Dependent territories

THE FRAIL ELDERLY
AND COMMUNITY
CARE

Una Maclean

MD, Ph.D, DPH, FFCM Reader in Community Medicine University of Edinburgh

The Nuffield Provincial Hospitals Trust

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INTRODUCTION

ALTHY INDUSTRIAL SOCIETIES HAVE A RANGE OF options when it comes to providing for people who cannot survive without some support and Britain has developed a succession of measures over the years to distribute the responsibility which those who are frail place upon the able bodied. Our society has been various termed 'post-industrial', the 'service society' or the 'information society'. The fact remains that certain individuals who are prevented from contributing to the national or domestic economy depend upon the active sector of the population. Construed formerly as personal or parish charity or in simple terms of filial duty, such obligations have usually involved elements of self interest. The fear of the envy and malevolence of beggars once underlay regulations regarding their dispersal or departure from a district; the need for a pool of fit military recruits or for strong labourers has prompted legislation on the health and welfare of school children and of the disabled; and the victims of injury sustained at war or at work received earlier attention than the claims of disabled housewives. The state of the economy and the availability of manpower for industry has determined how much attention has been directed towards preventive measures to avoid expensive accidents or to provide the means of rehabilitation. In such circumstances the interests of the state have prompted reform, creating differences in entitlement amongst people with comparable personal disadvantages. The needs of individuals are secondary to those of the society which they inhabit and the extent of support they receive is always liable to depend upon their perceived usefulness or worth and upon prevailing political and economic philosophies.

This is not to deny the influence of philanthropy or the reality of personal affection and concern. Charity does operate, even at the national level, and most statements of political aims and values include reference to social obligations and the means of meeting them. Policies suspected of being devised too clearly in the interests of those with most power and wealth are subject to attack. Repeated surveys of public attitudes in Britain have revealed continuing support for the NHS and for social security. Nevertheless, people receive more for what they do than for not being able to do for themselves.

The main dependent groups in Britain today comprise the young, the unemployed, the mentally and physically disabled, and the elderly. The extension of the period of compulsory education has increased the relative size of the youngest category of dependents. Unemployment, whatever its causes, adds to the numbers needing assistance at ages when, ideally, or in differing circumstances, they should be contributors to the economy. The mentally handicapped and ill form a substantial sector for whom special provision is required. Prisoners, albeit unwillingly, are also a dependent group. Finally, those with a physical disability or handicap are arbitrarily divided according to whether they are under or over a legislatively determined retirement age. The age designates, for fiscal and classificatory purposes, allocation to the category of the elderly.

It is arguable that the so called problem of an ageing population has been partly socially constructed. This is true in so far as society may have decided that regular paid employment should cease and pension entitlement begin at a fixed age. The encouragement of 'early' retirement of late has been directly related to economic recession and shortage of work for younger people. Removal of those at the upper end of the age range reduces their immediate cost in terms of pay and salaries but necessitates subsequent alternative support for a longer period of time. Alarmist statements about the 'rising tide' of old people and the 'burden' which they represent manifest underlying ageism and discrimination. They could even encourage conflicts of interest between the generations.

Apart from the manifest contrasts in the needs, circumstances and prospects of young people and the pensionable elderly, other dependent categories, covering mental and physical disability and employment or employability, overlap. Definitions of frailty, disability and handicap are difficult, involving various ranges, subdivisions and qualifications. However, the position of

the elderly today is in many respects unique, and there is general agreement that they need special care.

The demographic situation in which we now find ourselves, as the end of the twentieth century approaches, is shared by other comparable Western societies. All have low birth rates combined with low death rates.

In consequence of improvements in public health and living conditions in the earlier years of this century, infant and child mortality were reduced. A much larger population than ever before survived to adulthood and, then to old age.

In Britain during the twentieth century there has been a growth of 360 per cent in the population of people over 65. They now constitute 15 per cent of our total population. This would seem to be cause for genuine rejoicing. But the increase in the over 75s and, especially, in the over 85s has been viewed with unmistakable apprehension by economists and policy makers. As the elderly are already the dependent group requiring most social security expenditure and medical support, the very oldest among them are expected to have the greatest needs. The accompanying figure from Social Trends 1989 shows the changes in the population from 1951–1987 and projected

AGE AND SEX STRUCTURE OF THE POPULATION

United Kingdo	m								λ	Aillions
J	0-	5-	15-	30-	45-	60-	65-	75-	85+	All
	4	14	29	44	59	64	74	84		ages
Mid-year est.										
1951	4.3	7.0	10.3	11.1	9.6	2.4	3⋅7	1.6	0.2	50-3
1961	4.3	8-1	10.3	10.5	10.6	2.8	4.0	1.9	0.3	52.8
1971	4.5	8.9	11.8	9.8	10.2	3.2	4.8	2.2	0.5	55.9
1981	3.5	8-1	12.8	11.0	9.5	2.9	5.2	2.7	0.6	56-4
1986	3.6	7.2	13.5	11.5	9.2	3.1	5.0	3.0	0.7	56.8
1987										
Males	1.9	3.6	6.9	5.8	4.6	1.4	2.2	1.1	0.2	27.7
Females	1.8	3.4	6.6	5⋅8	4.6	1.6	2.8	1.9	0.6	29.2
Projections										
1991	3.9	7-1	12.9	12-1	9.5	2.9	5.0	3.1	0.9	57.5
1996	4-1	7-6	11.6	12.6	10.5	2.7	5.0	3.1	1.1	58-3
2001	3.9	8.1	10.8	13.2	11.0	2.8	4.8	3.2	1.2	59.0
2006	3.6	8-1	11.0	12.6	11.6	3.2	4.8	3.2	1.2	59-3
2011	3.5	7.5	11.7	11.3	12.1	3⋅7	5.2	3.1	1.3	59-4
2025	3.8	7-4	11.2	11.3	11-1	4.1	6.0	3.9	1.4	60.0

Source: Office of Population Censuses Land Surveys (Government Actuary's Department)

numbers until 2025. The number of people over 65 represented 11 per cent of the total population in 1951, they are now 15 per cent. It is the age group aged 85 or over which is expected to grow most rapidly in future, from a total of over 0.8 million to 1.4 million by 2025.

The table illustrates that the population of the United Kingdom grew steadily between 1951 and 1971 but since then the overall total has grown more slowly. Only slow growth is projected for the years up to 2025. The age structure of the population has changed more perceptibly in recent years, with a lower proportion of children aged under 15 in 1987 than in 1971, and a higher proportion aged 65 or over. The number of people aged 65 or over (8.8 million in 1987) is now over 50 per cent greater than in 1951.

Demographic projections are not new, but their extraordinary implications in terms of needs and resources have only recently been addressed. The ensuing account takes as its topic the changing mix of services and informal or private provisions which have been developing to support physically disabled and mentally frail elderly people. The extent of co-operation or separation and conflict between the different caring professions, medicine, nursing, and social work will be considered. The burden placed upon relatives and, specifically, upon women carers at home often themselves past their physical prime, is an aspect of the subject which has only lately received the attention it deserves. The domestic sphere has been largely ignored. It can be conveniently taken for granted or misconstrued in the construction of social service and pensions policy or in calculations of private profitability.

There is now an extensive literature on the development and implementation of social policies in this area and on local practices which have evolved in response to changes in legislation, in financial inducements, and in the responsibilities assumed by different services and agencies. In the account which follows broad themes and trends in the practical provision for these dependent sections of the elderly population will be elucidated and attention will be drawn to the most innovative approaches to the vexed question of community care.

CHAPTER

1

The epidemiology of old age

with ageing. More insidious than the fear of death itself is the dread of irreversible decline, the remorseless loss of our powers. The thought of our seventh age, 'sans everything', alarms us all. It also presents a formidable challenge for any state with an obligation to plan for all our possible futures. Will the old come to absorb progressively more of our national resources in boundless demands for medical and social care? Are we reaching the limits of tolerance?

Negative stereotypes of old age abound. Sometimes we seem to set up the old as scapegoats or witches, responsible for our vaunted troubles over 'resource allocation'. Demented old women appear as repulsive figures, prompting resentful guilty questions about their right to live for so long, in such a pathetic, useless state.

Countering these harsh and cruel judgements are widespread positive attitudes and evidence of much general benevolence. After all the great majority of elderly people are evidently still living independently, or close to caring relatives. Only a small proportion are in any sort of institution. Most old people seem quite capable of enjoying retirement and feel that they are well. It is questionable, however, whether they are yet being treated

with justice by the state or given the opportunities to which they are properly entitled as equal members of an increasingly prosperous society. There is now growing emphasis on the right of the old to personal autonomy, with the prospect of making choices about the circumstances and manner in which they live. (WHO, 1984).

Demography and epidemiology, since they purport to be value free, can perhaps counter the more extreme visions of old age and its implications for society. We have undergone a demographic transition since the start of this century, resulting in a society with unusually large numbers of very elderly people. From the perspective of the Office of Populations Censuses and Surveys, Alderson has summarised the changes affecting England and Wales (1988). The overall growth in population was most striking in the first twenty years of this century when it reached 16 per cent above the figure in 1900. But it has increased during this period from 32.5 million to over 50 million. The growth slowed down to only 1 per cent between 1971 and 1981. The change so far has been mainly brought about by a decline in deaths, particularly at younger ages, which has had the effect of increasing the expectation of life.

The increased longevity which so many now experience is only partially attributable to advances in clinical medicine. It is mainly a public health phenomenon, resulting from the superior social circumstances into which successive groups of todays elderly were born and reared and which helped them survive the vulnerable period of their infancy and childhood. Infectious diseases took a progressively lower toll, whilst diet and living conditions improved for both mothers and families. It is the projected growth in the numbers of very elderly people, over 75, which gives most cause for concern. They are the product of a bulge in the birth rate earlier in this century and mean that this part of the population, which was only 1.8 million in 1951, will reach four million by 1991.

What pessimists regard as a disproportionate growth in the very elderly has also been affected by a decline in fertility in the depression years following the First World War. Average family size in the late nineteen-twenties and the nineteen-thirties was much less than in Edwardian days and this has reduced the

numbers in the next generation of potential family careers (OPCS 1983). As there will be a relative decline in the numbers of 'young' elderly, the total of people over 65 will remain fairly steady. These projections are very complex, based on assumptions about the future survival capability of the old as well as the numbers born at a particular period in the past (Craig, 1983). The demographic transition has turned what used to be called the population 'pyramid', with a broad base of the young, into something much more like a tower (Davies, 1985). Women's expectation of life, which was already greater by four years than that of men at the start of the century, has since improved still more. In the early 1980s the expectation of life at birth for males was 71.6 years and for females 77.6 years. So a further characteristic of the elderly population now is that women greatly outnumber men. It is easier to make statements about the past than to foretell the future. Just as doctors are cautious when it comes to prognosis so demographers make qualifications about any population projections, since both fertility and disease patterns can change unexpectedly. However, it is undeniable that the fastest growing group in the elderly population are those aged over 80, a matter of profound significance when it comes to planning appropriate care for them in the future. The fact that they are mostly older women who have survived their husbands, is a further notable feature.

The convention of considering that old age begins at 65 is administratively convenient. Such an arbitrary cut-off has consequences for the prospects of everyone over retirement age and how they are regarded by others. As Townsend has maintained, old age is in part socially constructed (1986). The fixed start to old age tends to iron out the great differences in ability, activity, and health status which exist between individuals of any age and which characterise successive cohorts of elderly people.

Several intriguing questions have recently been raised by the application of epidemiological methods to the topic of ageing. Epidemiology employs subdivisions of any population, according to age, sex, disease, and innumerable aspects of experience in order to bring out contrasts in the present state of groups of people and possible associations between these findings and their past. When we talk of increased life expec-

tancy and quote average figures for the present day, what does it mean for the future? Are we now near the biological upper limit for our species as far as the maximum achievable age is concerned or can people still grow older? In 1980 Fries put down the first marker in what has been a hotly argued debate (1980). He reviewed the epidemiological evidence and came up with the attractive prospect of 'the compression of senescence'. In his opinion the maximum life span had barely increased over the course of a century in which the average length of life had steadily risen. He represented the phenomenon in terms of changing survival curves at different ages which were, he declared, adopting an increasingly rectangular shape. He was convinced that, as the century progressed, people had not only been living longer but living fitter. He declared his belief in 'natural death', which might occur suddenly once the maximum age span of about 85 years was reached. Natural death represented a final breakdown of homeostatic mechanisms and, according to Fries, it need not require the intervention of any disease process. He admitted that there was still a big burden of chronic disease, but he was confident that this could be greatly reduced in future by preventive measures in the form of healthier life styles. If Fries was right, most might in future expect not only long but vigorous lives, ending in a mercifully brief and precipitous senescence. His view harked back to that of the ancient Greek followers of Hygeia, who thought we were born healthy and could long remain so, if only we lived wisely and did not abuse our bodies.

Fries' thesis expressed a characteristically American spirit of optimism and self help. He spoke of 'the danger of attitudes towards the ageing proving self fulfilling. The older person requires opportunities for expression and experience, autonomy and accomplishment, not support and care and feeding and sympathy'.

It was not long before such a confident reading of the mortality augeries was challenged. Schnieder and Brody maintained, in the same New England Journal of Medicine three years later, that Fries had seriously misconstrued the evidence (1983). They made the point that cellular, physiological research into the human life span was still exceedingly limited and

that what had been discovered so far could not be generalised. As far as 'natural death' was concerned, they could find absolutely no evidence that this ever occurred in human beings. 'Although most organs undergo functional declines with aging none is compromised sufficiently, even at extreme ages, for death to result in the absence of disease', they declared. With regard to whether the population might rapidly be approaching maximum life expectancy, they observed that mortality rates, far from staying on the plateau they had reached in the 1960s, had resumed their decline in the 1970s and that the mortality rate for people over 85 was actually decreasing faster than for any other age group. Both the absolute numbers of people in this age group and the percentage of the population in the age group were clearly still on the increase. These researchers failed to discern what Fries termed the 'rectangularisation' of the survival curve and they maintained that the curve was still rising. In the context, they commended Manton (1982) who had written about changing concepts of morbidity and mortality in the elderly population. Brody and his colleague readily admitted that chronic diseases had largely replaced infectious disease as causes of death but they were of the opinion that the effect of this change would simply be felt over a larger proportion of the life span. According to their forecast the average period of diminished vigour which everyone could anticipate would be likely to increase.

Alderson and Ashwood (1985) considered UK figures over the same period according to different causes of death. They could not detect any recent decrease in the mortality rate of the over 60-84 age group in respect of ischaemic heart disease, but they pointed out that there had, however, been declines in mortality from cerebrovascular disease since 1950. Alderson expressed typical British caution in his summary of the overall implications of increasing survival saying, 'What is not evident from the projections is whether the improvement in mortality is associated with an increasing number of survivors who are healthy or with an increasing number of survivors who had chronic disease....' Referring to the well recognised differences between the patterns of diseases causing morbidity and those manifested in mortality, he stated that it was simply not possible meanwhile to be sure whether those with a potentially

fatal disease whose death was postponed would suffer from a higher prevalence of chronic illness.

The policy consequences of thse contrasting visions of the future are absolutely opposed and vitally important. If Fries is right and most people will live to a ripe and active old age it might not be necessary to plan for increasing medical and social expenditure on the elderly, but if Brody or Alderson are nearer to the truth, the need for care in later life may well expand substantially and our societies had better be prepared to meet it.

The WHO outline of the uses of epidemiology in the study of the elderly raised the issue of 'the expectation of disease-free life'. Clearly what most concerns both the old and those who might eventually become responsible for them is the point at which independent living is hindered by disease. But the WHO group admitted that the extensive morbidity data required for such projections was still sadly lacking in most countries (WHO, 1984).

Looking at the same question Katz and his colleagues used the closely related concept of 'active life expectancy' and used life table techniques to analyse information derived from two sets of interviews with non-institutionalised elderly people (over 65 years) in Massachusetts (1983). The results showed a decrease in years of active life expectancy, from 10 years for those aged 65-70 to 2.9 years for those aged 85 or older. One of the most interesting findings of this study was the observation that active life expectancy was shorter for the poor than for others. The difference in favour of the 'non-poor' ranged from 2.4 additional years of life for age 65-69 to less than one added year for people over 75. There was a further discovery, namely that women could expect a longer average period of dependency than men. As they put it, 'the percentage of remaining years of independent life was greater for men than for women-at all ages'. Katz and his colleagues fancied that this sex related difference might mean that 'women manage reactions to the stresses of impairment and changes in social role better than men'. Perhaps men succumb before their independence is ieapordised?

One of the central issues impinging on this key debate on the edges of epidemiology has to do with the popular notion of health promotion. It is now generally believed that there are certain harmful influences in our environment, relating to exposure to chemical pollutants, foods, and drugs. It should not be necessary here to recap the long running arguments connecting life styles with heart disease, stroke, and certain cancers. What matters for older people is whether any of the decrements in function which they have already suffered are potentially reversible. It might seem impossible in later years to do much about the legacy of a lifetime. Is it worth trying to live wisely when approaching the eleventh hour?

In Alameda county, California, observations were made over a period of ten years into the health related practices of the population and subsequent mortality (Wingard et al., 1982). Everyone was accorded a 'health practice score' of 0-7, depending upon seven items. These were:

never smoking cigarettes; taking regular physical activities; making moderate or no use of alcohol; having 7-8 hours sleep/day regularly; maintaining proper weight; eating breakfast; and not eating between meals.

The latter two items did appear somewhat arbitrary and, in the event, turned out not to be significant markers. However, a steady decrease in age-adjusted death rate was found with increasing health practice score although the mortality gradient was steeper for younger men than for elderly men. So possibly some benefit does accrue to the old as well as to the young from pursuing healthy habits. It would certainly seem sensible to encourage older people to keep up mental and physical activity and take a balanced diet.

It is often maintained that epidemiology is value free, but the epidemiological evidence outlined above has in fact proved open to widely differing interpretations and the future healthiness of the ageing population is still very much in doubt. The picture of vigorous, active American oldsters striding forth until they suddenly topple over the cliff edge of mortality may conceal a modicum of wishful thinking. Do we know enough about the present health of the elderly in Britain to help us towards a healthy pragmatism?

As noted, the very oldest sector of our population is growing the fastest. The Office of Populations Censuses and Surveys has indicated that, by the beginning of next century, we can expect close upon a fifty per cent rise in the numbers of over 85s (1983). Although mortality data is readily available, the state of health of any population is only reflected in a very limited manner by information on deaths from specific diseases. For instance, the three main causes of death for males aged 60-84 in England are ischaemic heart disease, lung cancer, and cerebrovascular disease; for women the diseases in rank order are ischaemic heart disease, cerebrovascular disease, and digestive organs cancer, (Alderson, 1988). But information concerning common causes of death tells little or nothing about how later life may be led, since the actual manifestations of disease, their symptoms, severity, persistence, and treatments are so variable. Another source of information is provided by hospital in-patient statistics demonstrating an increasing use of these facilities as age rises. Those who have a marriage partner are apparently being incidentally somewhat cushioned from the need for hospital admission. Both in relation to diagnoses on hospital discharge and regarding the conditions which underlie GP consultations it is possible to calculate the percentages which apply to the older population. Alderson has compared both of these morbidity measures with the commonest causes of death. General practitioners' help is mainly sought for complaints relating to the bones and joints. Surgeries are not full of old people with acute diseases or medical emergencies but with cases of chronic, longstanding ailments. Thus knowledge leads naturally to the matter of disability and its measurement.

In the late 1960s heightened concern over the adequacy of provision for the disabled prompted a nationwide survey by Amelia Harris into the extent of handicap (1971). At that time a quarter of women at home aged over 75 reported severe or very severe handicap; the figure was somewhat lower for men. A regular, annual source of information on disability in the British population since 1971 has been the General Household Survey. The format of the questions relating to health and the use of health services changes from time to time and the usefulness and validity of the survey and the analyses derived from this regular enquiry it have been criticised on a number of grounds. These reservations have been itemised by Cartwright (1983), who has pointed out that the length and detailed nature of the questionnaire may be confusing and very taxing for elderly informants.

From answers obtained in the 1983 household survey, however, it appeared as many as two-thirds of both men and women over the age of 75 reported some kind of limiting, long standing illness.

An important and much quoted study of the elderly at home was that of Hunt (1978). An OPCS survey, done in 1986 and 87, asked questions about specific activities and only limitations in performing them were included in the definition of disability (1988). It produced higher figures for prevalence than had been discovered by the GHS, but the authors considered that old people over 75 might not complain about limitations in activities. Freer reviewed the evidence on the health status of old people in the community and came to the conclusion that their frailty and disability had been exagerrated (1988).

Clearly there are persisting contradictions in this whole area, primarily arising from differences in the definitions which separate investigators use and also because of the continuous nature of the concept of disability, further confounded by the undeniable fact that lay people and professionals do not share the same perceptions of symptoms. In particular, the significance attributed to varying sensations and discomforts by the old will depend upon their own personal expectations of fitness and their personal judgements of what is normal for the age which they have reached. The medical sociology literature on the subject of the experience of illness is extensive (Fitzpatrick et al., 1984) but the old have received less than their fair share of attention. A useful review of illness behaviour in the elderly was made by Graeme Ford (1986).

In Copenhagen, Gjorup and his colleagues looked at the health related attitudes and reported behaviour of people over 77 years of age (1987). They discovered that the highest rate of consultation had been for locomotor symptoms, followed by cardiopulmonary complaints and eye troubles. In the US, Brody and Kleban (1981) found that some old people were not troubling to report symptoms because they thought they were 'no big deal' or that 'nobody cares'. It is unjustifiable to make direct comparisons between survey findings in Britain and those done in other countries and only general conclusions can be drawn, but it does seem that the way old people behave in respect of health or symptoms is not markedly different from

younger groups. Essentially their action depends on what their symptoms signify.

Closely allied to incidental health surveys is the question of screening the elderly population with the intention of discovering whether some have unreported needs. Williamson's early contribution to this field in Edinburgh is rightly famous (1964). Old people were found to have multiple disabilities, of the order of three per person, and for each problem known to their GP there was another which was undisclosed. In clinical parlance, faults of the respiratory, cardiovascular, and nervous systems were familiar to the old peoples' physicians, whereas symptoms suggestive of disorders of the urinary tract or of the mind (both depression and dementia) were unreported or missed. Williamson drew attention to the frequency of easily remediable foot problems. Left untreated they could lead to complete immobility. He remained a protagonist of screening (1981) because he was convinced that the kind of disorders his team originally uncovered were not trivial in respect of the ultimate impact they could have upon independent living; early intervention could often forestall a crisis.

Since the expansive sixties, when health needs and demands were seriously studied with a view to satisfying them, enthusiasm for screening has notably declined, partly on account of the cost and workload such activities entail but also because the actual outcome of these endeavours remains to be scientifically evaluated. According to Grimley Evans, 'Several authors have assumed that the discovery of unknown disease and social disadvantage must necessarily be beneficial. This clearly is questionable and it is difficult to see how anything short of a randomised controlled trial could answer the critical issues' (1984). Undeterred by such epidemiological reservations, both Barber (1983) and the Health Visitors Association together with the British Geriatrics Society (1986) have taken the opposite view and asserted the capacity of health visitors, albeit in augmented numbers, to carry out what their supporters regard as self-evidently desirable surveillance and health promotion.

