Chapter 1

Introduction

The purpose of this study was to examine the ways in which elderly people exercise choice in the care services they receive, both in the community and in residential care, the extent to which they participate in decisions about their care, and the extent to which they are satisfied with the care services they receive from all sources. There has been much stress in recent years on the desirability of ‘choice’ among users of services, and yet it has been unclear to what extent elderly people themselves have been choosing where they live and what services they receive. There has been little evidence to show what elderly people really feel about the kind of services they receive or the care they are given, what they think about the way in which services are delivered, and the extent to which they think their care needs are being met.

There has also been little discussion of the issues surrounding choice as it applies to consumers of care services as opposed to consumers of goods. We set out to analyse the ways in which elderly people could operate as ‘active’ consumers and participate fully in decisions made about their care. Recent policy statements from the Government encourage a move from a ‘service-led’ to a ‘needs-led’ model of community care. We wanted to see how elderly people can demonstrate their needs and how they can ensure that their needs are met in ways which bring them satisfaction. We were particularly interested in how they were helped to make choices by means of information, advice and counselling from informal and formal sources.

We also aimed to examine how the informal carers of elderly people were involved in the choices of the elderly people, and how they helped the elderly people to participate in decisions about care services. Since ‘caring for the carers’ has become so central to community care policy, we also wanted to see how informal carers could exercise choice in the services they, as carers, might receive. We were particularly interested in the extent to which the choice of elderly people and the choice of their carers might not always coincide, and how any conflict was resolved.

The contribution of professional workers in providing services and facilitating choice for elderly people is clearly crucial. Access to services is usually controlled by professional gate-keepers, and ‘need’ is usually assessed by professionals. We set out to examine how care professionals worked with
elderly people in order to help them make choices by means of information, advice and counselling, and how far they were able to put together and deliver a ‘package of care’ which could help to maintain an elderly person in the community. We also sought to explore their views on the best ways of providing services for elderly people and on the future organisation of care in the community.

This study took place at a time of considerable debate on the future role of social services and the organisation of community care. The front-line workers in the community and in residential care are the people who have to implement policy. We thought it important to hear the voice of the consumer, but we also thought it important to listen to the voices of those who provide and maintain care.

Background

There has been an increasing commitment by successive governments to a policy of care in the community, with an increasing emphasis on the desirability of elderly people staying in their homes in the community for as long as possible. There has been a general consensus that the question of residential or nursing home care should only be considered when elderly people have reached very high levels of dependency and when formal and informal sources of care can no longer maintain them at home for one reason or another. This policy has been based on two premisses: that this is what elderly people and their carers themselves want, and that this is the best way of using finite resources, in spite of the fact that it is recognised that community care is not necessarily a cheap option.

The nature of services offered to elderly people has been changing in recent years against a background in which the numbers of very frail and very elderly people living at home have been increasing. Social services departments have recognised a need to provide more intensive services to help maintain elderly people in the community, and there has been an increasing concentration of services on those most in need, with ‘packages of care’ being developed to help support people in the community who might otherwise have entered residential care in the absence of considerable help from the ‘informal’ network of family, friends and neighbours. The lead given by the Kent Community Care Scheme has demonstrated that it is possible to maintain very frail elderly people in the community, and many social services departments have been engaged in developing innovative and imaginative schemes designed to keep elderly people at home with an enhanced quality of life.

However, at the same time there has been a huge increase over the past decade in the number of elderly people entering private residential and nursing homes, with a high proportion of them funded by the social security budget, while the numbers of people entering local authority residential care over the past ten years has remained relatively static. There has been speculation about whether the elderly people themselves, with easy access to funding and no professional
assessment of need for private residential care, have chosen to enter these homes, or whether they have come under pressure from informal carers and professionals.

There are clearly conflicting signs emerging from these trends. On the one hand, elderly people are said to want to stay at home as long as possible, and yet, given access to public funds, they appear to have been flocking into private residential care, where up to now, there has been no assessment made of the extent to which they ‘need’ residential care. If they have qualified for income support, they have been able to receive funding from the social security budget for private residential care. Secondly, certain policies seem to have been in danger of pulling against one another, by giving financial incentives which may seem to encourage residential care at the expense of community care. There has been no support from the social security budget for domiciliary or community care services.

