Choice and participation in the package of care
Chapter 4

Choice and participation in the package of care

It was clear that very few of these elderly people living in the community had anything which could be described as a large or ‘intensive’ package of care. Only one fifth of the elderly people we interviewed who were said to be at the margin of residential care had three or more different ongoing community services in their packages of care, and few of these had home help more than once or twice a week. The extent of home help or home care assistance was usually the measure of the intensity of the package, although there were two instances of very intensive packages where home help was supplied only once or twice a week. On the other hand, there was an instance of home help being supplied five times a week with a bath nurse being the only other regular service, and no aids, alarms or sheltered housing in the package of care.

There was little evidence of elderly people having much private or voluntary care in their packages, either instead of or to back up statutory services. It is possible that this sample of elderly people, drawn from those known to social services departments, might be unrepresentative of elderly people as a whole, and that there were large numbers of elderly people in these three areas who were receiving plentiful private and voluntary community and domiciliary help.

For a number of reasons this appears to be unlikely. First, access to day care and short-stay residential care is usually available only through social services departments. These are services that are rarely provided by the private sector, and, indeed, although day care services may be run by the voluntary sector, they are usually funded by the statutory sector. Secondly, we had little evidence from social workers, heads of homes or carers that there was much private or voluntary care available which offered the kind of community or domiciliary care the elderly people we interviewed needed. A number of carers and elderly people were quite well-off and could have paid for help if they had been able to find it. Thirdly, as we shall see, there was very little evidence among those who had entered residential care of even minimal levels of private or voluntary domiciliary support.

Although social workers did not know a great deal about private and voluntary community and domiciliary care, there was no reason to believe that
there was much to know about. In some areas, the social workers were well integrated into the local networks, and it is unlikely that there were many services available of which they were unaware. What was lacking was a well-developed data base of potential private and voluntary service providers into which they could tap, and this will be discussed further in the section of this report describing the views and experience of social workers and domiciliary care organisers.

What were the reasons for the relatively limited packages of care we found among elderly people? To what extent did they arise because there were few services available and these few services were then strictly rationed? To what extent would people have liked more in their packages but were not able to communicate this to the ‘gatekeepers’ – the social workers or domiciliary care organisers or GPs? Was it possible that we were missing elderly people from our sampling who had big packages of care?

In this chapter we are concerned with the question of the choice and participation of elderly people in their ‘packages of care’. Before people can exercise choice, they must have information about the range of services available to them. Given the information, they should then be able to participate in discussions about the range of services and, in an ideal world, they should then be able to choose which services they feel would meet their needs and how much of these services they would like. The government has stressed its wish for community care to move from a service-led to a needs-led culture. How far along this road had community care moved in the three areas we were studying?

**Awareness of services**

We started by recapping on the services and aids received and professionals seen by the elderly people. We then asked both the elderly people and the carers to look back to the time when the elderly person first had the first service, aid or professional contact. We asked them whether they were aware then of the range of services available to elderly people. We followed up this question by asking them whether they thought they knew enough now about the range of services available.

Only 17 per cent of the elderly people thought they had been aware of the range of services available when they had their first service, and only 19 per cent of the carers thought they had known enough at that time. Four of the elderly people and one of the carers said they had no help now, so the question was inapplicable.

There were some variations among the elderly people, with all but one of the elderly people living with their spouses saying that they had not known about the range of services available, and the remaining elderly person saying he received no services in any case. Those living alone or with younger carers had been slightly better informed. Men had been considerably less well-informed than the women, but there was little difference between the areas.

Among the carers, those in the northern area had been markedly less well-informed about the range of services than those in the other two areas. Carers living with elderly people had also been considerably less well-informed than
non-resident carers. This was partially accounted for by the fact that all but one of the elderly husbands and wives who were caring for their spouses said they had not known anything about the range of services. This, combined with the lack of knowledge of the elderly spouses they were looking after, illustrates the vulnerability of some of these elderly couples which was such a striking feature of this research.

It should be remembered that there were six ‘professionals’ among the carers, and it was interesting that three of them said they had not been aware of the range of available services when the elderly person had first had a service or aid.

