surrey was provided through assisting ordinary home help clients; workers were also involved in courses run for the normal home help staff and attended sessions on home nursing and working with confused elderly people.[40]

While these training courses clearly increase staff awareness of the problems likely to be encountered in dealing with very dependent elderly people, they may also enable scheme organisers to assess, at an early stage, the suitability of individuals for work which, undoubtedly, can be extremely demanding both physically and emotionally.

Hours of service

One of the 'inflexibilities' of the conventional home help service has been its failure to provide help at times when it is most needed – early in the morning, late at night and at weekends. To a large extent it is their break with the traditional pattern of service that has enabled the new community care schemes to maintain elderly people in their own homes who would otherwise have to enter institutional care. Most schemes aim to provide cover for seven days a week where necessary. Twelve per cent of clients in Coventry received help on five or more days a week, including assistance in 'unsocial hours'.[69] In West Glamorgan, 50 per cent were provided with weekend as well as weekday care (although this was usually withdrawn if clients progressed sufficiently). Other schemes which provide cover seven days a week include Liverpool,[65] Bradford,[17] Bolton,[43] Cleveland,[62] East Sussex,[39] Kent,[1] Surrey,[40] and Sutton.[70]

Hours of work vary and in some cases employment of part-time staff is more practicable than taking on full-time employees. In Bradford, home care aides work in pairs from 7.30am to 1.00pm and from 6.00pm to 9.00pm.[17] In Liverpool, aides work five hours

a day between 8.00am and 10.00pm,[65] while in West Glamorgan care-staff work a 37-hour week, to be undertaken between 8.00am and 8.00pm.[73]

In East Sussex, 50 per cent of the service provided was outside normal home help hours, and over 6 per cent of the project hours were provided overnight (between 10.00pm and 9.00am);[39] in Oxford, service programmes were found to include more home care hours during the evening than during the day (2.16 evening hours compared with 1.75 day hours).[56]

In many schemes, clients are visited more then once a day if necessary (for example, Bexley,[58] Bolton,[43] Cleveland,[62] Coventry,[66] Surrey,[40] and Sutton[70]). The actual number of hours provided per client varies considerably from scheme to scheme and, according to individual needs, from client to client. Bolton provides an average of eight hours' home help per week,[43] East Sussex up to 28 care hours per week (for short periods),[39] West Glamorgan an average of 10-20 hours per week,[73] and Coventry usually one or two visits of two hours each.[66] The East Sussex scheme will provide a 24-hour service for short periods, where this is practicable.[39]

Matching of clients and home care staff

Because of the extended role of the community care worker, many schemes take great pains to 'match' clients and staff. One of the important functions of the Liverpool scheme's project co-ordinator is to match the personalities of aides to clients,[71] and Challis et al draw attention to the trouble taken in the Kent project to match clients and helpers for personality fit and relevant capabilities and interests.[67]

Summary of characteristics

The schemes discussed in this chapter have all arisen in response to changes in the needs of the elderly population. Many aim specifically to avoid or delay admission to institutional care, and to this end provide assistance with a wide range of domestic and personal tasks at times outside the normal home help provi-

sion. Clients are frequently on the margin of need for institutional care, with high personal care needs, and special training is often provided to enable staff to cope with work which can be physically and emotionally demanding. Services are interwoven with existing community care and services, and care is exercised in the matching of clients and workers. Special emphasis is often placed on the development of a close relationship between client and worker.

One of the most distinctive features of community care schemes is the way in which services are tailored to meet the needs of each client. The service provided by home care staff are carefully interwoven with other health and social services, and with existing community support to ensure that clients receive help of the right kind at the right time. The Kent Community Care Project may be seen as a pioneer in this field and the essence of this scheme will be discussed in the next chapter.

5 THE KENT COMMUNITY CARE PROJECT

The Kent Community Care Project is a collaborative venture between Kent Social Services Department and the Personal Social Services Research Unit (PSSRU) at the University of Kent. The research team at the PSSRU is also involved in the evaluation of similar schemes in Gwynedd, Gateshead, Hammersmith and Cambridge.