Elsewhere Grimley Evans has pressed the case for making sure that every existing spontaneous encounter with the elderly by general practitioners, nurses, or social workers is meanwhile properly utilised (1986). He was not convinced that any of these service providers were making appropriate assessments of the needs which they ordinarily encountered. At the level of hospital medicine, he emphasised the right of elderly people to receive the very best care which modern medical technology had to offer. They ought not to suffer any discrimination on account of age. Moreover, old people at home might be unfairly compelled to endure what he vividly termed 'aggravated ageing' if they were obliged to live in poorer, colder, more inconvenient housing than the rest of us.

Among the multiple influences combining to make us what we are, do we know which can be modified, prevented, or removed? Essentially it is a matter of distinguishing between intrinsic and extrinsic factors in ageing. Conceivably some of the latter factors might eventually prove susceptible to manipulation. However, Grimley Evans' research has indicated that the point in the life cycle at which an extrinsic factor has its significant impact may be surprisingly early. For example, obesity and hypertension in early adult life may make someone more liable to a stroke long afterwards.

Perhaps it is, after all, not a matter of prevention being better than cure, but of prevention having to give way to care? Ideally we require more longitudinal studies to sort this out. They are notoriously expensive and difficult but they would certainly yield more information than many cross-sectional descriptive accounts, cutting through several cohorts of ageing people at one point in time. We do possess many snapshots but most of them are vague and fading like old sepia prints. They singularly fail to reveal the complex processes which combine over time to determine our fate.

Meanwhile, there are some clear findings. Over 20 per cent of those aged over 80 are likely to manifest senile dementia and this condition, unlike other forms of frailty, renders a person who may appear physically capable of more years of life in need of total, twenty-four hour surveillance for their own protection. It is conceivable that research may yet come up with an 'extrinsic' cause of this disease. Until such a breakthrough occurs it is unreasonable to speak in terms of 'self help' and health promotion for such vulnerable creatures. Fundamental research into the ageing process and into the detailed circumstances and needs of various sections of the elderly population is

relatively recent. Even now Britain lags behind the United States, with its National Institute of Ageing, in expenditure on these themes.

In the next section an outline will be offered of some of the social policies which have modified the condition of old people in Britain. They mirror our changing attitudes towards the dependent and frail elderly. Some Americans may be criticised for their overly optimistic view of conditions in the States now and in the foreseeable future, since their rosy visions could result in underestimating the need for medical care and support or could impute unjustifiable blame to the ageing victims of yesterday's ills. Pessimism and alarm too can be self-fulfilling prophecies. For our part we have been creating in Britain a multiplicity of agencies, officials and workers whose tasks may all include a modicum of care for the elderly but who may seldom meet or appreciate one another's activities. Both scenarios may reduce the autonomy and dignity of the old.

CHAPTER

2

The evolution of care for the elderly

NE-HUNDRED-AND-FIFTY YEARS AGO OLD PEOPLE were rarely singled out as a cause for special concern or as the object of special state provisions. An unknown but probably very small proportion of the aged ended their days in Alms Houses associated with churches, charities, and particular professions. The Poor Law reforms of 1834 assembled the destitute under one roof old along with children, the sick, and the disabled, imbeciles and delinquents. The workhouse was used by the Poor Law Union and the Guardians as both the medium and the discouragement of public assistance for an assortment of unfortunate dependants.

Since that time opinion has swung between the advantages and disadvantages of differentiating groups of people who all need help but for disparate reasons. By 1905, when the Report of the Royal Commission on the Poor Laws was published, the mixed workhouse was seen as an unsatisfactory response to diverse needs. But even at that time some of the less satisfactory consequences of separating groups of deserving clients were also appreciated. Since the breaking up of the Poor Law could in some cases break up families who had previously been lumped together, the fear was expressed that, 'a multiplicity of officers would now be inclined to harass poor people in their own

homes'. Each official would be bent upon enforcing his own terms and conditions for assistance. Sixty years later the Seebohm Committee attempted to redress these very problems by bringing in generic social workers, whilst at the same time accepting the consequent loss of firm distinctions between categories of need and the risk of a possible fall in overall standards of care (1968).

It has been suggested, for instance by Penelope Hall (1976), that much of the early extension of welfare services was haphazard and that services for the old remained largely institutional. Few domiciliary welfare services were developed by local authorities until after 1948. The National Health Service Act of 1946 and the 1948 National Assistance Act had laid the foundations for the decentralisation of accommodation and other services for the elderly, but Hall considered that the post-war legislation did litle more than 'reallocate elements of the Poor Law regime to different agencies'. In contrast to the situation where children were concerned and where community care, by boarding out for example, was strongly encouraged, the elderly could still only expect residential provisions, as a last resort, when they or their families had become desperate.

In the 1942 Beveridge Report its author showed his awareness of the changing age composition of the population. This significant demographic change was expected to be maintained and the multiplication of the elderly members of society was seen to pose an economic problem, particularly because it would necessitate increased pensions, as part of the vaunted 'War on Want'.

The sheer size of the burden which it was maintained would be placed by 'non-productive' pensioners upon the working sector of the community became a frequent subject of both parliamentary and public debate. Being a matter which ultimately affected everyone, pensions were an emotive issue. A partial solution at that time was the official encouragement of older people to continue in work as long as possible and this was linked to the implied suggestion (supported by partial research) that retiral might actually carry the risk of a deterioration in health and morale.

Beveridge had envisaged a transitional pensions scheme with the elderly at a relative disadvantage compared with recipients of sickness and unemployment benefits, but the 1946 National Insurance Act, under the subsequent Labour administration, eventually provided full retirement pensions. Even these unexpectedly generous provisions were soon proved insufficient and some of the old were obliged to seek supplementary help towards their rent from the National Assistance Board (Lloyd, 1982). Since then the relative poverty of the old has persisted (Bosanquet, 1978). Meanwhile they are inevitably placed in a position of dependance and relating social disadvantage by our insistence on a fixed age and conditions for retirement (Phillipson, 1977).

Hospitals were only amalgamated under one common management in 1948 when the National Health Service was inaugurated. The original voluntary hospitals, supported by public charity, had been the place for patients with acute episodes of illness. The other institutions for short-term illness were public health hospitals which had, in 1929, come under the control of the then powerful Medical Officers of Health. The latter were also in command of what had formerly been the workhouses and were then called Public Assistance Institutions. They had contained medical wings or infirmaries to which elderly inmates could be transferred if necessary.

As far as these sick objects of public charity were concerned, their families were left in no doubt about their responsibilities. The Poor Law of 1930 stated, 'It should be the duty of the father, grandfather, mother, grandmother, husband or child, of a poor, old, blind, lame or impotent person... if possessed of sufficient means, to relieve and maintain that person'. Even for an old person inside an institution family contributions could be exacted.

The professor of geriatric medicine at Glasgow University, writing about the evolution of medical services for the elderly in the United Kingdom (Ferguson Anderson, 1972;1981) recalled how Dr Majory Warren had introduced the fundamentals of modern geriatric practice as early as 1935, when she set about sorting out the patients in the Poor Law Infirmary which had just been taken over by the nearby West Middlesex Hospital (1981). Hundreds of aged chronically sick people required to be classified. She sent some to welfare hostels, the seriously ill were properly diagnosed and given good medical treatment, and the remaining frail elderly were encouraged to become more active

and independent. In effect she had carried out one of the first emptying exercises upon a long stay institution and she finally needed to keep only one third of the beds originally occupied by old people.

Anderson drew attention to a student paper of the day for its vivid account of the fate of the old in the hospitals (Morris, 1942). After the initial medical examination on admission they received virtually no clinical attention beyond an occasional gracious wave from the lofty visiting physician with his retinue.

After the passing of the 1946 National Health Service Act public health departments of local authorities were entirely shorn of their former extensive management of hospitals. Previously influential medical officers of health would from now on only retain responsibility for environmental control measures and for the employment of certain categories of nursing staff, midwives, health visitors, and district nurses who worked in the homes of patients. At the same time general practitioners had become independent contractors, paid for by central government through Executive Councils. They undertook to provide primary medical care on demand to all who were registered on their list of named patients. Hospital consultants, after initial reluctance and intensive bargaining, agreed to enter a salaried service, administered by regional hospital boards, the eventual remuneration of many being supplemented by Merit Awards.

As Honigsbaum has exhaustively described (1979), general practice in Britain developed entirely separately from hospital medicine. The hospital sector had undoubtedly been accorded at the outset the highest status and thereafter became the summit of most young doctors' ambitions. In the setting of the acute general hospital a growing number of different specialists exercised refined diagnostic skills, aided by the increasingly sophisticated treatments which advancing technology and pharmacology provided. They controlled entry to their hospital beds for those patients whom GPs submitted to their superior judgement. GPs might constitute the NHS gateway to the hospital service but ultimate decisions regarding admission and discharge firmly rested with the specialist in charge. Consultants began to begrudge the occupation of precious beds by elderly

patients, who tended to have prolonged stays and who presented difficulties over discharge because of their home circumstances.

A need for specific geriatric assessment had become apparent during the nineteen-forties and this was actively promoted by the British Medical Association (1947). Old people were being proferred by their own doctors for hospital admission in more instances than the supply of beds could match. From this problem arose the idea of preliminary domestic visits by a special kind of hospital physician. In some parts of the country a geriatric consultant accompanied by an almoner would arrive at an overall estimate of someone's medical and social circumstances in the home and advise general practitioner accordingly.

After the Second World War not only was the speciality of geriatrics evolving but in the hospital setting numerous other, para-medical professions had arisen whose members all possessed skills applicable to elderly people. As well as nurses there were occupational and physiotherapists, speech therapists and chiropodists. The hospital social worker, whose predecessor, the almoner, clearly derived from the disbursing of charity, also made a contribution, particularly when discharge was imminent. Eventually the activities of all these different participants in care were subsumed under the convenient concept of the geriatric 'team'. This reassuring term has been applied to many other areas of medical endeavour, both inside and out of hospital. It has occasionally concealed or discounted interprofessional misunderstandings. In the best instances, however, the notion of a team could undoubtedly reflect effective joint working in the interest of patients.

A team has always been easier to assemble in a hospital ward than in the conditions of general practice. In a ward, in spite of the separate allegiances and roles of different professons, they can easily get together to discuss the abilities and home circumstances of individual older patients and the geriatrician can be advised about whether it is likely someone can cope in their own home setting. The good offices of such a hospital based team are unfortunately lost once an old person has left the ward. It is also the case that, whereas a consultant geriatrician will have sole resposibility for the use of his or her own beds in a designated ward, only advice can be offered if an older patient occupies a bed in the territory of another kind of clinician.

Professor Sir Ferguson Anderson (1972) was convinced of the value of special psychiatric units and the need for psychiatrists sufficiently interested in old people to appreciate that their mental illness and deficits deserved accurate diagnosis and appropriate management as much as any younger person. He also commended the day hospitals and sheltered housing and he deplored the paucity of homes specially for the mentally frail. Approximately one-in-five people over the age of 80 could be expected to suffer from dementia, presenting a formidable challenge to doctors and all the caring agencies.

The growth of geriatrics as a new speciality has been a striking feature of the National Health Service in Britain. In the early days its development provoked strong resistance from general physicians some of whom felt that the claim to distinctive expertise was invalid and that the same basic clinical approaches should apply to all ages, but the geriatricians brought to the scene a heightened appreciation of the way in which an elderly person's functioning could be enhanced or handicapped according to the nature of their surroundings. Housing conditions and the availability of human help and company could tip the balance between self confident independence and the need for medical or other residential care. Eventually other physicians saw that geriatricians could help with the rational allocation of hospital resources.

The elderly were often discovered to have several different illnesses or 'pathologies', each needing careful definition and treatment. Mental confusion, for example, could be the first sign of an infection, eminently amenable to antibiotic therapy. The emerging ideas of rehabilitation were just as applicable to the elderly as to the young. The existence of geriatrics meant that medical care for the older generation became imbued with an air of optimism which grew with the steady recruitment of able young doctors, fired with the desire to carry out research and make tangible progress in their chosen specialism.

Alongside the post war changes in hospital medicine, of which geriatric medicine was ultimately to be a most beneficial expression, there had been evidence of unsatisfactory standards of existing welfare provisions for the old in residential institutions run by Public Assistance Authorities (Means and Smith, 1985).

The enforced evacuation of old people during the Second World War had been met by providing small voluntary hostels where conditions were less stringent and uncomfortable than in most of the vast, former poor-houses. The latter were increasingly unacceptable and the Nuffield Foundation, charged specifically in its Trust Deeds with 'the care and comfort of the aged person', instituted the first major survey of old peoples' homes, in 1943.

The subsequent Report was written by Rowntree in an admirable style (1947). It vividly described the austere conditions in which so many old people were then existing, either in sub-standard housing or in public assistance institutions. In view of subsequent concern over the poverty of the old it is notable that their material circumstances were not then judged by Rowntree to be notably deficient. It is interesting to note that the increasing proportion of old people in the population was already being conceptualised and referred to as a cause for alarm. In fact a stern public warning was issued, to the effect that, 'the change which is taking place in the age-distribution of the population will, in the not very distant future, result in so great a preponderance of those in the older age groups that, unless the able-bodied among them continue at work after they reach pensionable age, the burden of maintaining the aged may become so great as to result in a lowering of the national standard of living.' The idea of the aged as a burden was born.

The report commended an innovation, 'the local authorities' home-help scheme', a service which fell far short of demand. An experiment with 'mobile canteens' had also proved successful, but it was also limited by post war scarcities. Home nurses and physiotherapists were desirable but exceedingly rare supports. Local authorities taking over the former workhouses had, as noted already, 'inherited buildings which were imposing in exterior appearance but grim and unsuitable inside. They inherited also all the accumulated hatred of the Poor Law'.

Rowntree's committee described buildings of 'two or three storeys, reached by steep, narrow, stone staircases. Narrow wards—lit by windows that are too few and too high up—lead one from another, and they contain far too many beds, sometimes as many as a hundred, separated from each other by less than two feet. Often the only furniture is a chair for each

resident, although most local authorities endeavour to provide small lockers... Day rooms... are usually large and cheerless, with wooden windsor armchairs placed around the walls. Floors are mainly bare boards . . . In large urban areas such institutions may accommodate as many as 1500 residents of various types, including more than a thousand aged persons . . . it is impossible to avoid an impersonal atmosphere, with inflexible rules and unduly rigid discipline'. They admitted that some had been modernised and that a number of new buildings had been put up. The survey committee listed humane recommendations, such as reducing the size of bedrooms, redecorating and furnishing sitting rooms, permitting personal belongings, supplying wardrobes and chests of drawers, and providing newspapers, radio entertainments, and pocket money at least equivalent to what was then issued to old people in voluntary homes. And men and women should not be separated but should be allowed to meet.

Homes provided by a charitable organisation or run for private profit were much smaller. It was recommended that some system of inspection should be instituted in these places as well as in public institutions since the staff ratio could be dangerously low and fearful instances of exploitation and neglect were cited.

Seeing no alternative to institutional care for large numbers of the elderly the committee recommended that in future there should be four types of smaller local authority home. The smallest would be for 'normal old people', no longer able to live an independent life. Next would come medium sized institutions, for up to 200. 'Senile dementia' needed separate accommodation. In addition some general purpose institutions would be needed to house 'difficult' old people who would not mix with the residents of any of these places.

The medical sub-committee, which included Sir Aubrey Lewis and Dr J. H. Sheldon, appended their own observations. They called for more research into the ageing process. Sheldon had already pioneered investigations in Wolverhampton into the illnesses and nutritional state of old people, taking account of all their physical or mental disabilities and any personal or family difficulties. He had observed that, 'it was often impossible to converse with a patient who had been three or more years in

hospital, so obsessed was he with the fear of transfer to unknown conditions'

The gerontological research recommended by the doctors of that time was firmly grounded in basic physiology and clinical medicine, relating to the morphological, functional, and biochemical changes which might be found to accompany ageing. It constituted a counterpoint refrain to the predominant social themes of the Nuffield Foundation survey.

In their valuable account of the development of welfare services for elderly people Means and Smith quote numerous public protests in the late forties about the deplorable condition of the old institutions, prompting a Ministry of Health circular which called for smaller homes to be built and a loosening of the restrictive regimes which so often still prevailed (1985). All these recommendations had stemmed directly from the outspoken Nuffield survey findings. The National Old Peoples Welfare Committee was also influential at this time and reformers generally were able to move with the tide of enthusiasm for social justice which characterised the post-war Labour Government under Attlee.

A major change brought about by the war had been the increased paid employment of women, who might otherwise have been restricted to domestic work in their own or other's homes. The resulting shortage of help for certain households at times of crisis, such as the illness, absence, or childbirth of a mother, was sufficiently serious to merit some official response. Included in the list of households which might need help were those containing elderly people who were 'infirm' or where one old member of a couple feel ill. Sadly, in the ensuing prolonged discussions about the administration and financing of any such home help scheme, the needs of the frail elderly come to be accorded the lowest priority. Eventually local authorities, or the Womens Voluntary Service acting as their agents, began to appoint organisers of domestic help in the homes of deserving clients.

Meals on Wheels services had an equally slow gestation and originally relied heavily on voluntary organisations. The fact that many old people were found to be inadequately nourished shocked the public. Food rationing during the war had been fair and beneficial for most of the population, but solitary old people

had great difficulty in obtaining and cooking proper meals for themselves from their meagre single portions. Beveridge had warned that the state 'could never see to the rendering of all the services that are needed to make a good society' (1948). A rough distribution of responsibilities was recommended and reached, whereby central government supplied income maintainance and medical services while local authorities provided residential accommodation and the voluntary sector offered a variety of visits and creature comforts for those confined to institutions. There was the intention to organise practical domestic help and some meals for the frail elderly in their own homes, but always on the clear understanding that such help would only substitute for and not supplement, far less replace, the attentions of next of kin. In this way the foundation was firmly set for the continued concentration of the statutory authorities upon provision of residential care, whether this took place within hospitals, in former national assistance institutions or in smaller homes. It was of course always possible for a minority of the wealthy to make their own arrangements, either paying for scarce servants or choosing private homes, of possibly dubious quality, but the poor never had the chance of benefitting substantially from assistance in their own homes.

Even the Nuffield Report, which had demonstrated the desperate discomforts of many existing institutions, optimistically anticipated their early improvement and expected that, 'many old people will no doubt prefer to enter homes rather than continue living in unsatisfactory conditions in private houses'. Few were prepared to contemplate the systematic organisation of domiciliary services on a scale commensurate with need. Thus the frail elderly of slender means were still obliged to accept a 'last refuge' at public expense. The 1948 National Assistance Act had clearly charged local authorities with the duty of providing residential accommodation for those old people who were described as being in need of care and attention, but there was no suggestion that families would be freed from the primary obligation to look after the needs of their elderly relatives at home, if they lived anywhere within reach.

Although local health authorities had power to provide home nursing and home help services, (from whatever source) under the National Health Service Act of 1948 as time went on the demand for both these services outstripped the numbers of supporters which different health committees could supply. Means and Smith have discerned one excuse for the continued inadequate provision of domiciliary help, namely the suspicion that it might discourage families from giving support. In general the very sick and the very frail had a prior claim on public resources, but the expected first duty of relatives, friends, and voluntary organisation was always emphasised. In this way a rationing process could be applied, saving public funds. Even domiciliary help was not necessarily free, since individuals were expected to contribute according to their modest means. Eventually local authorities came to resent the provision of a free service to poor clients or those who were in receipt of National Assistance as they felt that they were effectively keeping some such people out of hospital and so saving the Health Ministry money. So this middle ground, so important for the old people who inhabited it, became a battlefield between local authorities and hospital authorities and contributed to the continued limits upon the numbers of home helps. Admittedly, domestic work in the houses of the old was not a glamorous prospect, though attempts were made to upgrade it and improve its image as a human service, by short introductory training courses, for instance.

In 1962 the National Assistance Act was amended, Local authorities could provide meals-on-wheels services directly. The service had been scanty and irregular and varied greatly from place to place. With the new legislation some authorities chose to provide the meals themselves while others still used voluntary organisation as their agencies. The service did expand but constituted only a relatively small contribution to the nutrition of the old, with meals on occasional weekdays but none at weekends. By 1968 the Health Services and Public Health Act effected a much more significant change in local authorities' powers and responsibilities. The overall welfare of elderly people was to be their responsibility but, within this, they were obliged to provide a home help service. It took until 1971 to implement these clauses, by which time social services departments has been established, following the Seebohm Report's recommendations.

During the 1950s welfare officers had concentrated their attention, as far as old people were concerned, upon visits to assess their suitability for residential accommodation. It was a momentous decision for someone who was about to leave the privacy of familiar surroundings and enter an unknown public institution for the remainder of their lives. Peter Townsend observed that overworked officials 'were inclined to encourage old people to accept the only firm solution to their problems that they had to offer. Frequently they failed to take the wishes and feelings of an elderly individual sufficiently into account; and they also failed to offer enough information about the practical consequences of taking up residence in an institution'.

Townsend's own classic survey, The Last Refuge (1962), financed by the Nuffield Foundation between 1957 and 1967, still stands as a graphic account of the grim conditions which then prevailed in England and Wales in old workhouses run by the local authorities and in some voluntary or private Homes. In an appendix to his study he made an early contribution to the subject of assessment of the ability to undertake self care, a matter which was by then beginning to be seen as very different from the straightforward application of medical diagnoses and criteria. He had begun his own book by asking 'Are long-stay institutions for old people necessary in our society?', and he noted that the Ministry of Health had stated in 1958 that the underlying principle of services for the old should be, 'the best place for old people is in their own homes, with help from the home services if need be'. We now know that resources within social service departments have continued, after thirty years to go predominantly into residential care (Quereshi and Walker, 1986).

The 1960s produced major changes and reforms in the organisation of local government, the National Health Service and the social services. The subject of social work training had been tackled by a working party set up in 1955 under Younghusband. The inclination then was to aim for a general purpose social worker, with a good basic education, who would hopefully replace the many different types of officer then engaged with a range of clients. Individuals or families with special needs were judged by the Younghusband Report to merit the skills of a range of workers, from welfare assistants, who simply learned

'on the job', to highly trained professional case workers (1959). Means and Smith have noted that work with elderly people soon came to be relegated to welfare assistants and that no detailed consideration was given to the nature of the task of assessment, determining possible residential admission (1985).

The Seebohm Committee began by acknowledging the needs of the elderly, but the major effect of its 1968 Report was to influence the form and content of the Local Social Services Act of 1970. This Act revolutionised the organisation and administration of social work. New departments were created in each authority, entirely separate from the local health service. The two branches of personal care were thus decisively and dramatically divorced. The move was prompted by strong pressure to provide comprehensive 'family services' stemming from one clear social work source. Such a move was understandably resisted by medical officers of health, but their power had long been on the wane.

The decision made at that time was to effect a demarcation of work in terms of the professional skills of the new breed of social workers on the one hand and medical and nursing staff on the other. The guiding principle was not the consideration of clients' needs. A development brought about ostensibly in the interests of uniting the branches of social work, so that 'families' would be served from one common source, had the associated but by no means unintended consequences of setting social workers clearly apart from their medical and nursing counterparts. In essence what was achieved was a clear division between the respective territories of rival professions. Their elderly clients or patients would thereafter be viewed in terms of their social work or their medical and nursing needs, however bewildering or arbitrary this severance might feel to the subjects of such divided attentions.