The Griffiths report (Griffiths, 1988), the White Paper *Caring for People* (Department of Health, 1989) and the NHS and Community Care Act 1990 have all tackled the problem of the ‘perverse incentives’ towards residential care identified by the Audit Commission in its report *Making a reality of community care* (Audit Commission 1986), and the Wagner report (Wagner, 1988) looked at issues surrounding residential care. There has been no lack of debate about the future organisation and funding of care in the community and its relationship to residential care in the last two or three years.

This study therefore took place against a background in which many of the issues raised in the research were being widely discussed. Government policy was being developed and published. Consultation was taking place with services providers, and the views of elderly people and their carers were said to be paramount. An organisational framework was put forward and is due to be implemented in stages by 1993. And yet crucial questions regarding consumer choice and participation and satisfaction remain unanswered.

This report examines the issues, presents the results of our research, which was running concurrently to the policy debate, and discusses the findings. We designed an in-depth study looking at the experience and views of equal numbers of elderly people living in the community and in residential care, their carers and their professional advisers, as well as heads of local authority and private residential homes. We could not tackle all the issues on a broad scale, but we concentrated on some in great detail. We looked at the issues from a number of different points of views, and, above all, we listened carefully to what people had to say.

The study should be seen as a contribution to the much wider debate about the issues of choice and participation and how to hear the voice of the consumer. It should also give warning of the dangers of making assumptions, not only about the quantity and quality of care in the community at present, but also about the potential for developing this care. There was every indication in this research that a needs-led model of care provision for elderly people, incorporating widespread use of the independent sector, will prove very difficult to operate
without additional resources to support the development and maintenance of quality services, both within the community and in residential care.

**Design of the study**
The main focus of the study was elderly people living ‘at the margin’ of community and residential care. The reasons for focusing on the needs and experience of this particular group was that the point of possible transition from community to residential care highlighted many of the issues we wanted to examine. It can be a time of crisis and trauma for elderly people, and it is a time when the response of formal and informal sources of support is tested.

We were particularly interested in the factors affecting a request or decision to enter residential care, and we wished to examine the differences between those who made an application for residential care and those who did not. We paid particular attention to the question of choice and level of satisfaction with services provided in the community and examined the extent to which this affected the decision to enter residential care.

The evidence gathered in this research comes from interviews with elderly people, their informal carers in the community, and the social care professionals in the community and in residential care who were most closely concerned with them. We aimed at interviewing equal numbers of elderly people in the community and in residential care. Those living in the community were to be drawn from people who were generally acknowledged to be ‘at risk’ of residential care, while those in residential care were to have entered the homes within the last twelve months, half in local authority homes and half in private homes.

The study was restricted to elderly people of 75 and over who were not suffering from senile dementia. Issues of choice and participation may be of limited relevance to elderly people with severe mental impairment, and we wished to have as full a discussion of the issues as possible. If we found limitations on choice and participation for lucid elderly people, there was every possibility that the model of care might be even more ‘service-led’ for the mentally frail.

**Sampling and methods**

**Location**
The study took place in three local authorities: an outer London borough, a southern county and a northern county. These areas were selected to give a broad geographical spread, with a mixed provision of statutory, voluntary and private residential and community care services for elderly people. Within each of these three areas, three districts with different characteristics were selected for study. (In the northern area we worked in five neighbourhood teams within the three districts.) Further details of the characteristics of the areas, the provision of community and residential services for elderly people and the ways in which these services were organised are given in the Appendix.
Interviews with elderly people
The aim of the study was to interview 100 elderly people living in the community (33 from each area) and 100 elderly people in residential care, half from local authority homes and half from private homes (again 33 from each area). In the event, we interviewed 100 elderly people living in the community and 103 elderly people living in residential care, of whom 52 were living in local authority homes and 51 in private homes.

The elderly people living in the community were selected at random from lists supplied by the social services departments. They were all known to social services, although, as this report shows, the extent of their involvement with the department varied widely. They were all thought to be potentially ‘at risk’ of residential care for a variety of reasons.