The project has four primary aims. Firstly, to identify the benefits and outcomes accruing to experimental clients who have received project services for a year, by comparing them with a control group not receiving project services. Secondly, to identify and compare the costs to the social services, other statutory agencies, and the community, of maintaining clients of both groups in their own homes, using project and conventional services, and comparing these costs with the expense of residential care which would be necessary otherwise. Thirdly, to identify the motivations and rewards of 'helpers' and their experiences of the helping task. Fourthly to study the benefits to and experiences of families supporting clients of the project.[72c]

The Kent project and its replications seek to improve the cost-effectiveness of interventions by SSDs in provisions for elderly people on or above the margin of need for long-term institutional care by achieving a more thorough and comprehensive case management.[54] The organisers of the project are especially concerned to uncover the potential resources available in the client's own community (including neighbours and family).[67]

One of the key mechanisms in the provision of individually tailored services and careful case management is the 'decentralised budget'.[1] The project's experienced social workers are given control of a budget to spend on the services needed to maintain clients in the community and improve the quality of their lives. They are

able to 'buy-in' services, either statutory, private or voluntary, up to a limit of two-thirds of the marginal cost of a place in a residential home. To assist in decision-making, they are provided with information on the unit cost of existing departmental services, known as shadow prices', which enables them to make explicit judgements about the relative appropriateness of different forms of care. Additional services can be obtained by the negotiation of a contract with a member, or members, of the local community to provide specified services at a certain rate.[67] It is argued that the flexibility offered by a budget enables social workers effectively to undertake the activities stressed by Morris – close assessment of client need, selection of appropriate ways of providing care, providing the necessary degree of psychological understanding, and providing adequate and stable care.[77]

The Kent project has been the subject of careful and elaborate evaluation which suggests that it leads to improvements in the quality of life of clients (see chapter 7). A great deal of literature has accompanied the project and there can be little doubt that the rigour of its evaluation and costing schemes have set a pattern for future research.

6 EVALUATION OF COMMUNITY CARE PROJECTS

Many people involved in setting up community care schemes are keenly aware of the need for some kind of structured evaluation to be built into the scheme. Unless there is some way of measuring costs and benefits and satisfactions and outcomes in a fairly systematic way, much effort is wasted and little knowledge gained for the future. The innovative, experimental nature of the Intensive Domiciliary Care Scheme in Liverpool, and its potential importance as an example, made it desirable for an independent research project to monitor its development. The research was funded by the DHSS and based in the Institute of Human Ageing at Liverpool University.[71] From the inception of the Kent Community Care Project, fieldwork was monitored and evaluated by research officers at the University of Kent, and it was arranged that the replication of the project on Anglesey would be independently monitored and evaluated by research personnel from the University College of North Wales.[72c]

In many schemes, the use of a 'control' group is an essential part of the evaluation process – individuals who are receiving the new services are compared with individuals who are not – either with or without 'matching' of clients and non-clients. In Bolton, a comparison was made between elderly people receiving intensive home help and others receiving long-term residential care,[61] while in Hove the 'control' group consisted of elderly people in another social services division receiving normal home help services.[39] In Cleveland, a more extensive scheme of control was utilised: those accepted onto the scheme were compared with those referred but not accepted; with a group of elderly people admitted to geriatric wards in the area; and with a group of elderly people admitted to local old people's homes.[62]

Clients in the experimental area of Kent (Ramsgate) who had received project services for twelve months were 'matched' with similar clients in a control area (Margate) who had received conventional social services for the same period. Clients in Liverpool were matched with other elderly people in terms of their mental state, age and degree of social isolation.[71] Sometimes it has been impossible to form a satisfactory 'control' group, a problem which West Glamorgan has circumvented by using historical records of people admitted to local authority residential homes as a comparison.[73]

One of the biggest questions in evaluative research obviously centres upon cost-benefit analysis; unless information is available on the amount of benefit derived and its cost, little can be said meaningfully about the effects of a scheme. The Kent scheme set out to develop a detailed series of accounts of the costs and benefits to each group involved (for example the client, the social services and the National Health Service),[1] and in Coventry the costs and benefits were studied by an economist, James Hunt, in the local authority's economic unit.[69]