Around one in ten of the elderly people said they had been very fit and independent and had not needed to know anything at the time. Others added that they had known about some services, while others said they had learnt as they went along. The wish for independence among some elderly people was very strong, as this elderly woman pointed out: ‘Nothing registers looking back. I never asked – I’m too darn independent...’ Elderly people are often reluctant to seek out services – ‘People of our age are used to fending for ourselves. We don’t expect charity...’

But some of those who had not been aware of the range of services thought they might have been missing something, like this elderly woman living with her husband: ‘You are never told what is available. They just give you what they think...’ On the other hand, some of those elderly people who felt they had known enough gave the key to success, like this elderly woman in the London area: ‘You hear of things. It’s like this – people gossip. You have to keep your wits about you. I’m quick on the uptake...’

Being quick on the uptake was not apparently enough for most of the carers, let alone the elderly people. A daughter caring for her elderly mother pointed out the problems in getting to know about services: ‘I’d no idea about attendance allowance or bath attendant or domiciliary services. I heard about it from a friend. I don’t think there’s enough publicity. There’s a lot people don’t know about. Old people don’t have the gumption to find out. One of my friends looks after elderly people and told us. At first me and my mother used to bath my dad. We’d no idea what help there was available...’

Most of the carers who had known about the range of services available said they had known through their jobs in health or social services. (These were not necessarily the ‘professional’ informal carers we interviewed.) Other carers had their suspicions that this gave some people an unfair advantage, as this daughter living with her mother pointed out: ‘I don’t think anyone is aware of the range, unless they work in social services...’ The lack of knowledge of elderly spouses was underlined in many of the comments – ‘It is not something that is explained to you. You just accept what is offered...’

This lack of awareness of the range of services when the elderly person first received services could well have delayed their access to them. If people are so ill-informed about what might be available, it is quite possible that they and their carers have soldiered on without services which could well have improved the
quality of the lives of both of them. There is not much point in having a needs-led service if people do not know it exists.

We asked both elderly people and carers whether they thought they knew enough now about the range of services available. 49 per cent of the elderly people and 43 per cent of the carers thought they did, but six of the elderly people said they were not sure and 45 per cent said they did not know enough even now. Among the elderly people, those living alone or with younger carers were more likely to say they knew enough now than the elderly spouses, nearly two-thirds of whom said they did not feel well enough informed, even now, as an elderly husband explained: ‘There’s a lot I don’t know, but I don’t like sponging on people, so we rub along...’

The idea of being seen as ‘spongers’ or seeking charity was obviously a deterrent to seeking information or even to accepting services, as this son living with his mother pointed out: ‘I don’t know now (about the range of services available). We’re not spongers, and my mother pays for the chiropodist, physiotherapy, glasses, everything...’

It is perhaps disappointing that less than half the elderly people and carers felt they knew enough now about the range of services. After all, all those in the southern and London areas had seen a social worker, and everyone in the northern area had been in contact with a domiciliary care organiser. Some of the carers were desperately concerned about their lack of knowledge, like this daughter living with her mother in the southern area: ‘It’s difficult. If I don’t know about it, I don’t know that I don’t know. I so want to keep her here. If only I could get someone to help. I have advertised but have had no luck...’

It seemed clear from the responses to this question that social workers and other ‘gatekeepers’ were not necessarily giving elderly people and their carers all the information they might have given them. A daughter in the northern area said to our interviewer: ‘I had never heard of the laundry service or the attendance allowance until you mentioned them today...’ There were suspicions on the part of both elderly people and their carers that others might know more than they did, as this elderly woman in the London area said: ‘I don’t know anything because I haven’t gone into it... Some get a heck of a lot – they get everything. You wonder how they got it, how it came about. But I’m not jealous...’ Her doubts were echoed in the northern area by a son: ‘You never seem to get to know anything. Other people seem to get more help, but I don’t know how...’