The reorganisation of the health services which occurred shortly thereafter meant that a medical presence was finally removed from local authorities. Former medical officers of health were metamorphosed into community medicine specialists or community physicians and became the salaried employees of health authorities. The community nurses came under the jurisdiction of the chief administrative nursing officers of these same quangos. The latter development was evidence of the

increasing strength and autonomy of the nursing profession and of their growing acquisition of management skills, which then conferred status and career advancement. General practitioners continued as independent contractors. The ensuing division, between environmental health officers in local authorities and community medicine doctors at Health Board level, has been brilliantly analysed by Jane Lewis in a comprehensive and damning description of this entire process (1986). Health authorities would thereafter concentrate by far their greatest emphasis and their financial resources upon the provision and management of the hospital services. The division between health and welfare at the consumers' level was complete.

3

Community care: the growth of an idea

The CONCEPT OF COMMUNITY CARE FOR DEPENDENT people has underlain public policies for thirty years and generated an immense literature. It was first raised in relation to patients with chronic mental illness for whom large institutions came to seem both unsuitable and costly, but it is now the accepted best solution for the elderly, most of whom have always been sustained at home. They need assistance of many kinds, health and social services, housing, education, and transport. Social security is often vital once paid employment is over. However, the precise meaning of the term community care has proved elusive. Kathleen Jones put it well:

To the politician, 'community care' is a useful piece of rhetoric; to the sociologist, it is a stick to beat institutional care with; to the civil servant, it is a cheap alternative to institutional care which can be passed to the local authorities for action—or inaction; to the visionary, it is a dream of a new society in which people really do care; to social service departments, it is a nightmare of heightened public expectations and inadequate resources to meet them (1978).

The Chief Medical Officer later bemoaned less elegantly the semantic confusion which this seductive phrase had encouraged.

The word community could imply widely different settings and situations depending upon one's point of view. To NHS hospital staff the community had come to mean anywhere other than hospital. So it included both publically funded and private residential care. But the local authorities with responsibility for providing residential accommodation for the elderly limited the term community to the old people's own homes, from which they might have to be transferred and where their relatives might still live (Acheson, 1985). In Acheson's opinion the notion of 'community' had come to assume 'an ethos of virtue', and the assumption was wrongly made that it must invariably and inevitably be more beneficial for a chronically ill or incapacitated person to live somewhere other than in an institution. He believed it would be better to settle for describing precisely the type of care intended and to avoid the use of the confusing words entirely.

Abrams had earlier employed a very narrow definition of community care to argue his case: 'a matter of provision of help, support and protection to others by lay members of societies acting in everyday domestic and occupational settings' (1977). He believed that such care was both 'uncommon and improbable in our type of society'. Considering that such care was spontaneous he examined the factors necessary for its development. 'Resources and trust... and the incidence of... 'critical life situations' within any given network' were identified as the crucial variables. Abrams believed that community care in Britain was not based on a geographical community but upon kinship, religion, and race, with proximity being a special reason for care.

From this basis he went on to advocate a policy which recognised the needs of carers and for research which would determine the appropriate forms of such care, since such an approach might be as important as further research on the needs of the primary-client groups. He also advocated further studies into the use of 'therapeutic communities'—small communities constructed and contrived deliberately for people living together. His eventual conclusion was that 'if community care, in the sense of an integration of professional services with localised aid-networks based on extensive reciprocity, is to become a serious dimension of social policy, proximity must

clearly be given a stronger meaning than that... of a passive resource'.

Probably the first official use of the debatable phrase was in the Report of the Royal Commission on Mental Illness and Mental Deficiency (1957) where it referred to the arrangements for care and aftercare of mental illness and mental defectiveness which local authorities could already make under the 1946 National Health Service Act. However, the general assumption prior to the 1959 Mental Health Act had been that statutory authorities should concentrate their efforts upon providing hospitals. Consequently Enoch Powell, Minister of Health in 1961, caused a stir when he declared the intention of running down and closing most long-stay mental hospitals. This move was connected with the plans to develop district general hospitals to provide treatment for acute illness for defined populations throughout the entire country. Now the phrase 'Community Care' appeared in the text of the 1962 Hospital Plan and, even more explicitly, in Health and Welfare: the Development of Community Care (1963). Geriatric patients were to be included in these bright new plans. However, Jones cynically observed at the time that they were likely to represent little more than pious expressions of hope since it was actually the local authorities who were left with the key decisions regarding the practical arrangements outside of hospitals for any of the affected groups of dependent people.

Local authorities have since jealously guarded their autonomy and have resented suggestions as to how they ought to spend the rate support grant. Earmarked grants are anathema to them, as Hunter and Wistow, considering Community Care in Britain in an important 1987 Kings Fund publication, demonstrated when they looked at the variations on official central government policy which had by then been manifested in different parts of the country. Scotland, they noted, had never taken as enthusiastically to community care policy as England or Wales. Although this case study in political diversity happened to be focussed on the mentally handicapped the key conclusions are certainly applicable to any kind of community care, depending as it does upon compromise and collaboration or upon joint funding arranged between health and local authorities.

Community care may have by now become a familiar short-hand term, but it has never been clearly defined in key legislation. As Bulmer (1987) has said, 'The challenge has simply been avoided... there is a tendency to focus on the form rather than the substance of provision... by trying to improve co-ordination between services... rather than putting more resources into domiciliary care'. Behind repeated attempts to circumvent or subdivide an issue which involves several kinds of clients with very similar needs lay, 'the deep seated professional and organisational divide between the health and personal social services'. Webb and Wistow also emphasised this vital key to much failure in the field (1982).

The development of an ideal of community care as opposed to institutionalisation had brought the ideas of medical sociologists conveniently to the aid of hard headed planners bent upon saving public money. In the 1960s Erving Goffman had produced his famous definition of a Total Institution: 'A place of residence and work where a large number of like-situated individuals, cut-off from the wider society for an appreciable period of time, together live an enclosed, formally administered round of life'. From his personal observations as a worker in a large American mental hospital, he described in vivid terms the tightly scheduled regime, with inmates carrying out the otherwise dispersed activities of daily life in batches or packages, conveniently moulded to accord with the official aims of the institution and ease the work of staff. Such characteristics, Goffmann recognised and argued, were common to many other forms of enforced communual living, including prisons and the armed forces. A whole generation of intending social and 'community' workers avidly absorbed his arresting accounts and analyses which were supplemented later by more prosaic accounts of many similar situations. Eventually even medical students and doctors, ordinarily immune to sociological considerations, might encounter the medicalised notion of 'institutional neurosis'.

The conscience of the public was successively pricked by news of apparent neglect or actual cruelty within hospitals and long stay homes. Public inquiries followed, reassuringly allaying concern until the next scandal hit the headlines. The notion of an asylum as a place where the vulnerable might find a safe haven had been effectively discredited. This whole process has since been well documented, notably by Fred Martin in his detailed analysis of developments between two Mental Health Acts (1984). The two volume Wagner Report on residential care, A Positive Choice, devoted a valuable chapter in the first volume to the historical background to community care (1988). A profound change in public and official perceptions of appropriate care for the mentally frail was brought about and cost counting considerations were conveniently supported by the sense of what patients deserved. At the same time psychiatrists were encouraged to believe that, with superior new drugs, they could now control anti-social behaviour more easily than by the physical restraints used in the past.

Initially questions of need and demand were seriously debated and there was a genuine concern for equity in public service provisions for dependent individuals. Inequalities were deplored and providers dared to wonder whether the coverage they were currently providing was adequate. A focus of this kind was explicitly encouraged by government funded research, an example being Gruer's careful study of the needs of the elderly in the Scottish Borders (1975). One of her main conclusions was that it was the GP who was best placed to recognise elderly peoples' need. She had costed different levels of screening, but she judged that even to screen all the over 75s who were designated as 'at risk' groups might still leave half of their needs undetected.

Bringing the needs of the elderly to the attention this time of the local authority was the objective of a project by Chapman in central London (1979), quoted in one of the valuable Aberdeen Research Highlights in Social Work on developing services for the elderly (1982). The simple point was made that any elderly person had first to recognise that they were in some kind of difficulty, then feel that they needed outside help and, finally, know where and how they might obtain it. All kinds of factors could intervene to prevent the right sort of help reaching those most in need of it.

Another often quoted investigation in the same context was Hunt's study of the elderly at home (1978). This was intended 'to increase the chances that health and social services... used heavily by the elderly... could be deployed to the best effect...

in a time of stringency'. The conclusion was that some vulnerable groups were not receiving as many visits or visitors as seemed desirable. Even among the bedfast and housebound less than one-third had seen a doctor as often as once a month, only just over one-fifth had seen a health visitor during the previous six months and over one-third had seen a district nurse. Although home helps did seem to be going to those in greatest need (as defined by age over 85, living alone and being bedfast or housebound), yet a majority in each of these groups did not enjoy any such assistance. These studies are selected examples of an undercurrent of investigations which kept alive the client's perspective. The political climate was soon to be dominated by managerial and macro-economic considerations.

In the 1970s Kathleen Jones had wisely insisted that the important question ought to be 'what kind of care for what kind of patient in what kind of circumstances' (1978). The hospital should simply be included as one of many community resources. It was not helpful to think of community or home based care as being quite separate from care in a hospital, in a local authority residential establishment, or in a privately run Home. The same point had been made by Bayley who had originally marked the distinction by a catch phrase, 'care in the community versus care by the community', which would shortly prove useful to policy setters (1973). He had envisaged a pattern of services for the mentally handicapped, using whatever means were available, including family, friends, neighbours, voluntary organisations, and any statutory services. Approving his admirably catholic vision, Jones expanded it into a new view of social work saying, 'It broadens the concept of community care... making new demands on the social worker, whose tasks may consist more in constructing a support system than in offering personal insights in the case work tradition'. She was in effect describing some of the roles of a care manager, who has subsequently been envisaged as a new saviour to devise means of meeting the diverse and divided needs of the frail elderly.

The original disapproval of long-term hospital care for the mentally ill and handicapped had been easily transferred, as far as government policies were concerned, to the care of the elderly and, by 1981, this was expressed in no less than three DHSS publications, namely Care in the Community, Care in Action

and Growing Older. The pressure to keep old people out of costly acute hospital or to discharge them quickly after admission would not, however, imply any large transfer of resources from health service institutions to local authority domiciliary services. On the contrary, by the time of the White Paper, Growing Older, it was firmly stated that 'care in the community... must mean care by the community'. A subtle change in emphasis had occurred with the government now evidently intimating a judicious distancing of the statutory services from what was to be seen as community care. Calculations henceforth would mainly be made in terms of the effectiveness and efficiency of services and about the importance of establishing appropriate balances of care. Meanwhile informal carers, mainly family members, were unquestionably designated as those with the primary and continuing responsibility for old people outside of institutions.

The idea of joint planning arose in 1974, when simultaneous reorganisations of the NHS and of local government were brought about. Thereafter it came to be perceived as an adjunct to the new, divergent administrative arrangements. Interservice collaboration was piously stressed at the very point when health and social services were effectively being torn apart and, over the next ten years, repeated attempts were made to disguise or cover the rift. Hunter and Wistow have made a valuable analysis of the process (1987).

Initially attention was fixed upon the need to ensure coterminosity of boundaries of the health and local authorities. First, the authorities in England and Wales were placed under a legal obligation to co-operate with each other. Second, they were required to establish joint consultative committees (JCC's) to give advice on their duties and on the planning and operation of services. Thereafter, detailed guidance on 'effective joint planning' was issued to them at intervals. The process was said to be vital to the government's overall strategy of developing community based services, so that people could be kept out of hospital and other institutions and supported within the community. At this point the means to implement specific plans was an earmarked financial allocation, joint finance. However, the operation of this scheme was not mentioned and it was left to individual local authorities to employ this mechanism, or not, in

whatever way they choose. When re-organisation of the NHS in 1981 abolished the area levels for health authorities in England and Wales, the relevant health and social service departments ceased, in most parts of the country, to be coterminous with each other. Yet the DHSS was still placing emphasis on the importance of joint planning for community care (DHSS 1981 and 1983).

Hunter and Wistow concluded that, by 1982, although substantial formal planning machinery had been set up, 'there was widespread agreement that such machinery had failed to deliver the goods ... (it was) based on unrealistic and over-optimistic assumptions about the possibility of developing comprehensive rational planning processes across agency boundaries ... Joint Consultative Committees tended to be talking shops... Improved relationships should not be equated with effective joint planning'. In fact joint planning had turned out to amount to no more than 'parallel planning'. Most joint projects were joint only in name, being actually social service schemes which it had been necessary to process through the joint planning machinery as the only way of obtaining funding. The commentators were profoundly sceptical of the power of 'enabling structures' to effect change on their own. It was always necessary to take account of other factors, such as existing differences in financial resources and in service stocks and, equally significantly, the differing professional viewpoints and personalities involved in these exercises.

In 1985, a DHSS Joint Working Party Report was confidently entitled, *Progress in Partnership*. Paradoxically this review had been carried out precisely because of the deep sense of frustration and lack of progress in regard to the policies of the previous decade. The report acknowledged that progress could not be guaranteed by the approach which had so far been recommended and suggested, 'where genuine joint planning turns out to be achievable it may have to be accepted that one of the authorities concerned should take the lead responsibility for developing services for a particular group'. In this belated recognition of failure they seemed to be foreshadowing what Griffiths would say in 1988. But Sir Roy Griffiths was only brought in to undertake a review of community care policy in late 1986, after two important Audit Commission Reports had impressed the

government with the need to organise these matters more sensibly and economically. As these reports themselves represented comprehensive reviews of the field, they will now be examined in some detail.

Managing Social Services for the Elderly More Efficiently (1985), the first Audit Commission Report, was meant to help social service departments of local authorities decide:

- 1. How much residential care and community services should be provided locally, in view of likely demographic changes and the expansion of private services.
- 2. Whether clients were presently receiving the most appropriate care; in particular, were clients in residential care when it would be better, and cheaper, to have them supported in the community.
- 3. Whether existing services were being managed as effectively, efficiently and economically as possible.

The whole tone of the Report represented what Davies has called 'focussed managerialism' (1986), the assumption being that improvements in efficiency alone would generate enough money to provide the desired future levels of care without any additional funding. The Report began by covering familiar ground regarding the growing elderly population. By 1991 there would be an estimated increase of 15 per cent in the over 75s and of 30 per cent in the over 85s. Two per cent of the population over 65 were at the time using 55 per cent of local authority expenditure for the elderly, in residential care, whilst 13 per cent of old people were receiving community care, amounting to 45 per cent of LA expenditure. This clearly indicated, if incidentally to the Report's purposes, that over 85 per cent of people over the age of 65 were not in receipt of any kind of local services.

Looking at information from a limited sample of local authorities, the metropolitan boroughs, two minor shire counties and ten more LAs, supplemented with a review of national data and questionnaires to a further 25 LAs, the Commissioners came up with three main initiatives. These corresponded closely to their general aims considering, first, how much residential accommodation should be provided; second, how to minimise the need for residential care; third, how to improve value for money in existing services.

As far as minimising the need for residential care was concerned they cautioned,

Given that care in the community is better for many less dependent clients and generally more economic on a per client basis... authorities will want to ensure that long-stay residential care is provided for those that cannot be sustained in the community and only for those who would not benefit from other methods of support.

They also hoped that authorities would take steps to ensure that the levels of community care provision were sufficient to prevent 'unnecessary admissions' to residential care.

They advised LAs to try and discover the characteristics of the elderly outside hospitals who 'really needed' residential home places as compared with others who 'could manage with alternatives which can be arranged in the community'. They went further, asking for estimates to be made, not only of how many fell into different categories now but how the authorities foresaw the situation and numbers would change in the next five years.

Suggestions were given for categorising people according to three levels of physical disability, very severe, severe, and moderate. With regard to the worst group of old people, who were bedfast, chairfast or could not feed themselves unaided, the Commissioners acknowledged that:

most of the professionals contacted felt that the majority of elderly people with very severe physical disability require the type of twenty-four hour nursing care which is found in hospital....

Nevertheless the Commissioners asked LAs to consider whether more of even this group could be cared for instead in local authority residential homes, possibly with some nursing support. On the other hand, they stated that LAs should see whether the very severely physically disabled still living in the community were in fact receiving an adequate level of care, and whether their relatives had enough support. Their own research indicated that 4 people with very severe physical disability per 1000 elderly were in fact living outside like this, and they might need more services than they were getting. They specified that

co-ordinated 'packages of care', including nursing care as well as LA domiciliary services, would need to be devised for individual clients. Regarding the circumstances of the next category, those with severe physical disability, apparently over half of them were in the community, with little or no support. Some were in unsuitable residential homes, which needed structural upgrading. Others would prefer to remain in their own home. Again the home provision of 'appropriate packages of care' for them was recommended.

It was acknowledged that a particularly neglected group were represented by the elderly mentally ill who also had severe physical disability and behaviour disorders or who were suffering from profound dementia. These people were frankly acknowledged to be deprived of the care they merited. Policies in regard to these unfortunate were often muddled or totally absent. Psychiatrists, other medical professionals, including geriatricians, and social workers were all liable conveniently to conclude that such patients were someone else's responsibility. It was accepted that dementia could require constant supervision which, in the absence of family or friends, might ultimately be available only in hospital or in residential care. No solution was offered in the report. The area was simply designated as one which did demand attention.

This left the third group of disabled elderly, those with a moderate degree of physical disability. Only a minority of these should be in residential care since community care was both cheaper and better.

The Commissioners provided advice on how to go about deciding the probable size of these different categories of disabled old people in any particular locality. They supplemented their own study findings, from a limited number of local authorities, with other data and with calculations derived from previous DHSS research employing an approach popular since 1981, termed the Balance of Care, the details of which are available in an Appendix to the Report. It is worth noting that the tentativeness of some of the estimates entailed in the use of these methods was freely admitted.

All this section of the 1985 Audit Commission Report was in effect concerned with recommendations for sorting, classifying, and re-classifying the dependent elderly in the attempt to avoid having square old pegs put into round holes. The classification was evidently seen as a responsibility of local authorities, not of doctors.

In 1985, local authorities were recommended to 'develop and maintain explicit statements of the factors which will normally warrant admission of a person with only moderate disability'. The rationing and rationalisation of placements so as to make the best use of public funds was to be effected by applying strict criteria for eligibility. The policy was not the same as for the mentally ill and handicapped, whose long-term accommodation would rapidly close, obliging them to move outside. The plans for the elderly in future were intended to achieve a better match between need for and provision of public residential places to which the most infirm might lay claim.

The other side of the picture of care supplied by local authorities should be support in the community. However, many authorities had themselves concluded that it was not sufficient simply to expect home helps and meals on wheels to provide an appropriate alternative to residential care,' more intensive support, in "packages" specially designed to meet the needs of the moderately disabled elderly person, will be needed'.

The Commission proceeded to rank local authorities according to the amount they were currently spending on community services. Some places were spending twice as much per elderly person on those acknowledged to be in a High Public Service Dependency Group (HPSD) than was the case in other authorities. These were old people with very severe or severe physical disability, or with only moderate physical disability but little or no support from friends or relatives. The Report tied itself into knots in trying to be dogmatic about the advantages and disadvantages of providing social service support. Thus they approved those authorities who spent at a relatively low level because, 'the provision of social services to some elderly people has the effect of mobilising support from friends, relatives, and the voluntary sector, so keeping them in the low public sector dependency group-rather than persuading them that their efforts are not longer necessary'. In the eyes of officialdom an extremely delicate balance existed. There was always a danger that 'too much' support for old people might make some relatives act irresponsibly towards them and cast them completely upon the state, so it was confidently affirmed that 'most people who need personal care but have support from friends and relatives can manage without social service provision'.

However, a more disturbing discovery for the Commission was the evidence that some authorities were spending considerably above the average on community services. The authorities in question justified it on the grounds that they believed it was adding to the quality of the elderly person's life. This, in the opinion of the Commission, was a specious argument. They remonstrated authorities of this sort, saying they should 'clarify their purpose in providing these services ... If authorities are to be satisfied that community services are delaying the requirement for more intensive services, it needs to be demonstrated that community care significantly delays the process of becoming more dependent... and no direct evidence was presented to the study'. The Commissioners became positively pedantic on this point, 'It would be necessary to show that authorities were able to select, from the 90 per cent of elderly in the low public sector dependency group, those who were likely to become more highly dependent and were able to concentrate resources on this small group'. They were extremely dubious about the possibility of ever being able to identify the high risk individuals.

On the other hand, as far as the otherwise laudable low spending authorities were concerned, a modicum of caution was required and, 'they should review what steps are taken to avoid "high risk situations" occurring in the community'. By this phrase they may have meant old people suffering illness or accident whilst alone and without the prospect of any official visitor to save them. The only recommendation was that such authorities should 'cultivate local contacts with other organisations'.

The official line was to disapprove of those local authorities who provided more per elderly person per year than what had been worked out as the 1987 'low expenditure reference point'. Such authorities were encouraged to 'focus a reduced amount of community services so that additional support from friends and relatives can be mobilised'. In other words, actually removing supportive services ought to impel lazy or neglectful families to fill the void.

The report also touched upon alternatives to ordinary housing or residential care, in particular very sheltered housing. This required the co-operation of social service departments and housing departments, often with some NHS input. Again the key question arose as to whether the tenants in such schemes were at present the right people, with the most physical disability and dependency.

Only one paragraph was given to the matter of support for 'informal carers'. The Commissioners very pertinently noted that, 'often carers receive no help from the formal sector even though they may be saving their fellow citizens directly over £3000 a year for every elderly person looked after, assuming that the alternative is local authority residential care. Quite apart from the equity considerations involved, it makes obvious sense for these carers to be supported so that they can continue to carry out their current role'.

The circumstances of carers had already been the subject of a DHSS publication in 1984 on Fifty Styles of Caring, in which their rights had then been sympathetically enumerated as: time off for themselves, priority in receiving services and consultation in policy making, some training in caring and counselling, and choice over the type of support provided. It was appreciated that carers often urgently needed any services which might be available to their dependent relatives as well as information about where to try and obtain them. Health and social service workers ought to identify carers and support them or refer them to an appropriate organisation and they should encourage self help groups amongst them.

This Audit Commission Report touched briefly on a matter which was soon to receive more concentrated attention, namely the increasing number of old people in private residential homes. Little or nothing was known about the kind of people entering them. It was fancied that these homes might be inclined to take the rather less disabled old people who might subsequently become the responsibility of local authorities when they became more dependent. Uncertainty about the total provision of places made decisions over any conceivable increases in public accommodation very difficult and offered a partial excuse for inaction.

Much of the Report was about suggestions for improving the efficiency of community services, in the form of home helps,

day care and meals-on-wheels. Once again the approach chosen was to compare current home help expenditure and types of help provided in a range of authorities. There were great differences in objectives, assessment and allocation procedures, travelling times and the hours per week per client. Meals-on-wheels provision came from different sources, and might either be controlled directly by the home help organiser or else be mainly managed by volunteers. Since this 'service' was so sparse, only amounting to two or three meals a week, it could scarcely be supplying basic nutritional needs and authorities were advised to ensure that existing clients were being fed somehow on the lean days.

Finally the role of wardens in 'conventional sheltered housing' was raised. This kind of housing was purpose built for the elderly, consisting of flats grouped in a 'scheme' and with some contact with either a resident or peripatetic warden. Social service departments were told they should re-examine their procedures for allocating old people to such accommodation and should make sure that social service departments had sufficient say in the choice, training, and role specifications of wardens.