A new project at the University of Kent (PSSRU) aims to measure the marginal benefit of increased provisions, to establish the outcomes associated with different services and combinations of domiciliary services, and to estimate the cost of achieving specific outcomes in particular ways.[12]

In some cases, special efforts are being made to ascertain which client groups benefit most from which combinations of services; rather than ask what difference the scheme makes to clients as a group, the Kent project sets out to establish 'to which clients in what kinds of circumstances ... this scheme [is] most beneficial compared with existing provision.'[1]

The Gateshead evaluation asks a similar question,[37] and one aim of the Cleveland evaluation is to find out which groups of people are most suited to the scheme and in what ways they differ from those who are unsuitable.[62]

Some schemes have used the rate of admission to institutional

care as a criterion for evaluation. Survival and the avoidance (or postponement) of entry to long-term residential care are among the important evaluation criteria for the Kent project,[54] while in Oxford the number of admissions to residential care in the project area was compared with that in the rest of the country.[56] Another measure used has been the differential impact of a scheme under varying geographical and social conditions. The Liverpool scheme studied differences between the impact of the service in an inner city area and in a county town,[71] and the Anglesey replication of the Kent project set out to test the effects of similar service provisions in a totally different geographical location with widely differing needs, resources and structures.[72a]

Apart from assessing the effect of schemes upon the welfare and satisfaction of clients, some evaluations have considered the motivations and rewards of helpers; Kent for example has collected information on why helpers volunteered, the rewards they enjoyed, and how the modus operandi of the scheme could be developed to help them better.[78]

Two examples of evaluations built into community care schemes may help to illustrate the processes. In the Gateshead replication of the Kent scheme, effectiveness is measured by an initial assessment of each client's outstanding needs for care and his or her overall quality of life immediately before the scheme's intervention, compared with the same assessment a year later. Simultaneous assessments are made on a control group of clients living outside the scheme's experimental area and receiving conventional support services. The assessment takes the form of a detailed interview with the client covering physical, mental and social aspects of his/her life as well as environmental factors. Information is also obtained from social workers and, where possible, from principal carers (family or friend). This makes it possible to measure changes in the client's well-being and in the stress on carers, and to compare the outcome for matched individuals in the control and experimental areas. There is an emphasis on cost-effectiveness as well as on adequacy of care, and cost data

are collected from health and welfare agencies to allow comparison of the overall costs of experimental and control clients in different environments.[37]

An interesting evaluation technique has been devised in Coventry. In addition to a detailed comparison of project clients with elderly people receiving conventional home help services, a special 'simulation exercise' has been developed to test the extent to which project services have reduced demand for places in local authority residential homes. Thirty eight test cases were submitted as applications for residential care – all details entered on the forms being correct except that the number of hours of help received was adjusted to an amount that would have been received elsewhere in the city. Twenty nine of the 38 were given high priority classification or were considered 'too bad' for care in a residential home.[66]

7 COSTS AND BENEFITS

Costs

Where an attempt has been made to estimate costs and benefits of community care schemes, the conclusion has been that costs are, on average, below those of institutional care.[73] Comparative costs are difficult to assess accurately, and should be interpreted with caution; it must not be supposed that community care is cheaper for all clients, nor should economy be the only criterion. There are elements of costing which are difficult to value; the evaluation of the Coventry scheme included changes in the work status of clients and/or carers in its cost-benefit analysis, and argued cogently that factors such as the amount of leisure time available to carers should also be included.[66]

Many reports draw attention to the very significant savings involved in the prevention of hospital admissions (for example Bexley,[58] Coventry,[66] Sutton[70]) and schemes reported as cost-effective overall include Bexley,[58] Bolton,[43] Kent,[43] Thanet,[79] Essex,[19] Hove,[39] Oxford,[56] Coventry,[66] Sutton,[70] and West Glamorgan.[73]

Estimates of actual savings vary. Based on an average of 64 clients per week, and discounting the health service input, it is estimated that the total cost to the SSD of a client receiving the services of the Hove project amounted to only 59 per cent of the net cost to the department of a resident in a home for the elderly.[39] A report on the Oxford scheme (produced in 1982) suggests that, while overall average costs per client of project cases were £70 per week, the costs per residential week for social services accommodation were £84 and, for a geriatric hospital bed, £260.[56]