The elderly people living in residential care were selected from lists of those who had entered residential homes in the districts in the previous 12 months at the age of 75 or over. A random selection of elderly people was made where necessary. The homes themselves were selected from the districts in which the research was carried out. A random selection was made of private homes where this was appropriate. We interviewed in 19 local authority homes and 24 private homes across the three areas.

Interviews with informal carers of the elderly people
We interviewed 72 informal carers of the elderly people selected in the community. This represented 69 carers of the 100 elderly people interviewed and three carers of the elderly people we could not interview. The carers were identified with the help of the elderly people and professionals as the person who was providing most informal help or support to the elderly person in the community. The level of care provided by the informal carers varied widely and no informal carer could be identified for one fifth of the elderly people in the community.

We interviewed 74 informal carers of elderly people in residential care: 42 carers of elderly people in local authority homes and 32 carers of elderly people in private homes. This represented 73 carers of the 103 elderly people interviewed and one carer of the elderly person we could not interview in residential care. The carers were identified as the people who had been most involved in the decision to move into residential care. They had often been helping to support the elderly person in the community but sometimes they had taken a close caring role only when residential care was imminent. The carers were identified with the help of the elderly person and the heads of homes or home owners/proprietors. We could not identify an informal carer for 11 per cent of the elderly people in residential care (20 per cent of private home residents).

Further details of the characteristics of the elderly people and their carers are given in Chapters 2 and 6 and in the Appendix. Sampling methods are described in Chapters 2 and 6 and the Appendix.
Interviews with professionals

(i) Social workers, domiciliary care organisers and team managers

We interviewed 40 social workers and 11 team managers or team leaders (from all three areas) and 11 domiciliary care organisers (only in the northern area). The 35 social workers interviewed in the London area and southern area all had one or more of the elderly people we interviewed on their caseloads. In the northern area, very few social workers had any elderly people on their caseloads, so we interviewed one social worker from each of the neighbourhood teams in the three districts in which we carried out the fieldwork, resulting in five interviews with social workers in that area.

Domiciliary care organisers were responsible for most of the social care work with elderly people in the northern area, and we interviewed 11 of them in that area but none in the other two areas.

We interviewed 11 team managers or team leaders: three in both the London and southern areas and five in the northern area.

(ii) Heads of homes and home owners/proprietors

We interviewed 19 heads of local authority residential homes and 24 heads of private residential homes. They were all the heads of homes in which the elderly people we interviewed were living.

Further details of the characteristics of the professionals interviewed and the sampling methods are given in the Appendix.

Samples

The people interviewed in the three areas do not constitute a sample of the elderly population and their carers in the country as a whole. Strictly, they are no more than samples in three places. This limitation was inevitable given the resources available and, more important, the particular characteristics of the study, which was designed so that the experience and views of the elderly people in the community and in residential care, and those of their carers, could be examined in the context of the local services and the views and experiences of the professionals in the services could also be explored.

We took care in choosing the three local authority areas, and the local districts within them, as explained on page 5 in the Appendix. Although there were some variations between the areas and the experiences of the elderly people (including variations in the way in which the services were managed and organised), the picture that emerges from them is broadly consistent. We have for most analyses combined the results from the three areas, and throughout the report we describe the samples in combination as ‘the sample’. But the limitations of the survey need to be borne in mind.

Questionnaires and interviewing

All interviews were carried out on a personal basis using a series of questionnaires which were fully structured in that all the questions were asked in a
pre-determined order and the exact wording of each question was specified. Each person within the given category was asked the same questions. There was some duplication of questions across the groups. For example, many questions were asked of the elderly people in the community and the elderly people in residential care and the carers of both. Social workers and domiciliary care organisers were interviewed with a questionnaire which was slightly shortened for the team managers. Heads of homes and home owners/proprietors were asked a series of questions taken from the social workers/domiciliary care organisers questionnaire, with some additional questions specific to residential care.