There were worries that a hidden agenda of ‘rationing’ by professionals was operating, as an elderly sister living with her brother in the southern area explained: ‘I don’t think I know anything – not really. I could ask the social worker, but maybe they’re told not to divulge too much – like millions of pounds of unclaimed benefits...’

Around one in ten of the elderly people said they relied on their carers to keep them informed about services which might be available. Around one in five of the carers said they were worried that there might be more services available that they did not know about, but one in ten said that they were learning more as they went along, like this son – ‘We’re learning more every day. As things happen
we find out about the next thing. We haven’t gone out of our way, but we find out things as the need arises. We don’t go and look for information unless we really need it...’ – and this daughter – ‘We’re breaking new ground to us. You learn as you go along. You don’t think ahead. You don’t think you or your parents will ever come to it...’

There were a number of interesting commentaries among these quotes about the extent to which professionals so often appeared to leave it to elderly people or their carers to ‘learn as they went along’, and did not seem to have gone out of their way to present people with a series of options in terms of services or even to have told them about the range of services available. A rationing of information seemed to be the precursor of a rationing of services. Whatever the social workers and domiciliary care organisers said about designing and putting together packages of care, it did not appear that either the elderly people or the carers we interviewed really felt that they were presented with potential packages of care in the way that many of the professionals we interviewed indicated was their practice.

Information
A lot of research has been carried out into the provision of information about services and benefits for elderly people. It is well documented that elderly people are not well informed about services and benefits and that they often rely on family and friends for information (Epstein 1980, Victor 1986). However, as we also found in this study, not all elderly people have relatives or friends to whom they can turn. Much of the available information is provided in a written form, but research has shown that many elderly people do not recall receiving information about services and benefits, and even those who do remember often do not read all or even most of it (Salvage 1988). Research has also shown that written information is not always effective in increasing awareness and take-up of services and benefits (see Victor).

It is obvious that lack of information can be a very real barrier to receiving services and benefits. Elderly people may be unaware that services are available, they may be uninformed about their eligibility for services or benefits, they may be confused about which agency provides which services, and they may be uncertain about how to gain access to services and benefits. But there are sometimes other factors at work; elderly people might not promote their own interests, they may feel there is a stigma in applying for benefits and they may fear rejection. For this reason, elderly people may need encouragement as well as information about services (see Victor, Tester and Meredith 1987).

A number of studies have indicated that providing information in person is a more effective way of providing information to elderly people that written information (see Tester and Meredith, Salvage), and that information given in person is more likely to be remembered than information delivered through the door. It has also been noted that if professionals provide information in person
they are in a better position to assess the information needs of the elderly person and to offer encouragement (see Tester and Meredith).

**Written information**

There were many indications in this study that people’s awareness of services was based very much on picking things up from other people, as this elderly woman in the southern area said – ‘As you go around, people talk about what they get and don’t get...’ – and the same view was expressed by a carer in the same area – ‘It’s only if you know about these things yourself that you bring them up. No-one suggests them to you...’

The gathering of information on services seemed to be such a haphazard affair that we asked elderly people and their carers if they had ever had any written information on help or services for elderly people. Fifteen per cent of the elderly people said they had had written information, usually about one service or benefit, although just over third of them said they had had a book or leaflet about social services in general. Four of the fifteen had had a leaflet about benefits or a particular benefit, while the rest cited individual services, ranging from draught excluders to security locks to information about visual handicap. Social workers or social services were said to be responsible for about half the written information, with the hospital, Spinal Injuries Association and the post office having been the source of most of the rest. Three people said the information had come through the door.

Seventeen per cent of the carers said they themselves had had written information about services, 6 per cent said the elderly person had had such information and 7 per cent said both they and the elderly person had had some. The information was mainly about social services or benefits, but one carer reported literature about alarms and one had had an Age Concern leaflet, mainly because she had done a lot of voluntary work. The sources of information were similar to those reported by the elderly people, but it should be noted that a quarter of the carers said they had received the written information from work or through their jobs.

Some of the information was well-targeted and much appreciated, as this elderly woman living in sheltered housing said: ‘I get a fact sheet once a year from social services. Social services say if you’re in any doubt write to them and they’ll explain. We all get them here...’ But sometimes the written information did not seem to be quite so appropriate, as this elderly woman in the southern area pointed out: ‘I get information about services for the partially blind. But I can’t read it. My sons know what is available...’