Opit argues that there is little economic advantage in home care for seriously disabled elderly people,[80] and certainly some studies have highlighted groups of individuals for whom community care

cannot be cost-effective. Davies and Challis suggest that community care is unlikely to be cost-effective for clients with little potential for informal support, a tendency to reject rather than seek services, and with low dependency ratings.[79]

Judge et al conclude that for some very disabled people the costs of community care exceed those of institutional care.[81] The Avon report notes the much higher average costs of care for those unable to dress or get into or out of bed,[45] and Sinclair comments on the difficulty of maintaining in the community moderately or severely demented elderly people who have no relatives willing to care for them.[42]

Benefits to clients

A frequent observation of reports on community care schemes is the extent to which they enable extremely frail elderly people to continue living in the community – people who, without extra, flexible support, would otherwise require residential care. The report on the Liverpool scheme says that it is 'supporting a high proportion of clients who would normally be in social services accommodation or in hospital care ..'[71] while the Bolton scheme makes it possible to maintain in the community people 'who display similar characteristics to those who are admitted to residential care.'[61] While not wishing to make extravagant claims, a report on the Hove scheme argues that it is 'serving a more dependent group than is usual in the community ...'[39] and Rosemary Chessum has stated that the Gateshead community care scheme 'is proving very successful in being able to care for people who would otherwise require long-term admission to an institution. ...'[82]

Various reports draw attention to the reduction in admission to local authority residential homes and hospitals, for example Kent,[1] Thanet,[79] Gateshead,[76] Oxford,[56] Sutton,[70] Coventry,[66] and Wandsworth.[59] Some evaluations have found evidence of rehabilitation – in Bexley, almost totally dependent patients were able to return home,[58] while about 29 per cent of clients of the

Oxford scheme were eventually able to cope in the community without the project's services.[56] Higher survival rates were reported from Bolton,[61] Kent,[1] and Thanet,[79] where a marked difference in death rate was discovered between clients and non-clients: 14 per cent as opposed to 32 per cent.

Other benefits reported were increased morale,[54] decreased loneliness,[54,40,43,59,] improved physical and mental health,[40] increased mobility,[62] reduced dependence,[59] greater control over life,[54,43] increased social contact,[54] and increased capacity to cope.[54]

Attention is frequently drawn to the close relationships which have developed between clients and workers. In Coventry, for instance, project clients were more likely than others to talk about personal matters and to be able to confide problems to their home helps.They were also far more likely to describe the home help as a friend, or even a member of the family.[69] The close relationships which developed between clients and staff in the Surrey scheme proved to be 'one of the most important and valued elements of the service, and has made a significant contribution to the quality of life of the clients.'[40]

Benefits to others

Benefits have also been reported in coordination and cooperation between services. Thus the Bexley scheme 'has done much to provide better understanding and communications by advanced joint planning and early re-referral of new or renewed problems',[58] while in Surrey the anxiety of community nurses was alleviated when the responsibilities for clients were shared.[40]

Latto reports that home helps working in the Coventry scheme found their work more satisfying (if somewhat more stressful), and felt that their services were important to the client.[69] Little evaluation appears to have been made of the effect on carers, although Levin et al point to the value of community services in reducing the build-up of strain in supporting relatives.[9]

8 MEDICAL SCHEMES

All the community care schemes discussed so far have been essentially SSD-based. There are, however, a number of health service based schemes worth discussing since they have similar aims to those with a social services base.

'Hospital at Home'

The Medway Health District of the South East Thames Regional Health Authority runs a scheme of extended hospital care (EHC), which aims to provide continuing care between hospital and community, and, where appropriate, to reduce hospital stay.[83] Preliminary studies had indicated that some patients were staying in hospital after the need for sophisticated medical and nursing care had passed, and EHC was devised to enable them to be cared for at home. Between November 1977 and September 1979, 159 patients joined the scheme and 156 were discharged before the date of normal discharge. Hospital savings amounted to £15,530. Patients on the scheme favoured care at home and there appeared to be no difference in the early clinical outcome between patients on the scheme and those not on it, although no attempt was made to assess late complications or recurrences. There was sufficient evidence to suggest that substantial capital savings could be made if admission and discharge to an EHC type service could be taken into account when planning the number of beds needed in a new hospital.