A fairly high proportion of questions allowed for an open-ended response, and the interviewers were expected to record the answers verbatim. The interviews with all groups of respondents lasted on average for about an hour and a quarter, although interviews with elderly people could take from half an hour to more than two hours, while interviews with professionals generally lasted for an hour and a half or more. Fieldwork for the study took place between November 1988 and June 1989.

Interviewers included the authors of this report, other PSI staff and a small number of trained and experienced interviewers who work on a regular basis with PSI and other research organisations. All interviews with social workers, team managers and domiciliary care organisers were carried out by the authors of the report.

In addition, social workers and domiciliary care organisers completed short questionnaires about the services received by elderly people selected from their caseloads. Heads of homes or proprietors completed short questionnaires about occupancy and dependency levels in the homes.

Questionnaires were developed after extensive pre-piloting in London and the home counties. A pilot study was conducted with the help of a social services team in a large city.

**Data analysis**

The questionnaires were coded using the predetermined codes on the questionnaires, as well as coding frames developed from detailed textual analysis of the ‘open-ended’ questions. Verbatim quotes were also extracted from the questionnaires and selected for inclusion in the report in a rigorous manner in proportion to the numbers making such comments. These quotes capture the essence of the rich material gathered in the interviews. Our aim throughout the report has been to allow people to speak for themselves.

We analysed the data on elderly people, using the standards breaks of area, sex, age, marital status, number of children, with whom they were living and housing. In addition, we collected data on occupation and class which is presented in the Appendix. All the elderly people were of white British origin, reflecting the populations from which they were sampled.

The study was based on interviews with relatively small numbers of elderly people, their carers and professionals in three local authorities. However, we
thought it important to present a quantitative analysis of the material, partly to give a clear idea of the incidence of usage or experience, and partly to show how similar these relatively small samples were to those found in other studies, some of which were based on much larger numbers.

On the whole, we have used our quantitative data in a descriptive manner, rather than as a means of demonstrating differences. The standard tests of statistical significance have been applied and the report draws attention to differences only where the probability was less than 5 per cent that they could have arisen by chance.

However, there were interesting variations between the areas, or between elderly people living in the community and those in residential care, or between elderly people in local authority homes and those in private homes, which were not in themselves significant at the 5 per cent level, but were certainly indicative of differences. In some cases, the evidence was cumulative in that a number of relevant analyses pointed in the same direction, while in other cases the strength of the qualitative data, combined with factual information about local services and conditions, outweighed the fact that a ‘difference’ was significant only at the 10 per cent level.

**Structure and presentation of the report**
This report is divided into four main sections. Chapters 2 to 5 describe the research findings from the interviews with the elderly people living in the community and their informal carers. Chapters 6 to 9 describe the research findings from the interviews with elderly people living in residential care and their informal carers. Chapters 10 to 13 describe the research findings from the interviews with social workers, domiciliary care organisers, team managers or team leaders and the heads of local authority and private homes. Chapter 14 is an overall discussion of the findings of the research which was so wide-ranging and tackled so many issues of fundamental importance for the future of community care and social work with elderly people.

A detailed summary has been made of the main findings of the research. It should be stressed that this summary is concerned mainly with facts and figures. It cannot capture the essence of the rich material gathered in interviews and reported in this research. Our aim throughout the main report has been to allow people to speak for themselves. The quotes have always been selected in a rigorous manner in proportion to the numbers making such comments. This method of presentation requires detailed textual analysis of the questionnaires and the construction of a complicated coding frame, but is a conventional technique for dealing with the type of material collected in the course of research of this kind.

We use some tables in the text, but we have written the report in such a way that the reader does not have to refer to tables except to check details. We have made references to other literature when we feel it to be essential, but our main
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aim has been to present the results of an empirical study, addressed to a general audience rather than an exclusively academic one.

The material presented at the beginning of the sections on elderly people in the community and in residential care (Chapters 2, 3, 6 and 7) describes the informal and formal care provided to the elderly people interviewed. This type of material has been reported in previous studies and many of the messages are not new. However, we thought it essential to establish what care was being provided to the elderly people interviewed in this research in order to put the questions of choice and participation into perspective. The findings also indicate how little changed during the 1980s in terms both of the level of service delivery and of the extent of informal care available.