The conclusions of the 1985 Report consisted of advice to local authorities on how they should enumerate their present provision for the elderly, both in residential care and outside in the community, before asking themselves whether the level of existing community expenditure was adequate to prevent unnecessary or premature admission of clients to scarce and costly residential care. Clearly this was an extremely difficult question to answer and one which could only be partially addressed by looking at the kind of people who were presently in the community or in residential care in terms of their varying degree of disability. Authorities were faced with the living consequences of many past allocations and the priorities employed by any number of people who had previously made decisions about whether to admit some old person or to send home helps or meals to another.

The Commissioners were intent upon ensuring value for money and wished to have an assurance that the expenditure would be targeted upon the sort of people whom the local authority considered were entitled to have a priority call on its resources. In this respect they were to act very like former Poor Law Commissioners.

Time and again the Commissioners returned to the comforting theme of the limitless underlying sea of informal, unpaid support. Everything should be done to 'analyse and quantify the extent to which they could encourage support from friends, relatives and the voluntary sector—and thus reduce the requirement for services'. Misplaced cash was deplored, in so far as over a third of expenditure on community care, namely £100m per annum nationally, was apparently being spent on services for the less dependent. In their evident zeal for Victorian values they seem to have assumed an average Victorian size of family.

Bleddyn Davies has attacked the philosophy of the new managerialism which lay behind this report, with its constant refrain of inefficiency at the expense of inequity (1986). The 1985 Commission Report started from the assumption that those who must be getting the services were consuming more than they deserved, whereas formerly it had been perfectly acceptable to ask whether the overall coverage of services was adequate. Davies noted that it was said that there was 50 per cent inefficiency in the home help service with support going to the 'wrong people' and being both inflexible and inappropriate. He himself had applied figures nationally in 1980, using more appropriate definitions of target groups, and had come to the conclusion that the 'vertical target efficiency' of the home help service was then 75 per cent. Such calculations about how existing resources were disposed took, he maintained, no account of 'horizontal target efficiency' or the extent of unmet need for such services in the wider community. At the time of Davies' research the existing level of home help provision could meet only 50 per cent of existing need as defined by the targeting criteria (see also Gruer, p. 31 above).

He made the point that targeting of necessity involves a difficult and complex situation. Services are all potentially substitutable and informal care could easily be a substitute for any or all of the others. By their very nature, the sort of tasks involved in looking after disabled old people did not require high technology plant and equipment or arcane skills derived from long training. What the research so far had certainly not suggested was that a shortage of service provision of one sort (e.g. residential) was being made up for by high provision of community services. In either setting, with shortages of one or

another variety of formal public provision, it was possible to anticipate about the same basic underlying level of potential informal caring. He had found little variation between neighbourhoods of different geographical characteristics when it came to mobilising informal support. Davies concluded that the arguments of the new managerialists were valid but partial. Their arguments were excessively focussed upon the nature of existing inefficiencies and upon structural prescriptions for their reduction. Far too little account was taken of equity and of the multiple causal processes operating at field level.

Davies went on to offer his own prescription, which would improve the range of choices available to old people and match their increased expectations and improved standards of living. He deplored the 'enforced pauperisation' which was presently the fate of many who had to survive for a substantial period of time without any significant level of care. This was leading to the creation of a ghetto of grossly inadequate state services, consumed only by the poor. Davies' favoured suggestion was the creation of British-Social-Care-Maintenance-Organisations (BRITSMO), which would extend the range of sources from which long-term care could be financed by introducing insurance for those who could afford it (Davies and Goddard, 1987). Such organisations would act as brokers of both supply and finance in respect of long-term social care.

The subsequent 1986 Audit Commission Report, Making a Reality of Community Care, was a different kind of document from its predecessor. It escaped an excessively narrow managerial focus and, although it had naturally been prompted by a concern for the correct use of public funds, it provided a comprehensive and well written analysis of the existing obstacles to actually achieving adequate community care for those elderly, mentally ill or mentally or physically handicapped people who were increasingly being denied the protection of a hospital environment. The trend over the previous years had been to reduce long-term hospital places and to extol the advantages of life 'in the community', but it was proving considerably easier to run down NHS institutions than to build up alternative support systems to receive those who were discharged or to provide for those vulnerable and dependent individuals who might justifiably wish to gain entry to a diminishing hospital sector.

This report was prompted by the realisation that policies favouring community care were now being thwarted by the mushrooming growth of private residental homes. These had become profitable enterprises because a certain proportion of residents could receive help with their fees from Supplementary Benefits, amounting to some £500m a year. It is illuminating to find how, as hospital doors closed, the doors of homes and private nursing homes had conveniently opened. Many of these places were being paid for by the DHSS, but from the open ended, social security side not from the cost-limited health service budget. These anomalies applied to all three 'priority groups', the elderly, the mentally ill, and the mentally handicapped.

Private residential care for elderly people, who were conceivably less disabled than some of those admitted to local authority homes, was being positively encouraged by the availability of Supplementary Benefit payments. The Wagner Report expressed it clearly, 'The critical feature of the market for independent and residential homes . . . is that the social security system is a third party payer which alters the price of care to zero for a large segment of the population of potential consumers... (it provides) indefinite payment at set rates for all who obtain a place and are eligible because of low income and assets. This... also reduces the price of private residential care compared with home care for those eligible for Supplementary Benefit. The effect is to create a perverse incentive which encourages residential and not community based care. This is particularly the case if persons are not eligible for Attendance Allowance and if they are without a carer who can claim Invalid Care Allowance' (1988).

Local authorities had been repeatedly urged to produce arrangements for community care to make up for the run down of health facilities. But there were strong disincentives operating to prevent this happening. If they did use the joint finance arrangements they would only benefit for a few years before having to bear the full cost themselves. If they invested in any innovative community care plans, however primarily financed in the first instance, they would be liable to be penalised by having their rate support grant cut, as central government was not set upon limiting expenditures by local government.

The possibility of money being available for transfer from health authorities was small. In those areas where the RAWP (Resource Allocation Working Party) formulae operated to designate a poor health area as deserving extra funds, some resources might be shifted to local authorities. But the richer authorities would have all their monies locked up and most would be extremely disinclined to cut down their own health services in order to pass money over to local authorities to spend.

It was thus highly convenient for both health and local authorities to be able to save by tapping supplementary benefits for the board and lodging of poorer people who would otherwise have become a drain on local resources raised from rates. The Commissioners deplored the 'distorting effect' which this was having as it meant that types of private residential care qualifying for this kind of support were being preferred to the alternative of cheaper and, supposedly, better alternative community support. Their concern could only be viewed as theoretical, however, in view of the fact that the choice of such desirable community provisions was not actually on offer in anything like the volume required.

Domiciliary services had been struggling to keep pace with demographic trends over a period when beds in geriatric hospitals and places in LA residential homes had diminished. An extraordinary anomaly had been allowed to develop whereby two parts of one government department were apparently working against one another. Community care policies, encouraged by the NHS, were being vitiated by Social Security.

The expansion of private facilities to offset the decline in places provided by the public services had occurred in a totally unplanned fashion, in response to market forces and demands which were apparently stronger in some parts of the country than in others. The Report demonstrated clearly that the take up of Supplementary Benefits payments was not evenly distributed throughout England and Wales but was markedly higher in the South West and along the South coast. The seaside areas in proximity to the more prosperous parts of the country were offering more places in private and voluntary homes. These were areas chosen by many older people for their retirement. Subsequently, as their health and independence declined, they needed full-time care.

The availability of such residential accommodation might bear little relation, however, to the estimated needs for care per person over 75 in a particular locality. The effect was thus regarded as doubly perverse, in that it was working against the express policies for community care whilst not necessarily providing residential places for the people who most required it. What had happened was 'a shift from old, remote long-stay hospitals to new long-stay residential homes, missing out a wider range of more flexible, more cost-effective forms of community care on the way'.

Private homes were by no means all satisfactory. Because of their uneven distribution, they might be inconveniently distant from where old peoples' relatives lived. Standards of service could vary markedly. Meanwhile old people in some places might have neither adequate community services nor the opportunity of a place in any type of home.

The Commission summarised the underlying problems as follows:

- (i) The total amount of money then being spent (for all potential clients of community care) was in the region of £6b a year. This sum should be ample to provide greatly improved community services, but a suitable method of distributing the available finance had not so far been devised.
- (ii) For a successful transition to community care to take place both time and bridging finance were required, since hospitals were not suddenly shut and the staff summarily dismissed. As the process went on those who were discharged required supporting structures to be constructed to receive them. In other words, any change of this nature would be bound to cost money initially, whilst services ran in parallel.
- (iii) A fragmented organisational structure, at every level, was meanwhile causing delays and difficulties and failing to respond to the shifts in policy.
- (iv) Arrangements had not been made to retrain the hospital staff whose former services would no longer be required, nor had the implications of recruiting the additional staff needed in the community been faced.

The Report dealt with these aspects in detail, effectively disposing of the idea that community care could ever be easily standardised and costed. The Commissioners were cautious of

commenting on the adequacy of the total level of funding for different groups. This was partly because what might constitute the 'right' mode of care for different people with varying levels of dependency would always involve value judgements, and the provision of a range of choices was likely to be costly. They also firmly refused to be drawn into political judgements about whether or not enough total funding was being provided. They did, however, stress the anomalies of the situation, whereby an increase of community expenditure by a local authority could lead directly to subsequent reduction in the level of its rate support grant. Health authority plans and spending and their entitlement to aggregated funds under the RAWP formula meanwhile took place entirely separately from local authority plans for social services spending.

The position was summed up as follows: 'In recent years the Government has been restraining local authority spending in total in accordance with its public expenditure policies. At the same time community care polices are being endorsed that require an expansion of social services spending. Because community care policies require a shift in expenditure from health rather than any increase in public sector expenditure, there should be no conflict of interest. In practice such a shift would require complex adjustments. Thus, in order to promote social services expenditure the government would have to build in a higher priority for social services by raising personal social services GRE (Grant Related Expenditure) totals by a higher proportion than for other services, or by introducing specific grants... To date, neither mechanism has been used and no additional provision has been made for local authority community services. In fact, attempts by many local authorities to increase expenditure to fund community care on their own initiative have been heavily penalised by loss of grant'.

In the later parts of this report there was a valuable discussion of the extreme complexity of community services, with responsibility and accountability between different parts of the NHS and within local government, not to mention the voluntary sector. There was no incentive for the different organisations and professions to co-operate. Structural problems abounded at every level, national, regional, and local. Operational planning for community care of the elderly could involve any or all of the

following: doctors (both GPs and consultants); nurses (district nurses, practice nurses and health visitors); social workers (field, day and residential); home care organisers; occupational therapists; physiotherapists; chiropodists; psychologists; housing managers (and wardens of sheltered housing); social security officers. Each of these had a different background, training, perspective and roles. Moreover, most care professionals expected to function as completely independent practitioners and did not envisage being part of any new hierarchy or bureaucracy. So professional fragmentation operated to make effective community care exceedingly difficult to achieve since the idea of the integration of local services ran directly contrary to existing professional and bureaucratic pressures. Whilst professionals were by no means united behind community care policies, bureaucrats were specifically trained to maintain and protect existing systems rather than to change them. Managers, in both health and social services, were complimented for keeping their costs down, not for introducing new services. Staff, for their part, were deeply worried by the prospect of change unless retraining schemes were provided, since their future livelihood would be threatened. All these groups had an interest in resisting change.

Ever since the introduction of the Seebohm recommendations and the division between health and welfare in the early seventies the focus had been on services rather than on clients. Unlike clients and patients, service personnel were organised and clearly identifiable and featured on pay rolls. Meanwhile 'decisions about different services for the same clients were being taken in different agencies and might have to be referred upward through different professional hierarchies'.

The Report found that these deplorable divisions had resulted in both gaps and overlaps. A suggested solution might be a single budget and a single manager for each care group. For example, for elderly people a single budget in an area could be established by contributions from both NHS and local authorities. The resulting overall budget should then be under the control of a single manager who would purchase, from whatever public or private agency she or he saw fit, the appropriate services for elderly people in that area.

The Report closed by calling for an early high level review of the entire field, the main focus of which should be:

- 1. To examine how to transfer resources speedily from NHS to local authorities.
- 2. The removal of financial penalties to local authorities who wished to provide community care.
- 3. An effort to co-ordinate the bases on which central funds were allocated to health and local authorities (RAWP and GRE).
 - 4. The search for means of supplying bridging finance.
- 5. An attempt to remove the 'perverse incentives' whereby supplementary benefits were presently working against community care policies.
- 6. Rationalising man-power planning, the transfer of staff from health to local authorities and the training of staff.
 - 7. Avoiding starving voluntary organisations of funds.
- 8. Finally, a system must be devised to deliver proper care, to individual patients, at the right time, in the right place and at the right cost.

'What is not tenable is to do nothing', they finally declared, since otherwise the pattern of private care would simply become entrenched.

As soon as the Audit Commission Report was available, in December 1986, the government asked Sir Roy Griffiths to undertake an overview of community care policy. Griffith's previous recommendations, on the introduction of general management into the NHS, had been rapidly accepted and put into effect (1984). His new remit concerned a considerably more complex matter, involving both central and local government and, within central government, the two arms of the Department of Health and Social Security. In addition there was a whole range of voluntary organisations, the private sector and the bedrock of informal carers. After some delay the review was published in March 1988, co-incidentally with the Budget.

Like the Audit Commissioners, Griffiths did not venture to comment directly on the inadequacy of total funding going towards the care of the various dependent groups, although he did remark wryly that some people felt like the ancient Israelites, trying to make bricks without straw. Instead, he set out a better way of managing existing resources. He did not envisage rigid uniformity in services. On the contrary, there should be a structure which would allow innovation and local initiative, with a dependable background of resources.

The Audit Commission had convincingly demonstrated the failure of joint finance and the substitution for public provision of arbitrarily distributed private residential care funded by social security. Griffiths did not consider this was wholly bad, as many people would have needed residential care anyway and the numbers of people in Britain in such accommodation was quite modest by international standards. But the use of public funds in this way meant that less could be spent from overall resources for maintaining people at home. As things stood, it was virtually a matter of chance whether someone entered a geriatric ward, a nursing home or some sort of residential home.

Griffiths did not believe that a fundamental re-organisation of the central departments concerned would be either practicable or desirable. Instead he tried to clarify the responsibilities and accountability of existing health authorities and social services authorities in respect of community care. To this end he first proposed that there should be a Minister within the DHSS responsible for community care. This in itself would signalise the importance of the programme and give it visibility. The Minister of State would monitor the implementation of care plans. Local authorities should be given the primary responsibility for community care and, to this end, they should be funded by a specific grant, earmarked solely for the purpose. The grant from central government could possibly comprise between 40 and 50 per cent of the cost of the programme which the authorities proposed, but he left this open. The plans would require to be submitted for governmental approval. In the preparation of local plans adequate provision for the participation and support of voluntary groups should be demonstrated; the role of informal carers should be appropriately supported; the commitment and contribution of housing and health authorities must be convincingly shown to have been secured. At the same time he suggested that health authorities should prepare their own plans, 'allocated and fenced for community care' and that these parallel plans should also require approval. In fact the best arrangement would be the preparation and submission of joint plans, which had included support from local voluntary groups.

At the client or patient level, he recommended that specific care managers should be assigned to individuals to devise appropriate packages of care for them. This would involve coordinating a range of services according to clients' special needs. Such a manager could put together services, from either the public or private sector, within the overall budget for community care. 'The onus in all cases', he specified 'should be on the social services authorities to show that the private sector is being fully stimulated and encouraged'. He stressed this point because he believed that, whilst it was the role of the public sector to ensure that some sort of care was provided, how it was actually supplied was a secondary consideration, as long as real value was being obtained.

He put forward several methods of assessment of the need for residential accommodation and for deciding the proportion of social security benefit and social service grant money which would be payable in particular instances. He recognised that social security payments were made on the basis of individual entitlements and he did not venture to question this right. However, the maximum amount of benefit provided to pay for residential accommodation 'would be substantially lower than at present'.

By these practical means (further details of which can be found in the Report) Griffiths felt that repeated, fruitless exhortations to collaborate would be replaced by a requirement that clear evidence of collaboration and positive plans for action would be made a condition of an earmarked, community care grant made to local authorities. Within these restrictions, and depending upon a formula for need which would require careful preparation and application, local authorities would be free to develop their own initiatives.

He stressed the necessity for adequate information systems, since at the time this was completely lacking in any of the authorities. It must be in place if his plans were to be implemented and these authorities were put in charge of a specific grant for community care. Evaluation, to demonstrate the cost effective use of services, would also be a sine qua non in future.

He disagreed with the Audit Commission's tentative proposal for separate local arrangements for each of the three groups needing care, the elderly, the mentally or physically handicapped and the mentally ill. Circumstances ought to determine where the local emphasis would fall. Griffith's own definition of community care was idiosyncratic, (and perhaps set him on a collision course with Government thinking hostile to local initiatives), 'if community care means anything, it is that responsibility is placed as near to the individual and his carers as possible'. In his terms this involved letting the social services and the health authorities have the responsibility for their own local arrangements. Information about the resulting range of available local services should be available to all who might need it.

He deplored the existing insularily of the training for separate professional groups which led to misunderstandings about one another's roles, and he recommended the ideal of joint learning. However, as far as many elderly and disabled people living at home were concerned, their care did not necessitate esoteric skills and there was certainly a case to be made for 'a new multi-purpose auxiliary force ... with limited training ... to give help of a practical nature'. These would correspond to the new occupation of 'community carers' which the Audit Commission had recommended. Certainly there would never be enough highly trained, expensive professionals for these front line positions. Meanwhile there was no excuse for delay in agreeing upon the terms and conditions for staff transferred between authorities. Within social service departments more planning, budgeting, monitoring, and other skills would have to be developed and the proposed plans would demand a whole new style of management. With regard to health authorities, which had developed their own residential and other care functions which he now envisaged as being transferred to social service authorities, delicate negotiations would undoubtedly be necessary.

Griffiths ended by urging the government to 'make an early, clear statement of the objectives and values underlying its community care policies, clarifying its view of the role of the public sector'. He was convinced of the value of charging one person, at both the political and managerial level, with clear responsibility for delivering community care policies and having command of the necessary resources to do so. Tinkering with the existing system would simply not be good enough, instead the Government should adopt his 'care package' in its entirity. This report received minimal publicity and, at the

time of writing, the Government's response to the recommendations has not appeared—in marked contrast to their speedy response to his previous report on general management in the DHS.

4

The experience of caring

T IS KNOWN THAT NINETY-SIX PER CENT OF ELDERLY people in Britain live at home. So if carers are the key to unlocking what Government thinking means by 'community', what do we know of carers? Who are they? What does informal care involve? Do carers have enough recognition and information and sufficient help from other sources?

The support of those who cannot manage to look after themselves completely, for reasons of chronic physical illness or mental frailty, can be a haphazard affair as far as formal services are concerned, with the possibility of serious gaps and even overlaps. As we have seen, successive governments have emphasised the centrality of family responsibilities in this sphere and the present administration, intent upon restraining public expenditure and ensuring good management, has so far seemed unwilling to come to grips with the complexities of community care and exhortations are repeatedly directed towards families although there is no evidence of reluctance to do their best for their frail members.

It is easier to calculate the numbers of people paid to provide professional services to the old, the number of places in hospitals or in residential homes of various kinds, and the characteristics of successive occupants, than to find out about the circumstances of the great majority of older people who have possibly not come into contact with anyone in authority except their own GP. Most community care is a hidden affair, virtually invisible, shrouded in the mystery of private homes. There is usually neither incentive nor funding to probe behind the curtains of villas and council blocks. Health and social service practitioners and managers feel that they have more than enough to do with their current workloads. The arguments about 'screening' the general population were touched upon earlier. Nowadays this is less likely than ever before to receive official approval. No one wants to look for trouble or to uncover hidden needs. Economists, who think in terms of service costs and expenditure on pensions for the old, are far removed from clients' and patients' experiences.

So who does the caring? Comforting general assumptions about the strength of kinship ties helped policy planners but for long obscured the realities of caring. However, during the 1970s, as public expenditure was being cut, the development of the womens' movement at last brought out of obscurity the key role played by women in providing care at home. It began to be realised that community care, a benign and blessed concept with echoes of a fancied golden age of domestic harmony, amounted in large measure to the care of old women by typically only somewhat younger women. Of course, men did care for their wives and some sons cared for a dependent parent but, in the majority of cases, the caring task devolved upon a conveniently accessible and available female relative. Why was this so and was it inevitable and immutable?

In 1976 Moroney compared the availability of women aged 45–59, in relation to the retired population in 1901 and 1971. At the turn of the century, for every 100 old people there had been 83 'potential female caretakers'. By 1971 the proportion of the elderly in the population had increased from 8–19 per cent but the middle-aged women conveniently designated as their principal helpers had only increased from 6 to 8 per cent. Moroney maintained, in unashamedly sexist terms, that soon there would simply not be enough women to go round. His language assumed that women should care and he thought policy-makers should note the imbalance occasioned by the longer survival of an older generation who had themselves brought up relatively small

families in the 1920s and 1930s. The changes in average family size over the century had meant that, by the late 1970s, elderly survivors of large Edwardian families were depending on fewer adults of the next generation.

Before reviewing some of what has been written on the contemporary scene it is essential to recall Peter Townsend's influential study, The Family Life of Old people. First published in 1957, it described the kinship ties in the East London borough of Bethnal Green. Married working-class old people with children saw a great deal of them. They mostly lived nearby, within walking distance, and 58 per cent had visited on the day before the interview. Middle-class people too were in regular contact to almost the same extent, often visited by car. Both classes of elderly people contained about 10 per cent who were isolated. By 1962, in the same setting, 69 per cent had seen at least one of their children on the same day or the day before and 17 per cent had seen a child within the previous seven days. Townsend's wider review of the situation in most western countries at that time led him to the encouraging conclusion that about three-quarters or more of old people with children saw them either every day or at least once a week. Although lifestyles and housing in East London have since changed greatly (Cornwall, 1984), Townsend's study provided a bench mark and was an important example of a comprehensive sociological investigation of one neighbourhood.

By the 1980s studies of caring no longer concerned themselves with precise definitions of community or with anthropological explorations of kinship. Womens' experience was now in focus. The Equal Opportunities Commission funded research to discover the impact of current community care policies (for various categories of dependents) on women's lives and whether they were at a disadvantage compared with men.

The first EOC publication in 1980 was the report of a postal survey carried out in West Yorkshire. 2500 random households had been approached, 909 responded, 141 replies being from respondents with a dependent person at home. Of the 116 carers then interviewed, 70 were looking after elderly people. The respondents were clearly self selected rather than comprising a representative sample. It is, however, an extremely difficult matter to produce a sampling frame of all the carers for the frail

elderly in an area, far less to secure the agreement of chosen individuals to participate in a study. We must therefore accept that the findings do give a valuable picture of the experience of these particular families.

The responsibility for looking after an elderly dependent generally fell to the nearest female relative. It had usually been prompted by a crisis, and the designated women who suddenly took it on could not envisage at the time what a long-term commitment it would turn out to be. Caring essentially amounted to a full time job. An extension of 'normal' housework, in terms of shopping, cooking, washing, and cleaning, it nevertheless represented a great additional burden. The time and effort involved in physical and personal tasks was not necessarily the most taxing part. One of the worst features was having to 'keep an eye on' the frail person all of the time. Severe restrictions were placed on the carer's day-to-day life. They could not take part in outside social activities and holidays were virtually out of the question, unless respite care could be arranged. Meanwhile they were chronically short of money. Women often reported 'nerves', 'tension' and 'stress' and felt that their own mental health was being undermined.