A related study carried out in Scotland was based on the hypothesis that a proportion of elderly patients with acute or subacute illnesses were admitted to hospital for essentially negative reasons – a belief that they could not be treated at home coupled with an inability to provide sufficient support for them in their own homes.[25] It was the conviction that more old people should be

offered the opportunity of staying at home by providing an immediate home help and district nurse service that led to initial experiments by Professor J Williamson of Edinburgh's City Hospital, in which selected old people who were destined for hospital were treated at home instead. Results were promising, and research support was sought for a study in which such augmented home care might be tried out and problems of provision studied. Accordingly, local GPs were approached and the involvement and cooperation of the district nursing and home help services were sought. The scheme was highly rated by the three groups as well as by lay helpers and the patients, and there was nothing to suggest that delay in admission caused medical setbacks. Further, it was found that people receiving home care were able to make more rapid recoveries in basic function than the 'control' hospital patients. However, it is acknowledged that it is not known to what extent this difference was due to the adverse effects of the hospital environment.

Volunteer nurses

The Glaven Volunteer Nursing Scheme in East Anglia is well-established and at the time of a report by Allibone and Coles (1981-2) was using 52 volunteer nurses.[20] The nurses undertake three main tasks. Some are allotted to one elderly person and may call on the patient once a week over a period of time to give basic nursing assistance (bathing for example); others help the SRN who runs the Glaven Day-Centre Scheme; another group (usually those with a professional nursing training), help relatives and the community nurse to take care of patients dying at home. Analysis of this work showed that 57 per cent could be categorised as 'basic nursing' which enabled the community nurses to care for a larger number of patients than would have been possible otherwise. During the period 1980-81, the 52 volunteers made a total of 577 visits to 31 patients, and it was estimated that they reduced by half the number of visits in the Glaven area compared with two similar areas elsewhere.

Specialist health visitors

In two general practices in South Wales (one urban, one rural) two health visitors were specifically employed to care for a random sample of over-70-year-olds for a period of two years.[84] In the urban practice (Gwent), there was a statistically significant difference between experimental and control groups in terms of alterations in physical disability and mortality; in particular, there was a relatively small number of deaths recorded in the intervention group compared with the control group (significant at the 1 per cent level). Both intervention groups reported a higher quality of life than the control groups, and in the urban practice there was a considerable increase in the number of services provided for elderly people. 'The significant effect upon home help and lunch-club usage was particularly pleasing, for these are run by social services; our Health Visitor had obviously managed to pierce the sometimes seemingly impenetrable barrier between the health and social services.' While the health visitor in the rural practice appeared to have little impact, 'overall. . . .a Health Visitor making an annual unsolicited visit and related follow-up visits to the over 70s in an urban general practice increased the provision of services to these elderly people and reduced their mortality.[84]

'Elderly At Risk' register

A project undertaken by members of Devon's health and social services departments and Exeter University's Institute of Biometry and Community Medicine from 1975 to 1979 aimed to promote the integrated care of the elderly in the community by devising a register of the elderly at risk.[85] A secondary aim was that the recording system should aid coordination of health and social services for elderly patients; this involved the compilation of information on such characteristics as mobility, capability for self-care, physical and mental health, and family support. The design of the record card allowed all information relating to category of risk and need for health and social services to be recorded on one line for each assessment, so that a patient's current state could be

seen at a glance. Two practices operated the 'At Risk' register for two years and their experiences have shown that it enables all elderly people to be assessed for risk or dependency at least once a year, and in a simple straightforward manner.

9 CONCLUSIONS

The need for flexibility

Perhaps one of the most positive aspects of intensive community care schemes is that they are much more adaptable to the needs of individual clients than institutional care. Commenting on the Gateshead scheme, Challis et al note that it enables social workers to make continual, detailed adjustments to the help given as elderly people's circumstances change, and that this can be done quickly, without any time-consuming administrative procedures or references to centralised control.[76]

As has been noted, there is a high level of need for care not usually covered by the times or duties of the conventional home help service. Gregory observes: 'It may appear an elementary observation, but it is worth reinforcing that the timing of the service is of paramount importance in some cases.'[56]

Most of the schemes described are designed to allow maximum adaptation of provision to meet assessed need, with in-built assessment reviews to encourage swift variation in response to changes in circumstances. It would seem that Richards is correct when he argues that 'criteria for a viable and suitable scheme for community care should include flexibility ...'[34]

Support for carers

The Avon report observes that the importance of help from friends and relatives in maintaining elderly people in their own homes should not be underestimated.[45] Just how important the attitudes of relatives can be was demonstrated in the Surrey scheme, the report on which notes: 'When [relatives] are actively opposed to the client remaining at home, the scheme is unlikely to be successful or at least to run smoothly.'[40]

Given the very important contribution made by informal carers,

it is essential that planned services should interweave with existing carers rather than undermine or replace them. 'Too often', comment Challis and Davies, 'the introduction of domiciliary support has led to the replacement of caring by others.'[1] This requires the development of an active partnership between local authorities and informal carers. A carefully devised community care scheme can go a long way to supporting and making maximum use of existing community resources. The fact that breakdowns in caring networks have frequently been cited as one of the main reasons for admission to institutional care, suggests that carers must be given adequate support *before* circumstances force them to give up a full-time caring role. Levin et al cite as one of the most important findings of their study the effectiveness of community services in reducing strain in supporting relatives, and in their view action should be taken to channel these services to relatives who want to continue to care 'before they are exhausted.'[9]

Even with the provision of extended care, it is likely that there will continue to be a high level of need for periods of relief for carers. Levin et al found that day-care and short-stay admissions to homes and hospitals were rated very helpful by the majority of supporters,[9] and relief care in private households as described by Thornton[55] may also prove helpful for those on whom the burden of caring is greatest. Finally, the formation of carer support groups as in Canterbury, Newcastle and Wakefield[86] can provide a much needed opportunity for carers to discuss their problems and learn from the experience of others.

The need for coordination and cooperation

A subject which urgently needs more systematic research, as Judge et al point out, is that of collaboration between services, especially between the health and personal social services. They argue: 'Without a framework set-up by co-operation, it is certain that the problems and preoccupations of old people cannot be tackled successfully.'[81] Davies draws attention to the 'arbitrary division' between the two groups of services,[87] while Levin et al

argue: 'If health and social services do not plan together there is a danger that lack of provision in one sector (e.g. of the home help service) will cause a misuse of places in another (e.g. of hospital beds), and that each sector will rely on the other to meet recognised needs (e.g. for day care)'.[9]

Grundy and Arie see the split between health and social services as 'one of the self-inflicted wounds of our welfare state',[16] and the Essex report argues that, in practice, the actual care system available to elderly people is 'a set of discrete, relatively autonomous services controlled by different agencies.'[19] It is sadly noticeable that a number of schemes – especially in the home help field – still tend to consist of extensions of the services offered by one hierarchy without reference to other services or agencies. . . .'[3]

Undoubtedly, though, many projects have gone some way to breaking the barriers between health and social services. In Wiltshire, before the setting up of the Balance of Care Project for the Elderly, there had been very little participative joint planning, but organisation of the project brought together members of the Wiltshire Area Health Authority, the County Council and district councils and involved managers and fieldworkers from all of them. It also involved the Wessex Regional Health Authority and the DHSS in providing analytical skills, and helped to widen their understanding of care practices. The process of collaboration took about twelve meetings and 'a great deal of respect for alternative professional viewpoints between members' before a framework was finally drawn-up, setting out the possible patterns of care based on multi-disciplinary professional discussion on future planning.[64]

Whose responsibility?