They frequently needed but could not obtain adaptations to the house, to stairs and bathroom, for instance. A notable shortage of sources of help was uncovered. Help might be available, in the form of attendance or mobility allowances, a home help and practical aids, but the investigators found that, 'If there was a woman in the house a request for a home help was likely to be refused'. They also recorded 'A widespread belief that the authorities do not wish to know, so long as there is somebody who will take the responsibility for the dependant, and that this is particularly the case if that person is a woman'. Moreover, if any help was forthcoming there was no subsequent check was made to see how things were going or whether circumstances had changed. The study contained many harrowing first-hand accounts of the toil and toll of looking after an old person, from spouses, daughters, and daughters-in-law.

In 1982 a second EOC publication (based on the same data) specifically analysed the effect of community care policies upon womens' lives. The writers observed that community care meant in reality care by individuals on an unpaid and often unaided

basis in the home. Traditional attitudes in society continued to allocate to women the primary responsibility for caring functions. Thus, in addition to or following child care, many women found that they must take on the total care of frail older people. 'Badly supported by the statutory services... the allocation of caring responsibilities has major implications in financial, social, and emotional terms... taken on during middle life, when they are most likely to be economically active... trying to hold together conflicting and irreconceivable demands... many women have to give up work'.

The report then expanded upon the implications of community care for women, the scale of caring and dependency; the nature of the caring task; the economics of caring; the services available; finally, the effect of changing levels of public expenditure. Forty-four per cent of the carers had, at the time of interview, been caring for upwards of 5 years and almost 25 per cent for over 10 years. Caring sons were the least restricted in their ordinary lives by having a dependant while wives were the most restricted.

The caring task was broken down into various components. It entailed a great deal of physically heavy housework. Women usually had to carry out all the intimate personal tasks of toileting, feeding, and washing, as well as the laundry and cleaning. Emotionally the task was taxing; perceived as a duty, it needed much patience and was by no means always rewarding. The women concerned often found that themselves acting as mediators between the demands of a peculiar, difficult old person and other family members and this could lead to distressing conflicts of loyalty. Negotiating with the statutory services was difficult and disheartening. Unlike infant and child care, where publications and products abound, there was a dearth of information on how to meet the multiple demands and needs of an old person. A remarkable finding was that husbands of carers on average spent only 13 minutes per day in contrast to the 3 hours 11 minutes spent by their wives in directly looking after the dependent old relative who lived with them.

This publication deplored the dearth of information on the economics of caring. It was clear that loss or restriction of employment was often involved for the carer and that low household incomes were the norm. The various health and social

services supposedly available were itemised and attention was drawn to the anomaly whereby the provision of certain vital health services, such as home nursing, had apparently declined from 1972–77. The Invalid Care Allowance could be claimed by the carer in some cases but not, at that time, by married women. The dependent person might themselves be eligible for Attendance Allowance and Mobility Allowance.

The third EOC publication compared the different experiences of men and women carers of the disabled elderly (1984). They asked to what extent society in general and the Health and Social Services in particular were reinforcing and perpetuating traditional values and social roles and whether this was working to the detriment of women carers.

The methodology for this study involved 255 elderly people who had already been referred to the statutory services during 1979 and 1980. Interviews took place with 151 informal carers, at the beginning and end of an eight-month period. There was a predominance of women among the dependent elderly, matched by a predominance of women among the non-spouse relatives. Forty-two per cent of the carers in this group were themselves over 60 years of age and only eight per cent were under 40. A sizeable minority of carers themselves suffered poor health and it was noted that the distinction between carer and cared for could sometimes be arbitrary.

The heaviest caring tasks were for old people who lived with the carer and it was commoner for female than for male relatives to share their own household with a dependant (43 per cent versus 22 per cent). It was commoner for women than for men to continue coping with increasing dependency at home for a long period, since the women were usually prepared to make themselves 'available' at all hours of the day and night. They remained conveniently close for a lengthy and indeterminate period. Women often ended up caring for men who had never in their lives carried out any shopping, cooking, and household tasks for themselves. More than one-third of the frail elderly in this group were either moderately or severely confused. Women carers were more likely than men to be carrying out intimate, personal assistance with dressing, toileting and washing, and over a third of the old people in this group did require such help.

As far as the statutory services were concerned, there was 'suggestive evidence' that male carers were more likely to receive home help, meals on wheels, rehabilitation or assessment and, eventually, to be offered long-stay care. Women carers, on the other hand, were more likely to be assisted by day or respite care. There was little difference between men and women carers in respect of the degree of help they experienced from community nurses.

Most of the underlying care was provided by families, who comprised 89 per cent of all the carers interviewed in this study. Although neighbours and friends frequently offered some assistance, they had rarely fulfilled a principal carer role.

The writer observed:

Where carers can no longer cope with the demands made upon them the only solution provided by the services is to completely take over, by providing long-term care in hospitals or residential homes. It often seems a drastic step.

From the point of view of both the carers and the elderly what mattered was the combined support or lack of support, rather than what they were sporadically receiving from a particular agency. The study concluded:

The vast majority of elderly people live varied and active lives... nevertheless the needs of the minority of physically and mentally infirm old people place considerable demands on the rest of society... Most of the needs continue to be met by relatives and friends... (but) as the number increases, the number of disabilities causing dependency will rise also. We must have a clear understanding of the *realities* of care in the community.

Nissel and Bonnerjea (1982) were financed by the Joseph Rowntree Trust and the EOC to investigate the cost of family care of the handicapped elderly and the results were published by the Policy Studies Institute. It was a pilot study among families with an elderly dependent, contacted through the health service and voluntary agencies but without the co-operation of social work departments. It was carried out in Headington and the report was based on 44 respondents, husband and wife couples who were caring for an elderly person in 22 households.

Taped interviews were combined with time diaries. The activities which comprised caring were categorised into five groups, ranging from active help, involving the immediate presence of the carer, through incidental assistance, with finance and correspondence, to passive help or 'listening for' the old person.

It transpired that the wife took on most of the immediate tasks. In fact, 'the majority of husbands gave the impression of being quite distant from the situation' and often denied the existence of any problems. As noted elsewhere boys and husbands were excused from 'personal care', although they would give some assistance if the women was actually unable, for some exceptional reason, to carry on with her traditional role. It was even rarer, however, for help to come from voluntary organisations or from neighbours. 'Nobody', bewailed one women, 'will sit an incontinent grandma. Never'. Others had advertised unsuccessfully for granny-sitters.

Confirming other findings, the women told how they had first come to be the designated family member, chosen to care. Once a relative was settled with one particular household or child other relatives contributed very little. As far as others in the family were concerned the problem had effectively been solved.

Women carers spoke of the physical and mental effort and, even more wearing, the total responsibility which the caring role entailed. Many spoke of the effect which it had upon their own identity and the isolation and frustration they endured. Women who had given up an outside job felt their status had gone. They had no social life either and had mostly given up the right to any time of their own. Often they found themselves in a triangular relationship, trying to keep a balance between the needs of the old person and the demands of other members of the family. The 'woman in the middle' bore all the resultant tensions and suffered especially on account of teenagers who could not bring their friends home. Some were convinced their marital relationship had suffered as there was virtually no privacy with the old person constantly present. 'Our life isn't our own any more', one said.

Women caring for a confused old woman had also to endure the strain of a disturbing role reversal, in which their own mother had become their child. It could take time to work through the memories, guilt, resentment, and bad feelings which such a disturbing turn around entailed. Altered behaviour and sleeplessness on the patient's part were also desperately disheartening and tiring for the woman watcher. She could not hope for the steady improvements which characterise a developing child but envisaged an even bleaker future.

Most of the families in this study did have some statutory help, such as day care or intermittent respite care. Visits from doctors only occurred when they were called in to deal with a crisis. Nurses came oftener but social workers virtually never entered the scene. Four families were getting no outside help whatsoever, although they could have approached doctors or social workers had they realised their entitlement and need to do so. All these four had severe problems in communication and did not know where to turn for assistance.

Some of the women seemed to be 'born carers', confident in coping with problems. Others deeply resented the role or felt guilty, inadequate, or confused. The awful monotony and sense of being trapped for ever came across strongly in one woman's words, 'There's no yesterday or tomorrow, only today'. Several complained that there came a point when an old person was too ill for the usual type of old peoples' home but not ill enough for a mental home or a hospital and so the family simply had to battle on.

The researchers made a valiant attempt to compute the financial costs of caring. They noted that the lower rate of attendance allowance at the time would pay for only one hour of care per day, at the going rate for home and domestic help. Caring was a 365 day-a-year occupation, covering nights and weekends. The authors calculated that, on the modest assumption that wives and husbands spent, in a complete week, $3\frac{1}{2}-4$ hours daily in direct caring, the value at £1.80 per hour would be £2,500 per family before tax. They cautioned that such work was, in reality priceless since no outsider could be found to do it on these terms.

To properly estimate the opportunity costs involved one would need to consider the chance of securing outside paid work by those who wanted it. The woman's qualifications and the range of salary they could command would need to be taken into account, also the effect of their rising prospects over time and

their ultimate occupational pension eligibility. Some were already in part-time paid employment and having to pay for other help at home. Details of the calculations can be consulted in the text. The matter is extremely complex but undoubtedly deserves attention. It has been partially addressed by Tinker (1984) and by Wright and his colleagues (1981).

At present the state takes advantage of women's unpaid labour of love. Many of the women declared that it was not just the financial costs that mattered. Nissel and Bonnerjea observed, 'much is heard today of the benefits to elderly people of being looked after at home or "by the community", whereas what is really meant is that public expenditure can be avoided if institutional and other services are not used or available. Public awareness will less likely be wakened by the unheeded cries for help from the elderly and their families if they are muffled within their own walls'. They ended with a number of recommendations. There was a clear need either for day care which was more flexible, both in terms of hours and of the families' actual coping capacities, or some means should at least be found of helping families who found it difficult to maintain a 24 hour vigil at particular times during the day or at weekends.

All the families in their study would have appreciated more and better information about what help was available and how to get it. Many families were not even getting enough information from the GPs and hospitals which constituted the only service link for them. The social services appeared to have almost no input to this group of households. Carers felt a great need to talk about their problems, particularly the disruption which caring entailed for so many families. Obligations shouldered by the woman concerned seemed to offer no escape short of personal illness or mental breakdown. The idea of a symmetrical family, with both partners sharing tasks and having more or less equal rights and obligations, was totally illusory and bore no resemblance to reality.

Nissell and Bonnerjea cautioned that proper care would be bound to be costly, however it was given, they believed that the demand at that time for domiciliary services and for day care and short stay residential care was much greater than was being allowed for. Some of the caring families, in Headington at least, were near breaking point and some of the old people they were sustaining were considered to be clearly bad enough to merit residential care.

At the same period as the Equal Opportunities Commission was publicising the realities of caring Finch and Groves edited a volume on what they aptly called A Labour of Love (1983). Caring for someone meant more than love and affection, more than simply caring about them, it involved hard labour and tending. Hilary Graham described what caring really meant, Clare Ungerson asked 'Why do women care?' and Kay Wright described her own study of 22 single sons and 36 single daughters caring for their parents. In this investigation it had turned out that all except one of the men had a full-time job compared to half of the women. The sons were receiving more home help. It was more common for the working women to take time off work, whilst this had been out of the question in the mens' case. Mothers living with sons were more active than those who lived with daughters. The cause for this finding was debatable. Did mothers feel obliged to go on doing housework for their sons? Or possibly the most disabled mothers of working sons would be obliged to enter residential care whilst a women, off work or only working part-time, would be expected to manage their elderly mother themselves.

It was clear that home help, meals-on-wheels and short-term residential care could be very supportive to both working and non-working carers but such assistance was rare.

The editors concluded, 'Community care services need to be far more strongly developed before they really contribute to the support of highly dependent parents and relieve the strain experienced by both working and non-working carers'.

Clare Ungerson's own book on the subject was a small scale feasibility study to discover how much carers were prepared to disclose about the intimate and personal aspects of caring (1987). Her 19 informants were drawn from a list of local carers kept by the social service department in Canterbury. She did not claim that her respondents were representative, simply that these individuals had all reached a crisis in their lives that they wanted to talk about. She defended personal experience as a spur to a social researcher, arguing that the topic was particularly appropriate for a single women whose own mother was ageing.

The book provided vivid accounts of interviews with 15 women and 4 men who had a dependant at home. All the men were caring for their wives. Eleven of the women were looking after a non spouse member of the older generation. In general, the middle-class men and women carers received more statutory help than those who were working-class. Attending a carers' support group was mainly a middle-class phenomenon.

Looking closely at the carers' activities, only three did no more than housework, the rest all had to undertake intimate care. In households where there was a married couple and a dependent old person wives took it for granted that their husband's main job was to provide financial support whilst they took on the caring tasks. In the exceptional cases where there were additional resources to pay for outside help this could just maintain an otherwise informal caring relationship and avoid a complete breakdown in the domestic arrangements.

Ungerson illustrated the initial negotiations which had taken place when someone first began to need some support. Very close female kin were always regarded as the first resort, which could lead to tension in some cases when there might be a question of whether an elderly husband or his daughters were to take on the task. The selection of carer depended upon 'dominant, normative and gendered rules of kinship'. But the situation might not be explicitly discussed. A great deal was taken for granted. However, all were agreed that the dependent person should live 'at home rather than in a home'.

Thus the reasons for becoming the carer were complex. Whilst men were in paid work it was assumed they should be excused but, once retired, they suddenly became available for full-time caring. Most of the women in the group were already past child rearing age when seen but they had often taken on responsibility for a relative whilst their children were still around. So they might feel it was, in some sense, a positive choice, which had not seemed too hard at the time. At the outset the elderly person was able to reciprocate, helping around the home. In certain instances the dependent person was visualised as being like another infant in the family.

Some of the middle class women were 'career carers', they accepted it as a job in itself, which absolved them for any need to seek outside activity, while others cared in addition to outside

paid work. Some had taken on caring to fill the 'empty nest'. It was probably only better-off, middle-class women who could afford such choices, rejecting a two-earner rating for their family and feeling that caring at home was a legitimate alternative to paid employment. Indeed, 'where women expect to have to take on the full-time care of an elderly person at some time in the future this may well stop them from pursuing goals related to their position in the labour market'. Although certain women may have initiated caring at a point in their lives when the tasks were closely compatible with other activities, Ungerson considered that, in contrast to men, no women was really a volunteer. A woman was always subject to considerable ideological and material pressure to be 'the carer of last resort'.

Different main reasons for caring were offered by men and women. The men said they did the work because they cared about their wives whereas women cited duty much more often. Ungerson speculated about the reasons for this, possibly duty was generalisable, passing from one generation to another, whereas love was highly specific to a particular relationship. Women spoke much of guilt as well as duty. Some felt they had no choice but to do God's will, others expressed compassion, or felt natural gratitude towards the parent who had reared them. If the possibility of putting the dependent person in a home had ever arisen it had seemed tantamount to ending the marriage as far as the men caring for their wives were concerned. Several regarded homes with guilt and horror and some feared that the managers might reject their own old relative whose behaviour was so anti-social.

The retired men in this small group had approached caring for their wives as if it was a new job and they were keen to explain its novel details to the interviewer. They were systematically businesslike about it and considered that they had acquired a body of useful knowledge in the process. The women took extra housework for granted, not viewing it as something a female researcher needed to have explained. Instead they concentrated on the difficulties and emotional problems which the role entailed and their own feelings.

It was apparently harder for a woman to adjust to totally caring for her husband than vice versa. This somewhat surprising finding might relate to the usual, accepted role of a man as being in control, looking after his wife. Women caring for their own parent had problems over the distressing role reversal which was entailed. They might cope by ceasing to care about the person concentrating instead on caring for them, in a detached manner, as if they were strangers. Both these examples represented difficult changes in a previous balance of power.

Ungerson confirmed the EOC findings about the total effects upon families, remarking.

It is interesting that, while policy makers may think of the extended family as the most suitable place for the care of the elderly, it seems that married women carers find such care is potentially destructive of the nuclear family of which they are a part.

Whoever they were caring for the women felt guilty, all being convinced that they were not managing to meet the 'hierarchy of obligations'. No matter what they did they felt they should be doing more or doing it differently. Nevertheless, they often confided that there did seem to be potential alternative carers in their own kin network. They had been personally involved in a silent battle over who should take on a responsibility which turned out to be total. Most carers were invisible to the wider society. Carers support groups had partially helped some but, in the main, they were on their own, lacking appreciation or reward. One of the men and five of the women were most unhappy about their situation and could see no way out, although others confessed to a certain satisfaction from their devoted activities.

Ungerson foresaw a future in which old people who owned property would be encouraged to capitalise on it to pay for private care, either at home or in a home. The consequent loss of the family inheritance might well be unwelcome to close relatives. She feared that, whilst the rich would be wooed by private operators, there would remain a substantial minority who would have no access to this method of subsidised capital accumulation and who would consequently be obliged to rely upon uncertain state services, resulting in a highly stratified system of care. The affluent elderly would in future probably enjoy very superior circumstances to their poorer contemporaries.

None of the preceding publications pretended to give an overall picture of the characteristics of carers, in the sense of an epidemiological or social survey. The value of these primarily personal accounts lies in the insight they afford into the lives of individuals, mainly women, who have become carers of the frail elderly. By comparison Martin Bulmer (1987) offered a very comprehensive view of the whole social basis of community care, analysing the policy background and the sociological context before considering the nature of the personal ties and social networks which sustained care in private households. At the personal level he discerned altruism and beneficence alongside a sense of duty and reciprocity, set against a background of established traditional roles. He made much of a new notion of 'interweaving formal and informal care' and gave some examples of good practice. He did admit, however, that there were great obstacles to any such interweaving and that 'discontinuities' between services and family carers were still the rule. Bulmer saw absolutely no possibility of going back to the old vision of a caring local community with many close links. Kinship pre-dominated today, with friends and neighbours only available in crisis or to carry out limited good deeds. Isolated old persons who were also lonely urgently needed attention by the social services. As far as family carers were concerned, Bulmer accepted all the points made by the previous writers and used their findings to strengthen his own arguments.

Alan Walker has written extensively on social gerontology. In a 1986 paper he emphasised that community care no longer related simply to a specific location. Informal care networks ought to be the focus of attention today and, in particular, the relationship and complementarity between formal services and informal carers. He considered that kin and gender were of crucial significance, followed by links of friendship, occupation, race, and religion. All of these took precedence over neighbours and members of the local community. He made four main points. First, there was no evidence of a pool of unused family labour. Where the family was needed it was already caring. Secondly, there were strict limits to what friends and neighbours could or would do, being disinclined for arduous tasks or long-term commitments. Thirdly, informal and formal sources of

support were independent but the latter could prevent the build up of physical and emotional strain.

Walker's final point was to bring out the frequently forgotten and politically unpopular matter of the extent to which poverty sets strict structural limits to informal caring. What had happened in a neighbourhood, through industrial disinvestment, unemployment and housing decay could all affect the extent to which the families living there could manage to cope with caring. Income maintenance, employment, housing and levels of education were all bound to affect caring capacity. If the wider community, in his sense, was imbued with a broad approach to care which crossed service boundaries in the interest of providing properly for the vulnerable Walker believed that opportunities could be immense.

In the book edited by Phillipson and Walker (1986) on ageing and social policy the same theme is developed further. 'The process of ageing', they maintain, 'and the experience of old age cannot be understood without reference to the elderly person's location in the social structure and their relationship to the economy'. Meanwhile, as far as the family and the welfare state were concerned, female kin were clearly the principal carers of the elderly. This was a state of affairs which it conveniently suited the state to maintain. Walker hoped that social attitudes and structures could change in future so as to make it more acceptable for men to assume the caring role—even when an old person had a woman relative. The limited numbers of possible carers in future made such changes not only desirable but inevitable. In the meantime, older women in contemporary society were at a special disadvantage because of their inferior position on the labour market, probably having worked only part-time at poorly paid jobs. Their daughters would presently proceed to experience a similar fate as they tried to combine a multiplicity of barely compatible roles.

What emerges from all these studies is that for all practical purposes carers are found in households, usually very small households, and not in 'the community' beyond. Neighbours scarcely count. Most caring takes place by the family, in the modern small family, not in a romanticised Victorian, extended family.

CHAPTER

5

From care attendants to case managers

The absence of clear national policies, community care for the frail elderly has manifested a confusing myriad of forms. Professions and associations have been obliged to devise a multitude of local arrangements which have reflected popular pre-occupations or problems and the historical preferences, mutual allegiances, or suspicions of interested parties. The remarkable diversity which now prevails is only partly an indication of elderly peoples' varying needs in different parts of Britain and it certainly cannot be assumed that the extent or nature of the support which happens to be available outside institutions in any particular setting is necessarily adequate.

Aside from the central involvement of the ancient professions of medicine and nursing, associated health workers, like occupational and physiotherapists and chiropodists, have an important potential contribution but their activities are frequently felt by them to be both under-resourced and unappreciated (SHHD 1987). In the social work field since Seebohm direct contact with older people has taken second place to statutory responsibilities for child care (Stevenson and Parsloe, 1978). Although local authority provision of home help and meals-on-wheels involves the expenditure of large sums of public money, face-to-

face work with pensioners appears to have been an unpopular, ill-organised, low status area (Hedley and Norman, 1982; Nicholson and Paley, 1981; Sinclair et al., 1984). The Barclay Report on social workers' roles and tasks (1982) encouraged the development of what was termed community social work but the report was soon criticised for failing to demonstrate an effective way of channeling resources towards the elderly (Judge, 1983).

In a strongly worded dissenting appendix to the Barclay Report Pinker expressed serious reservations. In his opinion the very idea of community was fanciful and romantic and he doubted whether 'by dispersing a handful of social workers into local communities we can miraculously revive the sleeping giants of popular altruism'. The Report had advocated giving social workers more autonomy and scope for the exercise of their discretion. They should, it was maintained, enhance the rights of clients and carers but Pinker could see no clear way of combining public accountability and the need to deal equitably with many demands with social workers' desire to be personally accountable to individuals.

Housing departments have often developed something of a social function by developing innovative ways of overseeing the growing numbers of occupants of sheltered housing and keeping in touch with isolated old people in their homes through personal alarm systems. These were carefully reviewed and compared by Anthea Tinker for the Department of the Environment (1984).

A relatively recent development has been the introduction of care attendants, a new stratum of women with ordinary household skills engaged to give personal assistance to frail housebound people in their neighbourhood. Their usefulness has been increasingly realised in both the public and private sector, especially for dealing with crises in the lives of the old. Elderly people have meanwhile continued to recruit private domestic assistance if they have the personal means to pay for it (Midwinter, 1986).

In many parts of the country there are admirable voluntary schemes which ensure that the elderly are regularly visited and some of these arrangements have been deliberately 'interwoven' with the health and local authority services (Abrams, 1981; Age

Concern, 1985; Armstrong and Thompson, 1986). Volunteers have even been occasionally used to detect unreported medical problems (Beales and Hicks, 1988). The issue of the relationship between the personal social services and contributions from the private and voluntary sectors has been much debated and is certain to feature increasingly in future policy decisions (Leat and Gay, 1987; Mellor, 1985; Lewis, 1987; Tooth, 1987).