Consideration of the mutual interests of social services and health authorities raises important questions of financial responsibility. 'Clearly,' argues the Coventry report, 'in any major expansion of domiciliary services, local authorities would have a financial incentive to concentrate on keeping people out of hospital,

where the largest community savings are to be found. This raises a question about how future expansions of domiciliary care should be best financed so as to reflect more accurately the division of benefit between health and local authorities.'[66] Since the costs and benefits of community care programmes fall unequally between the two authorities it is argued that 'it might be necessary to finance expansions of care by the transfer of funds from the NHS or by some other arrangement.' Davies feels it is likely that the community care project 'will always tend to colonise the grey area of responsibilities of the two agencies, leaving the social services department to "carry the budgetary can" to a degree that is not merely unfair but puts at risk the higher rate of development of domiciliary care that is necessary.'[87] As argued in chapter 4 (page 00), the new joint finance should help to bridge the unnecessarily wide gulf between health and social services, and it seems essential that all bodies who stand to lose or gain by changes in care policy should come together in a spirit of cooperation, and recognising their mutual interest.

Economy, at what cost?

Opit has referred to domiciliary care as the 'neglect' of the elderly, arguing that unless substantial extra finance is allocated to it, it will become increasingly 'economic' simply because it is inadequate.[80] Similarly Richards argues that the evidence suggests that community care is cheap 'only because it is inadequate, and because the inadequacies are easy to conceal.'[34]

If it is argued that a new approach to the care of the elderly must cost less it has to be stressed that the caring must give clients greater satisfaction. As Challis and Davies comment on the Kent project, 'if [the scheme] were to keep people in their own homes at high cost only, or did so at the expense of a reduction in their overall level of well-being, the evidence for its sucess would at best be ambiguous.'[1] One factor which should perhaps receive more attention in any cost-benefit analyses of these schemes is the input by informal carers. It is undoubtedly extremely difficult to set

values on their assistance and the opportunity costs of caring, but unless this is attempted the supposed economic advantages of care in the community may conceal very significant 'uncosted' elements.

Final comments

If, as seems likely, community care is to be the pattern of future services for the elderly, it is our duty to ensure that we do not simply produce 'economy by neglect.'[80] During the last twenty years people aged 65 and over have increased by one third, and the numbers of those aged 75 and over will increase by some 830,000 between 1975 and 2001. This will mean growing numbers of people living alone and increasingly frail people living in the communiity rather than entering institutions. Whether we can meet this challenge and allow our elderly people to live their final years in relative comfort and dignity, or whether we relinquish the fight and sentence them to isolation and discomfort, depends, to a large extent, on our initiative, our inventiveness, and our willingness to ensure that our plans for the future reflect changes in their needs.

APPENDIX: CROSSROADS CARE ATTENDANT SCHEMES

As at February 1984, schemes existed in the following places:

Barnet
Basildon
Belfast N & W
Belfast S
Blackburn
Bracknell
Braintree
Breckland
Brent
Broadland
Calderdale
Cambridge
Camden
Carlisle
Castle Point
Chelmsford
Cheltenham
Colchester
Coventry
Croydon
Daventry
Delyn
Dewsbury
Dudley
Fakenham
Fenland
Guildford
Hackney
Harlow
Hillingdon
Huddersfield
Ipswich
Islington
Kenilworth
Lambeth
Llanelli
Milton Keynes
Northampton
N Warwickshire
Nuneaton & Bedworth
Oxford
Peterborough
Rochdale
Rochester
Rochford
Rugby
Sheppey
Southend
S Glamorgan
S Northants
S Warwickshire
Southwark
S W Herts
Stockport
Stratford-on-Avon
Tandridge
Tunbridge Wells
Tynedale
Warrington
W Cumbria
Westminster
Wirral
W Lancs
Woking
Worcester

Further information on Crossroads Care Attendant Schemes may be obtained from The Association of Crossroads Care Attendant Schemes Ltd, 94a Coton Road, Rugby, Warwicks CV21 4LN (Rugby 73653).

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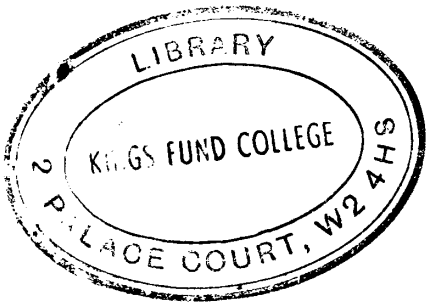

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