In spite of the multiplication of small schemes across the country it is rare for such projects to be subjected to the sort of strict scientific evaluation which is now demanded of new medical regimes, but a striking example of this sort of application of epidemiology was reported in the BM7 in 1988 (Townsend et al.). Care attendants were specially recruited and deployed in the community as the new treatment element in a unique, large scale randomised controlled trial among patients over the age of 75 discharged from Northwick Park Hospital, Harrow. A total of 903 patients were involved, 464 of whom received support from care attendants on the first day at home and for up to 12 hours a week for two weeks thereafter. The remaining 439 patients experienced standard aftercare. The intention was to estimate the effect of the use of care attendants upon the independence and morale of these elderly patients and on their use of health and social services.

The women carers initially had no qualifications beyond personal experience and willingness to help, but they had been given some inhouse training and supervision. Apart from lifting and moving they did not do any specific nursing tasks and so their introduction did not provoke overt conflict with the nursing service, although there were certainly some initial difficulties with the social services because of a perceived overlap with existing workers' roles (Townsend, 1988). In the course of their visits the women simply provided whatever practical help seemed necessary, they encouraged rehabilitation and helped to organise assistance from family, friends and the statutory services.

The patients were assessed at discharge and at two weeks and three months thereafter. The main differences became apparent in the longer term, 18 months after discharge, when it was possible to interview 84 per cent of the patients. At that point there were no demonstrable differences between the two groups

in terms of physical independence, morale or death rates, but hospital re-admission rates had been statistically significantly higher in the control group i.e. those without initial help from care attendants, and they had spent more days back in hospital. The research team concluded that, were such a policy of support after discharge to be extended to all patients over 75 living alone, an average health district could expect to save 23 hospital beds, at a net annual cash saving of about £200,000 after the care attendants had been paid. Alternatively, a health district could choose to increase its available beds. Such a successful and economical new method of dealing with elderly patients is likely to impress health service managers and hospital consultants.

At the simple, descriptive level there are innumerable instances of attempts to involve different kinds of helpers in helping patients after discharge or trying to avoid hospital admission. Age Concern, for example, itemised twelve such schemes in Greater London alone, but none were subject to any scientific evaluation (1985). An example from Scotland comes from East Lothian Local Health Council which has encouraged a partnership in care at the grass-roots level between the health board and the local authority (1988).

An encouraging, ethnographic study by Wenger of a North Wales community showed that the rural elderly, in this setting at least, were experiencing a fairly high level of support from their neighbours and were involved in more social activities than had been customarily reported among their urban counterparts (1984). The social anthropologists working in the area uncovered a heartening degree of interaction between the statutory services and informal helpers whose co-operation is so often no more than a pious hope.

A project which focussed on a similar theme of interaction among helpers but which produced a much more dismal picture was carried out in a mining village in Yorkshire (Bayley et al., 1983). The investigators looked at the extent to which the informal sector, comprising relatives, friends and neighbours, was relating to the statutory services being given to a group of people over 75.

The study confirmed what was described in the last chapter. Highly personal care, only needed by a few, was mainly being supplied by women relatives. Fifty-eight per cent of the old people currently in receipt of services lived alone and had a poor social life. Although they had an average of 9 visits a week from family and friends, the range was vast, from none at all to 66. A low level of contact between statutory and informal carers prevailed. Even although both sides were aiming to fulfill similar needs there was no attempt here to co-ordinate care.

The team found no evidence to support optimistic government pronouncements about the scope for expanding the informal caring networks still further. On the contrary, many family support networks were already stretched to the limit and 'very fragile'. Whilst the authors thought that there might conceivably be a case for involving non-frail elderly people in the care of their peers in the future, they certainly could not be regarded as an unlimited resource.

Part of the General Household Survey of 1985, in which Hazel Green organised the interviewing of a representative sample of 18,500 adults living in private households throughout Great Britain, has at last produced national figures for the extent and nature of caring. This comprehensive and important survey defined carers as 'people looking after, or providing some regular service for, a sick, handicapped or elderly person living in their own or another household'. One adult in seven fell into this category, or about 6 million people altogether. 1.7 million people were caring for someone in the same household.

Women were more likely to be carers than men although the difference between the sexes was not so striking as had appeared from the smaller studies already quoted. The peak age for caring was 45-64. One in four carers, about 3 per cent of all adults, spent at least 20 hours per week on such activities. The commonest form of assistance was practical help with household tasks and only one quarter of the carers received any outside help themselves.

The great demand for more and better information about what resources may be locally available has at last been recognised and many scattered efforts now go towards providing it (Tester and Meredith, 1987; SHEG 1980). This is only one aspect of the multiple needs of family carers which have already been listed at length. As evidence of their near desperation and isolation has accumulated another panacea of sorts has been

recommended in the encouragement of local support groups where the relatives of disabled old people can at least come together to share their woes and pool information (EOC, 1982; Wilson, 1988).

The plea for better co-ordination, interaction, networking and so on, has continued to issue from innumerable sources. Levin and his colleagues, writing for the National Institute of Social Work, reported on a large study among the supporters of the confused elderly at home and made the now familiar argument for joint planning at both local and individual level for such potential clients of the social and health services, but they failed to come up with any new mechanisms for achieving these admirable ends (1983). They deplored the lack of initial assessments of need, the absence of regular reviews of care programmes or even the simple follow up of people who had once been clients of social services. It was particularly unsatisfactory that family carers should have to re-apply repeatedly for help as their circumstances changed. These criticisms were coupled with serious concern about the apparent overall shortage of resources as compared with needs, a matter which few dare raise nowadays.

The involvement of economists in the topic of joint planning for the elderly has already been mentioned and a number of them have in fact set out guidelines for achieving the optimum balance of care (Wager, 1972; Mooney, 1978; McClenehan et al., 1987). It was the DHSS which originally prompted these exercises, involving the use of a computer model to perform the quantitative analysis (Gibbs, 1978). Any balance of care exercise is ultimately bound to be based upon assumptions about the future need for care. For instance, there are inevitable value judgements about the extent to which further help of a fairly basic sort may enable relatives or friends to continue to tolerate someone at home but few have tried to cost informal caring in any systematic fashion.

Probably the best attempt so far to sort out the complex economics of informal care of the elderly has been that of Ken Wright (1987). His analysis was based upon a questionnaire to 186 carers to discover the major problems or difficulties which affected peoples' coping ability. Some were classified as 'able to cope', having either no difficulty or expressing a degree of

satisfaction with their caring role. Different costing bases were then applied to the sub sample of households where the carers were currently having to provide more help than they would have wished or where their personal opportunities to take up outside work or to enjoy leisure were seriously curtailed. Some kinds of help, at night or with intimate care, were a great burden. Ultimately the costs of the statutory services which would be needed to relieve stress were calculated.

The detailed tables accompanying this valuable analysis of opportunity costs vividly illustrate the actual problems experienced and the price of introducing a suitable helper, either a home help or a nursing auxiliary, for a variable number of hours every week. Wright concluded that the notional costs of home care would rarely exceed the costs of residential care or, even more rarely, the costs of hospital care. The instances where the costs of adequate care at home did approach the costs of residential care occurred most frequently when the caring relative was a spouse. Presumably in such cases the potential carer was also of advanced age. Sometimes the provision of minor assistance, like the loan of a wheelchair or small adaptations to the home, would have made a great difference to the task of the principle helper who often only ventured to request the most modest amount of help.

Another informative study by economists at York University was done expressly to produce evidence for the Griffiths' review (Gray et al., 1988). A sample of six District Health Authorities, chosen to be representative of NHS district based community care provision, was examined. It included a wide range of services provided by local government, other public sector agencies and private and voluntary organisations, but excluding primary care and acute hospital care. The elderly formed only one category of the groups under consideration but the overview of facilities for them was extensive, including designated community health service personnel, general community services, such as home-help, luncheon clubs, laundry schemes, and services relating to housing, transport, employment, and education. Hospital provision costs and those for residential and institutional care were only examined in order to compare these with expenditures in the community. For a similar reason, a few private and voluntary homes were scrutinised, to discover the type and level of financial support which residents received. Any paid for service in the community, from religious or voluntary organisations or from social services was also taken into account, but no attempt was made to put a figure upon the personal expenses incurred by families or neighbours.

Well over half (54 per cent) of all public expenditure was attributable to services for the elderly. In two health districts it amounted to 70 per cent while in another it was less than 30 per cent. The per capita expenditure on all community care client groups per year varied widely, from £100 to £170 in the six districts. The 'balance of care' was clearly still tipped in the direction of institutional care, which amounted to 85 per cent of all the health authority expenditures for the groups in question. The total expenditure on the elderly population was also very variable. In two health districts the annual per capita expenditure, including hospital in-patient costs, was less than £700 for the over 75s, while in another district it was over £1700. If all the different providers of care were taken into account, the balance of care lay very heavily with institutional facilities. amounting to three quarters of all public resources directed towards the client groups. Less than one fifth (18 per cent) was spent in community services.

The study made it abundantly clear that there were very large variations in all dimensions of care in the community, across client groups, between providers, across the country and in the types of provision. This monograph deserves close examination because it has put hard figures to the separate contributions to community care from various sources, revealing the stark imbalances and unjustifiable geographical differences which persist. The demonstrably wide variations in all dimensions of care in the community throughout the country were deemed by the economists to be the result of a total lack of policy direction. The beginnings of efforts to balance different forms of care for the elderly were said to be discernible, but there were yet no signs of such developments for the mentally ill or the physically and mentally handicapped.

It appeared that the previously much vaunted joint finance programmes had, in effect, amounted to no more than 3 per cent on average of the total spending by health districts and local authorities and in some cases it had been a mere 1 per cent.

Meanwhile the growth of expenditure through DHSS board and lodging payments had introduced an uneven and much larger element of resources, completely overshadowing anything provided by RAWP (Resource Allocation Working Group formulae used by the NHS).

One of the elements missing in the rational provision of community care has been any effective direct means of coordinating such services as are available in the interest of individual frail old people and their families. The idea of care or case management has become a new prescription for curing the admittedly deplorable social ills of the elderly in Britain but it raises all sorts of questions. Who might perform this role? Which profession or group of workers has the requisite skills? Who has sufficient motivation?

The concept of case management came from America but the use of a designated 'contact person' has been familiar in Scandinavia for some time (Uldall-Hansen, 1980). The absence of uniform public services throughout the United States may have prompted the development there of a new occupation, existing in the interstices of other professions and providers. Denmark, by the way of contrast, has good financial provisions for its elderly population but still feels that designated contacts, who may be nurses, home help supervisors, or case workers from the social service administration, should have the responsibility for co-ordinating all measures of care for elderly persons. The benefit of such 'liaison personnel' is widely acknowledged. Theoretically it should be possible in Britain for the representatives of different professions to act in this capacity. The next chapter will consider the definitional issues concerning appropriate case managers and the potential conflicts of interest which can militate against the introduction of this new kind of co-ordinator.

CHAPTER

6

Disputed territory: who should manage care?

ITHIN THE WIDER SOCIETY AND WITHIN THE caring professions the hum-drum business of providing care for the elderly lacks prestige. All the material so far reviewed has indicated that very old frail people are at a disadvantage in respect of their personal appeal, their financial and social prospects, and the kind of attention they are likely to receive. Yet the elderly cannot simply be ignored by any whose regular work entails close contact with them. Indeed there have been strong statements from interested parties in many quarters about the best direction for future public policy. Even a territory of field work and professional practice which is generally despised and neglected can become a cause for boundary disputes once it is a matter of deciding upon the appropriate division of power and public resources. Consequently, in the period prior to and immediately following the Griffiths' report, a number of different champions of the elderly have presented their credentials and set up alternative scenarios in which they would play a central part.

Consider first the position of hospital doctors in the acute sector. They have been reluctantly obliged to come to terms with the ageing of the patient population and the fact that half of their beds and much of their time must be invested in the treatment of pensioners. In these costly medical or surgical wards there is constant pressure to move patients out quickly, to keep waiting lists down and the dread syndrome of 'blocked beds' is universally deplored. Places occupied overlong by the elderly not only work to the detriment of other patients waiting in a queue but damage older patients themselves, as their frail bodies cannot tolerate extended periods of immobility. Dependency grows and skills are lost. The current managerial drive towards more efficient use of health service resources is, however, no longer simply a matter of reducing the hospital stav of elderly patients admitted for specific medical or surgical treatments. As was noted earlier, the whole notion of institutional care has become discredited and the closure of large costly, psychiatric and mental handicap hospitals and chronic wards is proceeding apace. Far from the increase in total numbers of very frail, older people in our society being matched by the provision of more beds or communal living spaces by the statutory services, places are actually in process of being reduced (Andrews, 1985). These developments, whilst ostensibly in the best interests of patients, clearly reflect the central objective of reducing overall public expenditure and derive from a determinedly optimistic view of long term future needs.

In these circumstances it is not surprising that specialists in geriatrics and psycho-geriatrics have come to assume great strategic importance. These relatively new doctors of the old did annexe some disputed territory, in the form of beds, from other consultants but they have been able to offer very welcome expert assistance in exchange, in the form of advice on how to maintain an old person's functional abilities as long as they remain in hospital ('rehabilitation') and when and where to discharge them. Assessment and placement of the old are skills clearly valued by other doctors who have neither the competence nor the inclination themselves to contemplate social factors in illness and the complicated correlates of ageing.

The development of geriatrics, and the community services with which it is associated are achievements for which this country is rightly admired (Barker, 1987). Through outreach programmes from hospitals, by the provision of day hospitals and respite services and by assessments in old peoples' own households geriatricians have aimed to bring appropriate care

swiftly and economically to those who need it. Perhaps this service is not yet as comprehensive as might be desired but it is an expanding and respected speciality. The best geriatricians work with multi-disciplinary teams whose members have all become skilled at sizing up the situation of housebound elderly people.

The British Geriatrics Society issued its comments on the Griffiths' recommendations in 1988. They saw the primary care team, comprised of general practitioners and community nurses, as pivotal for the old, so long as they were able to cope at home. GPs 'must have ready access to a wide range of resources—home helps, social workers, aids and appliances, etc'. Suitable housing for the elderly was also essential and informal carers merited more support. This first part of the geriatricians' advice sounded as if general practitioners were being cast in the role of case managers for the frail elderly.

However, the commentary went on to outline the unique contribution of geriatrics, as an available resource for elderly people in the community with multiple problems, medical, mental, and social, as well as for patients in various hospital ward settings and in long-term residential institutions. Close collaboration with psychiatrists should be fostered. At all times, the specialist geriatric service should be capable of an immediate response to the needs of individual old people, whose condition could deteriorate with such alarming rapidity. 'All need in old age is urgent', they declared, 'and bureaucratic barriers must be swept away'. The geriatricians finally claimed that they personally were already operating as Griffiths' type 'case managers', by providing individual programmes of care, based upon detailed multi-disciplinary assessment. They sternly warned against the future damage which could ensue from transferring such responsibility to social service departments. These departments, they maintained, 'are not only experiencing grave difficulties in meeting their own existing responsibilities, but also are notably lacking in suitably trained personnel with a detailed knowledge of ageing and the interest and motivation to provide a comprehensive service'. It would, they considered, take many years to train a group of new workers with the appropriate knowledge and skills to match what was already available among the doctors, nurses and others in the geriatric service.

The Royal College of Psychiatrists came up with an even longer statement about Caring for a Community (1988). Whilst they appreciated the argument for social security money, at present spent inappropriately on private residential care, being 'ring-fenced' for genuine community care in future, and whilst they thought that money from the closure of large psychiatric hospitals should go towards the same purpose, they were most unhappy about the increased role for local authorities envisaged by Griffiths. Like the geriatricians, they were sceptical regarding both the motivation and the existing skills in social service departments, 'so bedevilled by politics, pre-occupied with child abuse, and with such a patchy record for developing community care for the mentally ill'. They would prefer the money to be held by health authorities. However, they freely acknowledged that the organisation of community care (for all categories of patient or clients) should be the responsibility of a single body, who should assess need and provide services flexibly.

The role of GPs in regularly assessing those elderly people in their practices who might be at risk of psychiatric disorder was vital. In the psychiatrists' opinion, 'trained professionals', by which they presumably meant doctors, must in future assess elderly people before their placement in residential care. Psychiatrists should also undertake to monitor the care of mentally disordered old people who were already living in private residential homes where their welfare might be seriously neglected.

Family stress should be partly relieved by the payment of adequate attendance allowances, which presently compared so miserably with what was easily made available directly to managers of private residential establishments. Finally, they warned that the imposition of the planned community charge or 'poll tax', by adding still further to the cost of keeping an elderly relative beneath the family roof, could prove a serious disincentive to domestic care.

Elaine Murphy, of Guy's Hospital department of psychogeriatrics, denounced the multiple organisations and confused responsibilities which worked to the disadvantage of the frail elderly (1987). Her observations immediately preceded the publication of the Griffiths Report and foreshadowed several of its recommendations. She maintained that Regional Health

Authorities in England and Wales did not know what kind or level of services they should be providing. The funding of community care was split between the NHS, the rate support grant to local authorities and individual claimants' social security entitlements. Inflexibility in social funding and lack of coordination were the order of the day. Meanwhile general practitioners were frequently forced to demand emergency admission for their older patients as the only response to a crisis with which the existing tenuous network of community care could not possibly cope.

In the second of her two papers on this theme Professor Murphy (1988) recommended several solutions to the existing chaos, along the lines of a King's Fund memorandum, (which will be referred to shortly) and the 1986 Audit Commission. She was attracted by the concept of case management, but she feared there could be problems over 'managing the managers'. A third party, in the form of a joint board of statutory agencies with an earmarked budget for the elderly might be a sensible move in the right direction. If care of the elderly was to come under local authority control it would be subject to 'political' pressures and it would require major restructuring of the funding of both health and social services. Even if a major NHS reorganisation was not contemplated, leading to a comprehensive designated health service for the elderly, much could still be achieved. This would only occur if there was a firm central government commitment to this client group along with clearly articulated principles for action. Murphy followed many others in stressing that it would be essential to involve service users and their families. An additional pre-requisite for change would be to ensure that additional resources were made available in each locality prior to any hospital closures to provide the bridging finance for complementary community services. She feared that nothing was likely to change without co-operation at the highest level, between the DHSS and the Department of the Environment, the two ministries concerned.

In Britain GPs have, so far, always been available on demand to attend to old people at home and, if necessary, ease their entry to hospital specialist services. Could their contribution be improved? Thompson observed that the provision of long-term social care for the elderly had little attraction to young doctors, being 'low-tech', involving various voluntary organisations and local authorities and complicated by the ready availability of private residential places (1988). Young GPs did recognise that the problems of the old depended as much on their social needs as on their medical condition and were clearly aware of the extent of unmet need and how resources currently failed to match them, but old people were expected to make their demands directly known to their GP before anything was done; yet the very fact of their declining physical and mental capacities might prevent them from doing so. The writer advocated more attention to the criteria used for allocating various services and criticised the existing tasks done by some home helps substitutable, in his opinion, by volunteers. As for private residential homes, they were growing so fast that GPs could not possibly supervise their occupants adequately. Thompson feared that current political attention to the AIDS epidemic and to the matter of better hospital management left little resources or thought for the frail elderly. He did not, however, suggest that GPs would envisage themselves as care managers or coordinators and he made no proposals for any different form of organisation of primary care.

Mary Davies (1988) commented on the role of general practitioners in supporting the carers of the elderly. Observing that there were well over a million lay carers and that a study in Tyneside had found there were more people looking after frail and disabled dependents than mothers of children under 16, she wondered why they had so far received so little attention from GPs. The primary care doctor 'should be in the best position to initiate an assessment of needs and refer carers to appropriate agencies and services. General practitioners . . . have a key role in ensuring that medical and social assessments of carers are initiated, for it is to them that families turn'.

It was disturbing to find that GPs visiting an elderly patient at home might not actually talk to the family carer. There was a clear need to raise the awareness of health professionals of this unfortunate state of affairs, since carers themselves were often reluctant to make their own burdens known. They might be disinclined to bother a 'busy doctor' or might think their relative was merely old, not ill. Carers deserved to be recognised and given all possible information and advice. Nurses or health

visitors could greatly assist by training relatives in practical aspects of home nursing. Carers should not have to improvise, without recognition or help. Harper et al. (1988) have described a Liverpool scheme in which GPs could easily obtain short-term care for disabled elderly people to relieve their relatives.

The very important contribution of nurses to community care has not always been recognised. The Cumberledge Report on Neighbourhood Nursing was published in 1986. The team which put forward this new proposal for organising community nursing declared that they were not calling for more resources, they simply wanted 'a better use of existing funds to enable people to have a realistic choice of being cared for at home rather than in a hospital or other institution'. They recommended that neighbourhood nursing services should be established in each Health District, to cover the needs of 10,000-25,000 people.

The contentious detailed recommendations of the Report, which sought to give a new breed of community nurses more independence, and which aroused much criticism from doctors, cannot be covered here, but the application of their proposed scheme to elderly people is relevant. For this category of potential patients the broad duties of a future neighbourhood nursing team would be to monitor and improve the nursing services in a local area.

Questions should be asked by the nurses concerning the broad aims of the health authority, the availability of relevant information and advice programmes for early detection of disease by the primary care services, whether regular visiting of certain vulnerable elderly people took place and so on. For our immediate purposes the following recommendations of the Report are noteworthy. For elderly people requiring home nursing care it was proposed that individual care plans should be drawn up and maintained, with the agreement and understanding of patients and their carers. All nurses working with elderly people should be able to give advice on how their clients might obtain other services, such as para-medical services, aids, equipment, domestic support, and welfare benefits. When more than one agency or health care professional was to be involved in the care of any elderly person, arrangements should exist to ensure that the care was properly co-ordinated and the advice was consistent. 'The appointment of a key worker should be considered'. This latter

suggestion reflects the concept of a care or case manager. The nurses tactfully refrained from specifying which precise breed of health or social worker would be best suited for the task but they could clearly see themselves acting in this capacity.

Nursing journals have publicised the activities of community nurses in certain settings. For instance, Frances McCabe reported on how, as a district nurse, she tried to cope with 110 unsteady, housebound elderly patients. The skilled interventions which a nurse could make on two visits were valuable but of necessity strictly limited. In a third of cases no solution presented itself, where 'clients needed a visitor to reduce the time spent alone there may be no family, neighbours may be incapacitated and no volunteer scheme exist'.

The King's Fund Centre's primary care group considered Decentralising Community Services in a 1987 publication, reporting on the views of general managers from 50 health authorities assembled to encourage support for this new approach. A participant observed in passing that, as a group, general practitioners were deeply suspicious of being 'managed' by anyone. The idea of 'neighbourhoods' had by then become popular and it was suggested, that this might 'become a new operational tier, particularly important for the elderly, those with mental and physical handicap, the mentally ill and for the organisation of primary health care'. The managers fancied that some sort of neighbourhood organisation could conceivably prove a way of providing care on a multi-disciplinary basis in future, without being identified with any single profession or group of staff.

The group were pleased that DHSS policy was encouraging health districts to develop appropriate services in their own localities. Devolved community services might provide more support and staffing for primary health care teams in future and this would be a desirable development, since most people went first to their own general practitioners in times of crisis.

Apart from their vagueness, the major weakness of these recommendations of general managers lay in their exclusive focus on community care as conceived by health services. In this context 'multi-disciplinary' working meant no more than the occasional involvement of nurses in tentative plans, drawn up by health service managers and mainly intended for doctors.

Reading between the lines, deep rivalries became apparent, even within the ranks of community nursing. Para-medical workers too were evidently demanding more autonomy in the effort to establish their own professional identity. There was great uncertainty over how 'neighbourhoods' would be defined and speculation about how they would relate to 'patches', the term used for the small geographical areas served by social workers (Sinclair, 1983).

A catalogue type survey of health services for elderly people was also produced by the Kings Fund summarising innovations in the United Kingdom between 1982 and 1985 and drawing upon information provided by NHS district general managers (1986). It simply consisted of an alphabetical list of schemes, with their characteristics, whether the locality was deemed to represent an example of good practice and the name of the key person concerned.

GPs can play a pivotal part in mobilising certain services for their frail patients, as was demonstrated by Hunter and his colleagues in the course of a comparative study of the structure of services for the care of the elderly in Scotland. Perhaps these primary care doctors might not have conceived of themselves as case managers, but they exercised a high degree of autonomy and, in effect, were operating, 'not merely to distribute services among clients but also to distribute clients among services'. Their experiences and conclusions have been reported in several publications (Hunter et al., 1985; 1988).

What the authors aptly called a 'juggling act with the elderly' became clear during interviews with 20 GPs about the mixed reasons which might necessitate referring old people to the geriatric or other services. These doctors found it hard in practice to separate patients' physical and mental problems, but they were keenly aware that the receiving hospital consultants expected strict demarcations of their own respective domains. Other misunderstandings, to do with the perceived division of care responsibilities between GPs and specialist services, had taught the old peoples' personal physicians to be extremely cautious and even cunning over the way they presented a case to potential receivers. Knowing the local hospital service well, they were likely to aim first for the sector most likely to ensure immediate admission, in the hope that an initial acute referral

might lead thereafter to a geriatric bed for their patient. Sometimes a GP issued a veiled threat in a referral letter, for example, 'In view of her decreasing mobility, I suspect the sooner she could be taken to the day hospital the better or she may go "off the legs" completely'.

The GP had to be constantly sensitive to the criteria and aims of the receiving services. Expediency took precedence over fine distinctions between psychiatric, geriatric, and social services. 'A clean delineation is absent, as GPs try everything in order to get something.' The robust pragmatism which prevailed among doctors in the front line contradicted all the orthodox planning theories taught by academics. As to whether GPs were capable of assuming more explicit case management responsibilities in future, Hunter and his colleagues have been cautious. They considered that by no means all primary care doctors were equipped to function effectively in this manner. If a top level agreement to confirm them in such a role were to be reached they would certainly require special training in entrepreneurial and managerial skills and would have to be prepared to participate in planning in a manner and to a degree so far utterly inimical to independent practitioners.

From the same Scottish research came an account of interprofessional co-operation showing how another kind of medical key worker could effectively perform a linking role on elderly patients' behalf (Hunter and McKeganey, 1986). In this instance four clinical medical officers had operated as a 'community services for the elderly team', funded by the local health board. This team worked to resolve differences between the social work department, the housing department and hospital medical services in the best interests of individual patients or clients. Their advice about placements also extended to general practitioners and to managers of residential homes.

The work of the doctors on this team required a keen sensitivity to the interests of other professionals and the capacity to act convincingly as disinterested advocates of the elderly. Historical circumstances in this case had determined that clinical medical officers undertook to see all the old people whose placement was in question. They formed a buffer between consultants and social workers. In fact they had a fairly limited remit, not being concerned with community care in the

sense of care in old peoples' own homes, but rather using the term to cover any care outside of hospital, which meant that they were mainly concerned with negotiating transfers between the NHS and social work residential establishments. This group of young doctors had convinced others working in the locality of their usefulness and impartiality. The authors did not suggest that the model was necessarily transferable to another setting, but they put it forward as a successful example of joint working and case or care management.

In the final research report on the same Aberdeen based project on the care of the elderly several other important points were made (Weir et al., 1987). The study had completely failed to uncover evidence of the implementation of planning of services for the elderly as conceived from the top. 'Policy for the elderly, as it is framed nationally and, to a lesser extent, locally is broad, abstract and disconected, split between a number of agencies and departments... (But) at least three sets of delivery-level decisions are important in determining the effects of policy for elderly people: first, service providers' decisions about who gets access to which services; second, old peoples' own decisions to enter particular services and, third, relatives' decisions on whether or not to seek assistance and under which circumstances'. In other words, grass roots decisions were all important.

There was no evidence that people were moving logically through a continuum of care, from independent living, to sheltered houses, then on to residential homes and, ultimately, to hospital. On the contrary, the old zig-zagged back and forth and in and out of different kinds of care. Service providers had scope for discretion and consumers too were capable of exercising a fair amount of pressure. The important role of the 'front line operators' should always be appreciated.

In passing, the surprising amount of autonomy which Scottish social work departments granted to home-help organisers and supervisors should be noted. The latter 'were more or less left to exercise individual judgement and discretion', regarding both the recipients of help and the nature of the assistance which was given. They did not concentrate on any particular type of elderly clients, instead help seemed to be forthcoming on a first come, first served basis. Sometimes it was invoked to keep an elderly client at home. Otherwise, the services appeared to be

'purely reactive and situational'. The precise role and tasks of these women were also very ill defined, although a home-help was viewed more as a helper than as a friend she often did act as a companion.

The Kent Community Care Project has probably received more attention and acclaim than any other in Britain, in part due to the extensive documentation and publication on the subject by its originators Challis and Davis (1980). Their early account outlined their novel approach to the community care of the elderly. The aim was to mobilise or generate extra help in the community to meet the needs of vulnerable elderly people who appeared on the point of requiring residential accommodation. The innovators ambitiously attempted 'to meet the accountability needs of the local authority without unnecessarily constraining or delaying decision making by the field workers'.

The essential key to achieving these dual objectives was a decentralised budget. It had been difficult to persuade the local authority to grant this but, once it had been secured, experienced social workers were then able to use this money to co-ordinate care for individual elderly clients. Certain clear guidelines were set to ensure the necessary accountability. First, the clients were restricted to those who would be eligible for residential care but for whom continued independence in the community was preferable. Secondly, a fixed limit was set upon the weekly expenditure for all departmental resources per client. This must be no more than two-thirds of the marginal costs of local authority residential care. Thirdly, to help them decide which services would be most appropriate, the case managers had available unit costs for all the existing departmental services.

Having a budget, the workers in charge could shop around for help outside the statutory services, paying willing helpers in the local community by the hour or even contracting with a private agency to provide specific services at a suitable rate for a particular task. This introduced a novel and notable degree of flexibility which the statutory services could not match. For instance, it meant that local helpers could assist the elderly early in the morning, late at night and at weekends and holidays, when home helps were not on duty. Such care attendants did not substitute for home help, instead they provided a complementary service as and when required.

The scheme was originally set up using a quasi-experimental design. Two groups of elderly people were selected from towns with similar socio-demographic characteristics. There were many retired people in both places and the residential care and hospital facilities were comparable. Only the experimental group of 35 received the new case management treatment, the others being left to the usual mix of services. All the elderly people were assessed at the end of 12 months to compare the reduction in their needs or improvement in their welfare. By this time only four clients from the experimental group had entered residential care whereas 12 from the control group had been admitted. Twenty-four of the experimental clients remained at home in the community after one year, only 15 of the controls did so.

Using scales to compare the quality of life of survivors within the community in each locality, there were a number of measurable improvements, at a level of statistical significance, in the experimental group. The research team pointed out that a higher proportion of the experimental group of elderly people had been particularly needy at the outset and they might have been expected to require admission to an institution, yet their well being had improved substantially.

Since then the Kent system has been described and discussed in detail in a large volume (Challis and Davies, 1986) and a stream of additional papers have come from the Personal Social Services Research Unit in the University of Kent, at Canterbury. The original basis idea of case workers as brokers has been developed into the BRITSMO concept—British Social Care Maintenance Organisation (1987a), mentioned in Chapter 4. This plan purports to demonstrate how to develop the role of the local authority 'in the most efficient and equitable way possible', in relation to responsibilities for the long-term care of the elderly. The original idea of social workers as brokers is now envisaged as capable of major extension, applying to the better off elderly as well as to the poor, and involving buying care from a wide range of sources. Ultimately the idea has been carried even further, towards proposals on the future insurance of the risk of long-term care (Davies, 1987b).

A scheme modelled on the Kent experience was set up in Gateshead (Weare, 1983; Luckett et al., 1985; Challis et al.,

1987). The northern team consisted of a team leader, who was a senior social worker, two additional social workers, an evaluator and a clerical officer. As in the south of England, the team had a budget of up to two-thirds of the cost of a residential place to look after an elderly person at home. Great emphasis was placed upon flexible, suitable care, closely matched to each old person's requirements. Assistance could be brought in from locally recruited care attendants. The detailed accounts of the admirably sensitive manner in which assistance was closely tailored to clients' detailed circumstances are worth reading carefully. The central aim was to render help to any existing family carers so that they could continue to cope, and the managers were careful not to undermine relatives' efforts. The stages which the procedure followed should by now be familiar. Again, the worker operated primarily as the client's advocate and she was prepared to back her own judgement against that of other professionals if necessary and to take sufficient time to win the confidence of friends and neighbours. After this scheme had run for twelve months in one social service district a dramatic reduction in the local waiting list for residential vacancies was noted. Accountability had been satisfactorily assured. District nurses, home helps, and others had been re-assured that their own jobs were not in danger and local doctors and the relatives of elderly patients at home had all recognised that the help given was reliable and of good quality.

The most important feature of this arrangement was 'its ability to cope on a long-term basis, seven days a week, 52 weeks a year with very frail elderly people'.

A third experiment, using a community team, has been operating in the London borough of Lewisham, to deal with the needs of elderly people who are mentally ill. Professor Murphy, of Guys Hospital psycho-geriatric unit, developed the scheme because of local need and a shortage of in-patient beds (Murphy, 1986). The components of what functioned as an assessment team in this instance were a consultant psychiatrist, two junior hospital doctors, two social workers, two occupational therapists, a clinical psychologist, a part-time physiotherapist, two community psychiatric nurses, and two secretaries.

The co-operation of the health service, social work, and voluntary organisations had all been previously negotiated,

although this had not been easy. Unlike the situation elsewhere in the country, where GPs act as the sole gatekeepers for hospital facilities, it was proposed that cases could be directly referred to the Guy's team from any agency. The new idea of open access initially met with strong resistance from the British Medical Association and from the local Family Practitioner Committee but it was eventually accepted. On receipt of a referral, any team member could go to the old person's home to make a domiciliary assessment of medical, psychological, and social problems. This had necessitated prior training for all concerned and the establishment of mutual trust. Any member of the team could admit a patient to one of the assessment beds in an emergency. Case conferences, with rotating chairmanship, took place weekly.

Over the course of a year, 180 out of 451 referrals came from hospital consultants, but 115 were directly from social workers (home care organisers) and only 102 from members of primary care teams. Relatives and neighbours had directly referred 11 people and 3 had referred themselves. Forty came from residential homes. Initially there were only eleven assessment beds available and the team had no impact on admissions to long-term care. However, once the assessment facility was enlarged, a 75 per cent reduction in admission to long-stay beds was achieved.

Subsequently the Guys' research unit, together with Age Concern, have been assessing the effectiveness of using care attendants in two matched areas of two urban areas, Ipswich and Newhaven. As in the Kent and Gateshead schemes, a cost limit was placed upon the amount which a 'development worker' could pay for locally recruited home care. The project has brought considerable satisfaction to dementia sufferers and their families.

A related project has been started by the Open University and the Policy Studies Institute and funded by the Nuffield Provincial Hospitals Trust (Johnson et al., 1987). In this three-year experiment three 'care co-ordinators' for elderly people have been based in general practices. The co-ordinators assess individual needs, using a novel biographical approach, which takes into account old peoples' past experiences and expectations. Packages of care are then devised to help them remain in their

own homes. Each care co-ordinator has a case load of 30-35 old people and the clients' average age has been 82. In the course of the scheme the key workers or co-ordinators have enlarged their own personal skills in counselling, their familiarity with welfare rights, and their understanding of the roles of all the other professionals working with the elderly. Throughout the project the key workers have always taken the needs of carers into account, but the investigators were cautious about the value of 'respite care' which could dis-orientate an old person, although day care was approved. The co-ordinators did not have a budget, they were working as members of primary health care teams and funded by research grants.

The Gloucester project has been mainly 'action research' but the intention is to carry out more systematic evaluation later. It has emphatically not been a case-control, before and after experiment. Instead, changes have been successively introduced in the course of the scheme as all concerned have learned from experience and have adapted to new circumstances. So far a series of project papers have issued from the team (Johnson et al., 1988; Dant et al., 1987; 1988). These reports are useful sources of literature on the whole subject of care of the elderly, dealing with identifying, assessing, and monitoring as well as with structured dependency in old age and the continuing poverty of many pensioners, in spite of social security.

In 1987 the King's Fund published the memorandum which they had submitted to the Griffiths review. Promoting Innovation in Community Care reflected these analysts' views on the prevailing sad state of affairs and endorsed the Audit Commission's 1986 diagnoses. The Institute aimed to publicise a number of notable small-scale developments which had already appeared. They did not favour major organisational change. The writers put it concisely when they said, 'The central challenge facing community care policy and practice is to make happen on a large scale what is already occurring on a small scale for a few people in some of the best services across the country'.

The main recommendations in the King's Fund briefing paper were along the following lines:

There was a need for clear values and principles about what community care services were trying to achieve. (So far, principles for the mental handicap services had been articulated more clearly than those for the elderly). Any service should clearly serve the interests of individual clients. Choice, consultation, information, participation and autonomy were vital; the days of 'welfare paternalism' and professional dominance were long past. New developments in professional knowledge and techniques must henceforth be harnessed to help clients realise their full potential. Access to appropriate general opportunities and services should be made easy. The agencies concerned included housing, employment and leisure services as well as the NHS, social services and social security.

The Kings Fund paper summarised the Audit Commission's six important shared features of good innovatory schemes, namely: the existence of strong and committed local 'champions' of change; a stress on action rather than bureaucratic machinery; locally-integrated services, cutting across agency boundaries; a focus on the local neighbourhood; a multi-disciplinary team approach and, finally, partnership between statutory services and voluntary organisations. But the Kings Fund did not accept all these assumptions. They thought that reliance on charismatic champions was ill-advised, since such exceptional individuals might reduce their followers' initiative. Instead there was a demonstrable need for a programme to train people in the basic skills of negotiating between services and agencies on clients' behalf. There must be willingness to delegate responsibility to the local level, where any action would occur. Real progress was always the result of 'developments at the so-called micro-level', although an agreed overall strategy was undoubtedly a prior necessity.

People in a locality must be consulted and encouraged to participate in planning the health and social support services, and, in this connection, they praised Crossroads care attendant schemes. Flexibility at the local level was certainly important but it should not be at the cost of poor overall co-ordination or service quality. They commended Dalley who, when discussing NHS community units, warned that, although a decentralised unit sounded like a neutral notion, 'it exists in reality in a value laden environment where competing values and pressures abound' (1987).

With respect to the government's often repeated plea for partnership between statutory and voluntary organisations, the Kings Fund authors were in no doubt that the latter sector could never replace state provision. Volunteers could however, usefully act to orientate other agencies towards the needs of informal carers, so far grievously neglected by service providers.

The Audit Commission had advocated and Griffiths subsequently advised making local authorities the lead agencies for community care of the mentally and physically handicapped. In pursuit of this policy suggestion it had been proposed that there should be a specific local care manager specifically for the elderly, with an earmarked budget, overlooked by a joint NHS and local authority board. The Kings Fund rejected the idea of fundamentally redrawing agency or service boundaries. Instead they thought future developments should grow out of the many good local schemes already in existence. Financing was a key issue, particularly since the use of social security board and lodging allowances had encouraged private residential care. Here the Fund was cautious, simply saying, 'mixed sources of financing which contribute to agencies' overall budgets give them a degree of flexibility'. They were of the opinion that the necessary public accountability could still be assured, provided that a manager was made responsible for co-ordinating such arrangements and carrying out what would amount in effect to a brokerage role.

The writers strongly recommended that more attention should be given to the idea of 'case' managers. As they used the term, case managers were not the same as Griffiths' 'care' managers, who would certainly be operating at a higher organisational level. Case managers would be the 'key workers', who could have a range of previous backgrounds, but whose task would be to assemble 'packages' of services and sources of care for individual elderly clients. They regarded the Kent Community Care project as an outstanding example of this manner of working and cited other valuable illustrations, in Pimlico, Hackney, Newham, Bristol, Greenwich, Stockport, Southwark and Camden.

The Kings Fund itself supported a brief, experimental case manager project in Camden, evaluated by The City University (Anderson et al., 1986; Pilling, 1988). The objective had been to provide local adults with physical disabilities with a package of services which would meet the client's wishes. It would make

the best use of the available existing services, which might be unknown to those who need them or who were unsure of their eligibility. Client orientation was absolutely central to this exercise. It involved, first, identification of the client and a holistic assessment of their needs. Next, an agreed plan was drawn up with the client, regarding the tasks that had to be accomplished. Eventually the case manager tried to facilitate the provision of services, either by the client, who was by now properly informed, or directly, on the client's behalf. The case manager monitored all the arrangements, smoothing out difficulties, calling case conferences if necessary and generally acting on the client's behalf. It is important to appreciate that in this instance the case manager had no budget, being entirely reliant upon voluntary co-operation by the representatives of local agencies. The plan was based on North American models which had been viewed at first hand and the originator and executor had been a social worker (Anderson et al., 1988).

In addition to the primary aim of providing a client oriented service for people in Camden with severe physical disabilities, this trial scheme had two other objectives, namely, to give relevant information to local service providers and help them with co-ordination and, lastly, to provide a general overview of existing service provisions in terms of their perceived appropriateness and adequacy.

The modest pilot project dealt with 142 referrals in fifteen months, 38 per cent being elderly people of 65 years and over. Most of the clients had previously experienced difficulty in obtaining help and 75 per cent later expressed satisfaction with the service. However, a control group, who had not come into contact with the case manager, proved equally contented with their lot. The experiment was deemed to have been no more than a qualified success, partly defeated, it was thought, by the sheer shortage of facilities in Camden and Islington.

Other professionals in the area were asked whether they might have wanted to act personally as case managers. Only occupational therapists seriously envisaged themselves any such role. It is noteworthy that social workers did not aspire to work in this capacity, seeing it as incompatible with their customary wide ranging, generic responsibilities. They also felt that they were seen by members of the public as authoritarian figures, far removed from individual client advocates and they fancied some people would feel a stigma attaching to any contact with them. For their part, the local general practitioners had no personal desire to be active co-ordinators of other services for disabled patients, although they certainly welcomed assistance with such tiresome tasks. A health service manager caustically observed that the position of GPs in the NHS structure made them totally unsuitable as managers, since there was absolutely no control over such doctors themselves and their concept of independence was quite different from that of any project manager, who had at least to be responsible to those who funded the experiment.

The concept of care or case management has been helpfully clarified by David Hunter in the publication *Bridging the Gap* (1988). He examined why this idea has recently come to seem the answer to long established problems about poor co-ordination; what it might amount to in practice; how public accountability could be ensured, and what special skills or new training would be required.

Hunter drew attention to the persisting confusion between the need for increased efficiency and public accountability on the one hand and clients' requirements of participation and advocacy on the other. People wanted to choose what services suited them best. Comprehensively managed care demanded from its practitioners both political and interpersonal skills. Tact and diplomacy were essential as well as familiarity with all the available local resources.

If the idea of case management were to be taken seriously, decisions would have to be made about programmes of special training and the necessary qualifications to fit people for this key task. The vexed issue of compatibility between independence and the use of agents' discretionary powers versus their departmental allegiance, within the social services for instance, would need to be addressed. How far could what would amount to a new 'profession' of this kind continue to act primarily as client advocates if they had a personal stake in the system, as its employees?

Comparing the different models and multiple meanings beneath the specifically attractive notion of case management, Hunter cautioned of the obstacles to introducing a new category of worker into territory to which so many other professions had already laid prior claim. His book supplied descriptions of three projects: in Camden, in St Bartholemew's Hospital and the work of the disability team for Westminster, Kensington and Chelsea.

The role of client advocate may only be one part of a case manager's work and, in some instances, they may act in a more directive fashion. The experiment in Camden and Islington has already been described, where the case manager tried to function empty handed, in between the various statutory services and with no sanctions. Similarly, in Gloucester the new co-ordinators have simply been researchers. Griffiths had apparently envisaged 'care managers', who would not merely be administrators but would also work on individual clients' needs, but he was not very clear on this point. His Report had recommended that no-one should be discharged from a long stay hospital (for the mentally handicapped, for instance) without having a 'key worker' to arrange appropriate community provision. But his suggestions were minimal with regard to people with care needs who were still living precariously in the community and had never had an encounter with the hospital service.

There is clearly continuing uncertainty about two different kinds of activity, on the one hand that undertaken by someone trying to maximise the use of community resources for one particular client and, by contrast, a manager of resources. Should case or care managers be both organisationally and financially independent of the local social services department and the NHS, as was the case in Camden, or should they be actually located in and deriving their authority from a social service department? Griffiths seemed to be advocating the latter solution.

Towards the end of 1988, when no government response to Griffiths' recommendations was forthcoming, the Kings Fund Institute undertook a survey of health service managers and social services directors across the United Kingdom to elicit their views on reforming community care policies and their attitudes to the proposals in the Report (1988). Of directors and managers, 91.3 per cent considered that action was required, the social service directors being marginally more emphatic than the managers. Community care was universally perceived as a problem. Change was essential.

There were, however, marked differences in response to

details of the actual Griffiths proposals. A significant minority of health service managers were opposed to Griffiths, nearly one-third reserved their position, even those in favour were lukewarm. By contrast most social service directors were enthusiastic.

The formal views of health authorities and of social service committees were also sought. Again there was a contrast in the degree of support. Health authorities were rather more inclined to support than oppose, but a large proportion of health authorities (60 per cent) and of social services committees (31 per cent) reserved their position, prudently awaiting the government's lead.

The Kings Fund performed a further useful service at the time by scanning practitioner journals and the national press. As a result they ranked in order the key issues which were causing concern: resources; social service departments as lead agencies; care management; a Minister of Community Care; the health care/social care divide; collaboration and planning; training; information and monitoring; community carers; housing; voluntary organisations and, at the foot of the list, the private sector. Some of these major policy issues will be raised again in the final chapter.

CHAPTER

7

Who will care?

when no specific policies for community care have yet been announced. The Government's White Paper on the NHS, Working for Patients (1989), surprisingly sidetracked the subject. The hiatus and confusion have encouraged much speculation and some special pleading. There is little point in recommending yet another speculative scheme. Nevertheless it is possible to draw conclusions from a number of encouraging experiments and initiatives and to lay down broad guidelines for better practices in the future, or at least criteria by which any future policies can be assessed.

From either side of the main professional divide between social work and medicine there are demands for change. Everyone agrees that something should be done to make planning more effective and local action more flexible. The good innovative schemes which have already been cited are only a sample of what exists. Health Boards and Social Service Departments in many parts of the country have drawn up tentative plans for improvements but their implementation has been prevented by the lack of clear central decisions and guidelines on responsibility, financing and staffing. In Scotland, for instance, the official document on Health Authorities' Review of Priorities for

the Eighties and Nineties put the problems of dementia and the care of the elderly at the top of the list (SHHD, 1988). Their views were endorsed by a statement by the Association of Scottish Directors of Social Work (1988). Voluntary organisations, notably the churches, have contributed imaginatively in Scotland to the well being of old people, both in the provision of Eventide Homes and by initiating care attendant and good neighbour schemes. Bodies likes the coalition of age related organisations called Scottish Action on Dementia have had a notable impact on public awareness and professional concern for the most vulnerable of the frail elderly (1986, 1988). Some charities anticipate a greater role in the future under a government which professedly favours voluntarism, although reductions in local government finance and the ending of MSC schemes which made possible the employment of young people as community workers by voluntary bodies have so far had a directly contrary impact. In Scotland as elsewhere the private sector has continued to increase the provision of residential places without showing any inclination to diversity into the much less profitable and more neglected area of home care.

The worst that could happen would be if those who are already actively working for frail older people should be discouraged. The lack of co-ordination which presently reduces the impact of all services and agencies undoubtedly needs to be addressed. Standards will have to be set and examples of good practice brought within the reach of all. Meanwhile certain clear principles can be laid down as guidelines for policy in the interest of those whom all the existing organisations are designed to help.

(i) Frail older people are entitled to the same respect for their dignity and their human rights as anyone else. The mere fact of having lived for a certain number of years does not mean that someone should have to accept poor housing, inadequate heating, indifferent diet, and a low quality of life. Both in their own homes and in hospital the old are entitled to the same high standard of medical care as younger patients who fall ill. When they need assistance with the activities of daily living at home or when they can no longer manage their own personal hygiene, the old must be treated with respect and understanding, with the

aim of ensuring for them the maximum autonomy. Those who bring them assistance should try to comprehend what it is like to be old and disabled. The helper must attempt to put themselves in the place of the other and envisage how best to improve a life led under duress. There can never be any excuse for offering a poor service simply because clients are poor or for reducing the level of care because of someone's reduced life expectancy (Campbell, 1985).

The principles of fair treatment for older people should find expression not simply in the allocation of appropriate direct care or in charity. It involves organising taxation, pensions, social security benefits and housing so as to make it possible for more elderly people to have the quality and kind of life they themselves would choose. The experience of ageing in contemporary society is modified for better or worse by the financial, material, and social circumstances in which people are compelled to exist.

Poverty and lack of creature comforts are often allied to bereavement and sheer monotony in a manner and to a degree which the young would find unendurable. We have to get rid of the assumption that because someone is nearing second childhood they should have to put up with second class treatment, becoming literally second class citizens. The matter of inequalities in health has been much debated, starting in the early years of the NHS and recently revived in the context of arguments over a divided Britain (Maclean, 1988). Thane has argued that such inequalities may be notably reduced for future cohorts of the old (Thane, 1988). Meantime the recognisable consequences of a deprived upbringing upon substantial numbers of today's older people must be mitigated and not worsened by indifferent living conditions.

(ii) The elderly should be entitled to forms of support that do not presume the existence of family and friends or burden them beyond reasonable endurance. The pressures on carers have now been demonstrated. Many certainly feel affection and a sense of duty towards their elderly relatives, but their own personal needs for respite and self-expression deserve recognition. The great majority of older people continue to live in private households. For their support to be adequate it needs to be

targeted and to involve consultation with any family carers who exist, picking up where they cannot cope and supplementing their efforts. It must be appreciated how much ageing is a feminist issue (Allan, 1988). Most of the old and most of their carers are women. Because of demographic change we shall soon have less young people in the population and even more women working away from home. Their availability to look after disabled relatives can no longer be assumed (Wicks, 1988). The government has been giving recognition to the need to free younger women for paid work by accepting the case for increasing nursery provision. What about the needs of the old, whose carers may now number six million? (OPCS, 1985). We do not yet know the effect which high levels of divorce and separation in past decades are going to have upon people as they age and how family dynamics will operate. As matters stand, the needs of the young for supervision will probably take precedence over the demands of old people. Signs of an intergenerational conflict are discernible. Not only under school age children but young AIDS victims are likely to have priority as objects of increased attention and resources. From many aspects it looks as if there will be more very old people with fewer unpaid family carers. This situation will result in demands for increased medical and social services and for more care attendants. Men may even be induced to play a larger part in support activities at home in future, although changes in gender roles are certainly not easy to bring about.

Until family responsibilities are redistributed, anyone involved in providing or devising packages of care for the frail elderly should envisage them as part of a family or of groups who contribute to their welfare and who also deserve consideration. The unrecognised, invisible work of tending and surveillance, going on 24 hours a day, for months or years, can eventually turn a second person into a patient. Doctors, nurses, home-help organisers and those finally deputed as a 'keyworkers' or case managers need to be alert to signs of strain and desperation which relatives may often be reluctant or ashamed to admit.

(iii) Another criterion for satisfactory care must be a means of identifying the frail elderly. To decide who would best be

responsible for this is by no means simple. Instead of envisaging a large extension of health visitors and the institution of age sex registers in every general practice, it might be preferable to institute something similar to the Guys Hospital team (see p.92) where any one of a number of people, from varying backgrounds, could report centrally upon the need for early assessment of a particular old person. Or it could be made a statutory duty for community nurses to locate the frail elderly. This would certainly mean training and employing more of them as well as changing legislation to make the very old as much of legal a responsibility as the very young. Under present Government policies this is most unlikely.

On the other hand, community nurses and in particular, district nurses are already more acceptable and familiar visitors in the homes of old people than social workers, whose attentions have come to be associated in the public mind with a certain stigma. Practical assistance from district nurses is enormously appreciated. But it is difficult to envisage such practical nurses, with their present very necessary skills, functioning as case managers. This would certainly require a mechanism for commandeering further resources, in the shape of augmented home help, for instance, or care attendants whose tasks would have to complement without threatening those of the nurse. In addition, these nurses would require a modification of their present training to include the diplomatic management of a range of sources of assistance, without distracting them from their invaluable bed-side tasks. Here the whole question of division of responsibility and accountability cannot be baulked.

There is, unfortunately but perhaps not surprisingly, little mutual trust between nurses and social workers. They may be operating on much the same territory but with different aims and background training and, most significantly, serving different masters. The Cumberledge Report briefly mentioned an instance where a community nursing team was 'joining forces with a local authority social service department to run a dusk, night and dawn service'. The same document, however, found absolutely no support for the idea of returning community nursing to local authority control (1986). Instead, Cumberledge proposed neighbourhood nursing services which would operate much more independently of general practitioners than at

present whilst still constituting, in some sense, separate primary health care teams.

A means must be found of improving the motivation of nurses and maximising their vital contribution to the care of the elderly without exacerbating their existing suspicions of doctors and social workers. They themselves have argued that the money saved on hospital care could go towards increasing the members of nurses in the community and modifying their training. But inter-professional rivalries persist. It has happily been possible in some settings for a key worker at 'street level' to ensure the co-ordinated contributions of both nurses and local authority workers in the interest of disabled older individuals. Whilst these detailed local arrangements do pre-suppose agreements at higher administrative levels, the value of specified patient advocates, or case managers, close at hand, has been borne out time and again.

(iv) There is little doubt that in the interests of older people alone improvements in general practice ought to be encouraged. But how realistic is the suggestion that GPs should be designated for the role of case manager? On the face of it, the GP might seem to be admirably placed, since everyone in the NHS in Britain has direct access to a primary care physician who is obliged to respond to their health needs. Many doctors now operate in 'teams', with associated nursing and other services, and there have been occasional experiments in locating social workers within health centres or group practices. Doctors supposedly have a close relationship with individual patients, whom they may perhaps have known for years. And the elderly make increasing use of doctors as their age increases.

However, the actual situation is often less their satisfactory. Cartwright and Smith noted that, whilst GPs did have a rather better relationship with their older than with their younger patients, being less inclined to regard consultations with the old as inappropriate and trivial, yet there was actually a much smaller increase in consultation rates with age than in reported sickness (Cartwright and Smith, 1988; OPCS, 1985). So elderly people were probably being seen less often than their state of health merited. At the same time there was a notable rise in prescribed medicines with age and these were not being moni-

tored adequately. More home visits might be merited by the very elderly, who were likely to have special difficulty in getting along to the surgery. If doctors did visit the homes of old people they would certainly be able to assess their circumstances and the degree of support and company they had. But a third of the random sample of old people throughout England interviewed for Cartwright's painstaking survey on health and medicines had never been visited in their homes by their doctor. The doctor's personal attention would be re-assuring to patients and would help them feel that someone was taking a close personal interest in them, so it is unfortunate that considerations of time and other pressures are reducing this habit. Cartwright's evidence does not support the idea of having a doctor as the one person who would note and respond to early need for assistance since the very fact of someone's increased immobility might well inhibit the direct call for help which is presently needed to trigger a GPs reaction.

It is also well known that the quality of general practice, measured in the simplest terms of accessibility and availability, varies across the country. Conditions for people living in inner London are particularly unsatisfactory (Acheson, 1981). Even if energetic attempts are made to rectify this situation, geographical differences in the quality of primary care are bound to persist for a considerable time, thus rendering some elderly patients at a special disadvantage when it comes to mobilising home, as opposed to institutional care. Evidence already provided (see p.84 above) has suggested that few GPs at present have the inclination, the time or the skills to act as case managers. Yet the fact remains that, as matters now stand in this country, primary care doctors are the professionals with what amounts to direct statutory responsibility for the care of their elderly patients. But the GP can interpret quite minimally the obligation to respond to calls for specific medical attention. Perhaps GPs increased involvement could be judicially encouraged in future by further financial incentives? Part of the problem lies in the overlap of medical and social needs, with doctors inclined to concentrate upon the former, even though everyone on a GPs list is, in some sense a patient.

Theoretically, matters in general practice are splendidly organised. In the words of a statement by the Community

Medicine Department of a Scottish Health Board. 'The multidisciplinary primary care team, based on a GP in his practice ... would consist of the GP, health visitor, district nursing sister, social worker, physiotherapist, occupational therapist, chiropodist and medical secretary ... supported by Regional Authority services and voluntary organisations. This team should be in a position to provide most of the services required'. However, an important caveat was offered, to the effect that such a team could only function properly 'if there is excellent co-operation between them and if there is informed support from the home help service, voluntary groups, Meals-on-Wheels, laundry services, etc, etc.' So this may be an ideal vision (Lothian Health Board, 1988).

Supposing the responsibility for community care of the frail elderly came to be placed, not upon local authority social service departments, as Griffiths recommended, but upon general practitioners, what are the minimal criteria for improving the delivery of care to this group? First the existence and location of the old would have to be known. Computerised age sex registers should make this easier to arrange. But there is no point in having registers without a system for regularly contacting the elderly deemed most at risk of deterioration, collapse, or loss of support. This contacting could, as we have already seen, be the responsibility of people from a range of backgrounds, but they would all need at least a modicum of training before they could be engaged and delegated with the responsibility. They could operate amongst the elderly in one practice in a systematic, screening fashion. Alternatively they would have to make it their business to pick up information from a range of other sources and individuals who were in contact with old people. In the nature of things, it is the most isolated elderly who would be liable to be overlooked. Once aware of a need for support or for medical assessment such workers might then have to arrange for the elderly person to be seen by the doctor or sent for geriatric scrutiny. How far a lay person or, at least, someone 'nonmedical', would be acceptable in this capacity is debatable, although the Guys Hospital out-reach scheme which has already been described provides one encouraging example of what can be achieved.

The main point is that it would not be enough simply to

designate GPs themselves with the responsibility for community care. A person under their direction, paid for by the health service or a community care budget, would need delegated responsibility for this expanding area of work among disabled elderly people so as to give it the time and skills required. Neither such a system nor such case finders or case managers exist at present and, unless community nurses were to be decisively diverted from other tasks, it would required expenditure on both salaries and training. This leaves out of consideration the vital matter of also recruiting and paying for the care attendants who have proved valuable in filling the gaps in any day between professional visits and attentions. The use of the word 'valuable' is deliberate, since care attendants can undoubtedly save the NHS money, as the Harrow work has shown in reducing re-admission of old people to Northwick Park hospital.

We would have to ask how far someone with clinical medical skills, working within the health service and who was moreover, an independent contractor, could ever become the agent for managing or securing the services of people from other backgrounds and other professions, in the public services or beyond. Whilst the few community occupational therapists, physiotherapists and chiropodists who are around might conceivably be 'called in' by GPs, their own increasing drive towards autonomy and professionalisation would tend to militate against such a system. Relationships of primary care doctors with geriatricians or psycho-geriatricians and the potential assessment teams of consultants should, theoretically be easier to improve and organise in a manner conducive to everyone's satisfaction, including the patients.

It is difficult to envisage a GP, or her colleague in a practice team, being able to demand immediate home support for someone, thereby over-riding the discretion presently exercised by home help supervisors accountable to the local authority pay masters. It is not impossible to mobilise help, as has been demonstrated in experimental case manager projects, notably in Kent and Gateshead, but there would probably be an exacerbation of latent antagonisms between medicine and social work if primary care were to be officially acknowledged as the operational centre of total community care. Relationships between the two professions have never been easy, quite apart from the

separate structures and hierarchies which are entailed. The outlook of doctors, trained to diagnose disease, and that of social workers, with an eye to the environment, differ widely and ideologies acquired in early training are daily reinforced by separate experience and practice. This topic was well explored by June Huntington (1981), drawing on her experiences in England and Australia.

Improved care for the frail elderly in the community will not automatically derive from building on the GP's role as the natural first source of clinical help in a storm (Marks, 1987). It will need fundamental changes and increases in financing and in the staff available at this level to detect and dissect individual needs and enlist and pay people to fulfill them. Case management and caring attendants cannot simply be conjured out of thin air. At present it is certainly the GP who decides whether to send someone to hospital, but this should be a last resort and not the only available supportive measure in adversity.

Turning now to the essence of Griffiths' own preferred prescription for community care, we have the prospect of responsibility for care devolving upon social service departments. This proposal does not, however, constitute a simple scenario and might not necessarily prove the best way of improving the lot of the old. There are a number of obstacles to its implementation, both concerned with the probable acceptability of such a policy and with its practical implementation in terms of levels of available staff with appropriate skills.

As Deakin has observed, the present administration has been a centralising one, which has systematically reduced the powers of local government and challenged the basic legitimacy of its activities (1988). Paradoxically this process has proceeded at the same time as individual citizens have been exhorted to exercise more initiative and personal choice. One result has been that councils which have ventured to introduce innovations in care, supported by temporary joint NHS/local government funding, and who have subsequently picked up the bill for continuing a service, have actually been penalised for 'over spending'. Meanwhile, as the 1986 Audit Commission showed, the number of residential care places for the old provided by local authorities in England and Wales have remained virtually unchanged and domiciliary services which allow the older

elderly to remain in their own homes have been struggling to keep pace with demographic trends.

Griffiths' recommendation was that local authorities should in future draw up plans for their proposed expenditure on all those requiring community care and that central government should provide a specific component of the rate support grant for that precise purpose. Money would also come from the Social Fund and from local sources. Community care money should be 'ring fenced' and recipients of assistance would be means tested. Griffiths anticipated that a great deal of prior work would be necessary even to develop indicators of need for each locality. These would thereafter form the basis for the distribution formulae. The money eventually granted could not be used for any purpose other than community care of the key client groups.

Local authorities so far have been strongly resistant to the idea of receiving money reserved for a designated purpose. Such a limitation strikes directly at the essence of their treasured independence and remaining freedom of choice and would be likely to be seen as still further evidence of domination from Whitehall. It seems at any rate inherently improbable that a central administration which has so far consistently endeavoured to curtail the powers of local government would decide to increase their direct funding and responsibilities, even if the money was to be cost limited and for specific purposes. This reservation regarding the Griffiths proposals is not offered on the grounds of the desirability or otherwise of putting local authorities in charge, it simply makes the point that they are most unlikely to be made the new champions of the elderly and the mentally disordered in the prevailing political climate of Britain.

Could local authority social service departments actually operate in the way Griffiths envisaged, planning and managing the funding of community care? They are certainly not equipped at present to take over all the community care elements of health authorities. In fact, they would presumably not be expected to act as monopolistic care providers but would have to engage in close consultation with the other service. But the financial and planning responsibilities envisaged would have to go far beyond the present management of home helps, meals

on wheels and residential homes. Care managers would be concerned with balance of care considerations and would be obliged to shop around for the cheapest forms of care for clients, trying to estimate the entitlement of informal carers, voluntary organisations and private providers to a share of the limited funds available. Means testing and assessment of clients would certainly feature in this scenario as the elderly, or their families, could no longer choose to apply directly to a private home and then have the bill picked up by social security. They might be obliged to remain in their own home, in spite of deteriorating faculties, whilst their entitlement to and the level of support under their own roof was being determined by social workers. Care managers in social service departments would be given considerable additional discretionary powers in the allocation of any domestic resources to 'deserving' or 'needy' elderly people who have so far at least managed to escape the stigma of such unwelcome scrutiny at the point at which they opt for a private home.

Leaving aside the matter of recipients' individual basic rights to welfare payments as against the distribution of means tested benefits, the social workers operating a Griffiths type scheme would be asked to behave in a manner unpleasantly reminiscent of workhouse managers. They would be required to decide, first, what categories of clients needed certain proportions and kinds of the available cost limited, community care funds. Then it would be a matter of deciding which individuals merited financial or practical assistance and which of them should be told that they must make their own private arrangements.

So much for the difficult and invidious tasks which would face community care managers working in social service departments. Do the right kind of workers presently exist at the street level able to perform as case managers in the fashion repeatedly outlined in this book? Social workers at present have little or no direct personal contact with elderly people in their own homes but, in future, employees of local authorities would have to decide whether and what sorts of home support was needed to enable someone to continue living independently, over and above the present home-help service.

As has been stressed, this task would require diplomacy as well as the power to purchase the services of care attendants. It

has been suggested that some home help supervisors might perform in such a role (Kent, 1988) but it is unlikely that many would have the abilities to extend themselves so far beyond their present limited responsibilities or that they would command the respect and secure the co-operation of the related health professionals upon the scene. Geriatricians would be certain to question the capacities of such workers to make proper first-hand assessments.

The case managers' case has already been sufficiently argued. If an improved service for frail elderly were to be organised by local authorities, early decisions would have to be made about the kind and numbers of social service personnel needed to act as client advocates. Thereafter suitable people would have to be trained. None of this could be done without financial resources which, in the case of a Griffiths type innovation, would presumably have to be found from the community care budget. It would also take time.

The central objective must remain the provision of adequate, acceptable, accessible, and flexible care. If, in spite of the reservations offered, the decision is made to give local authorities the responsibility for ensuring such care, they must have the money and the staff to organise the detailed, individualised packages and programmes for elderly people with differing needs. It must also be kept in mind that old people often require many different forms of immediate help. A rapid response must be available through a known and, preferably, familiar figure. Any social service scheme which necessitated lengthy means testing and the scrutiny of financial circumstances by superiors higher up in a welfare bureaucracy would simply not match the needs of the moment. There are frequent occasions when, for instance, an old person has just come out of hospital and needs immediate support or when domestic care is deemed by a doctor to obviate the necessity for the institutional admission of another elderly individual.

We are in the familiar bind between the necessity for local services to be accountable and clients' requirements for prompt and appropriate action when they fall into difficulties. Deakin has declared, 'In order to survive into the 21st century local authorities will have to satisfy the minimum test, that is to ensure that the services for which they are responsible are locally-rooted, responsive to user preferences and cost effective (1988). He would like them to get down to the level of local people to tap their choices and enlist their active participation. Such a broad aim for local authority services would certainly be admirable where the frail older elderly and their families are concerned.

We already know enough to re-emphasise the usefulness of additional, locally recruited attendants to fill the gaps between visits by nurses and others, even if it may occasion fears of 'deprofessionalisation' among social workers, but a means should be found to fund and administer this extension to the existing services. It is important to remember there is an alternative, which is to make sufficient public money directly available to carers or to the mentally competent frail elderly themselves for them to enlist help. Either way the improvement in the quality of daily life and continued independence for an old and very frail person will necessitate a range of assistance, whether professional or not, co-operating in the provision of continuous attention.

If no steps are taken to improve the present haphazard and disparate arrangements, more elderly disabled people will end up having to be summarily taken to hospital or into other residential accommodation when they suddenly become much worse or their customary supports fail. GPs have always operated at this crisis point, being expected to bring pressure to bear upon consultant colleagues to open the gates of the NHS hospital system. If restrictions are introduced in future, making eligibility for admission to private residential care dependent on an old person's financial circumstances, the pressure upon hospital beds will increase. When the point has been reached that nothing but full time nursing supervision will suffice, there will be no time to test someone's means, they will have to be promptly admitted to the 'free' service of the hospital. It would be disastrous if some 'opted-out' hospitals were to become off limits or if the personal budget scheme for some GPs made doctors reluctant to spend money on hospitalising elderly patients.

The idea that relatives and families should take primary and continuing responsibility for their disabled members is continually pressed and has so far been largely borne out by what happens in countless households. But the very old who live alone or who have no carers or whose family can no longer cope simply cannot make their own arrangements when they are suffering serious mental or physical disability. This is where the services of a care manager, whether from the NHS or from the local authority, is essential.

The alternatives of primary care doctors or social workers as case managers have been reviewed. Primary care doctors in Britain have no community care or other budgets at present, what they provide are their own skills and time, together with their influence upon other, related professionals. It has been suggested that Health Board might in future manage GPs together with other community health workers, such as nurses. But this would not necessarily give the doctors direct authority over the community nurses and others or imply a modification of the independent contractor status of the doctors. Few GPs so far have envisaged themselves as personal managers of total community care for the elderly. It is conceivable that the offer, under the Government's new proposals, of a budget at their disposal could change their minds as they become financial managers.

Such a budget would permit places in hospital to be purchased for deserving patients and money saved to be invested in better primary care. How would the old fare, with their chronic conditions needing more medication and longer hospital stays? If their community care is not rationalised future demands on GPs to arrange costly crisis admissions to hospital could face them with grave ethical dilemmas.

Elaine Murphy, whose concern for geriatric patients has been amply attested, favours an intermediate solution, with the creation of a community care development agency (1988). This would hold and be responsible for ring fenced funds from every source, would oversee the development of community care plans for a defined local area and would monitor their subsequent implementation. Such a new agency might by pass the resentment which the allocation of responsibility to either health or social services would be likely to arouse in the 'defeated' candidate. It would also express the present Government's dislike for local authorities.

Finally, the informal carers of the old have been desperately short

of information about where they can turn for help. So far it has only been possible to demonstrate a shabby patchwork instead of adequate community care cover. The documented sources all point to very considerable variation in provision from one part of the country to another, from good services within the reach of a first rate specialist geriatric team or within the aegis of an innovative local care and case management scheme to indifferent and occasional attention elsewhere. To stress the provision of information is, however, useless unless a comprehensive system of care and support actually exists. The mere realisation of inadequacy can be confusing and disheartening.

In this connection the importance of information regarding entitlement to social security benefits must never be forgotten. Enough is known about the characteristics of good, flexible, coordinated services. Older people with disabilities are entitled to good quality care and a good quality of life and, in a wealthy society like our own, the means to provide both equitably are undoubtedly to hand. Our policies should aim to eliminate and not exacerbate the difficulties of those who are old and poor or alone and should give the families of older people the reassurance that acceptable help is close at hand.

The character of the service needed is reasonably clear. The case is strong that the provision of more help at home for the elderly, mediated to each individuals' different needs by a casemanager, will reduce even more costly hospitalisation. Who controls it, NHS or local authority, is finally a political decision, and there are arguable advantages and disadvantages in each case. But it is more important for a decision to be made about who is responsible for community care, for the Government to make up its mind, than to be absolutely sure that the decision is right. The remorseless facts of demography demand an urgent response if suffering among the frail elderly is not to increase.

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