There were few signs that information was routinely given to carers, but one of the elderly wives looking after her husband in the southern area had had some information: ‘I get the carers’ letters which tell you many things. I got them from the welfare lady...’ There were indications that elderly people had to rely largely on their carers to help them with information, but that the information often came at too late a stage, as this carer living with her father-in-law explained: ‘We showed him the attendance allowance thing, and he worried that he might lose
There was not much evidence that elderly people or their carers were given sufficient written information about services. Only a small proportion had had any written information at all, and much of this appeared to be specific to particular services or benefits. There was very little indication of comprehensive booklets describing services which might be available to elderly people, and this appeared to be a major gap in the provision of services to elderly people. There is really not much chance of exercising a great deal of choice about services if professionals hold the key to the information, not to mention the access to the services, and nobody sees it as their responsibility to make elderly people or their carers better informed.

Discussion and participation in the choice of services
There have been many indications, particularly in the literature on residential care, that elderly people have little choice in what happens to them and that many feel ‘disempowered’ and caught up in events over which they have little control. We tried to explore the extent to which elderly people felt they had enough discussion about the services which would be most helpful to them. We wanted to establish whether they felt that people took enough notice of what they wanted.

Only 53 per cent of the elderly people said they felt they had had enough discussion about what help or services would be most helpful to them. 20 per cent said they had not had enough discussion and 27 per cent said they were not sure. The elderly people in the southern county were the most likely to say they had had enough discussion (59 per cent), and those in the northern county the least likely (47 per cent). Those living with elderly spouses were more likely than the others to say they had not had enough discussion.

We asked those who had had enough discussion whom they had talked to and what they had discussed. Over a third said they had talked to a social worker or social services, while nearly a fifth had spoken to the domiciliary care organiser. But these proportions were quite different in the different areas, with social workers hardly being mentioned in the northern area, and domiciliary care or home help organisers not being mentioned in London or the southern area. One in ten of those who had had enough discussion had talked to their GPs, and the same proportions had talked to their carers or other relatives. Others had talked to hospital doctors, hospital social workers, occupational therapists or nurses.

The main discussion centred round the provision of services and the problems the elderly people were encountering. One of the elderly people had discussed residential care and two had discussed sheltered housing. Some of the elderly people had discussed services they did not want at the moment: ‘My social worker told me about home help and day centres and did I want them, but – she’s really lovely, my favourite – I don’t really need them...’

Most of the elderly people who felt they had had enough discussion were satisfied with the outcome, but this was by no means true of those who had not
had enough discussion. We asked them what they would have liked to discuss and with whom. Some of the elderly people found this question difficult to answer since it had not occurred to them that they might actually discuss services with anybody, like this elderly woman in the northern area: ‘They assume that what they give you is right. Who can you discuss it with?’

Others said the need for discussion had not really arisen, like this woman in London: ‘I haven’t had any discussion, but it’s my fault. I’ve never asked. You can’t expect people to knock on the door. If I wanted it, I’d ask...’

There was some unease among the elderly people at the lack of discussion about what services might be available or, more frequently, about access to more home help hours or benefits. There was some evidence that ‘assessment’ by social workers or domiciliary care organisers did not always meet the high standards described by the professionals we interviewed, as this woman in the northern area explained: ‘When we were assessed, all they said to me was, "What does your husband not like doing?" I said the ironing, and that was it – he was expected to do everything else...’

If there was relatively limited discussion about services, did the elderly people feel that people took enough notice of what they wanted? We were interested in their feelings about professionals and carers alike.

Two-thirds of the elderly people thought that others had taken enough notice of what they wanted, but the elderly men we interviewed were much less likely than the women to feel that their views had been taken into consideration.

On the whole, the elderly people who thought their views had been taken into account had nothing but praise for the professionals, like this woman in the London area: ‘I’ve never wanted anything. I ask you, what could I want? They gave me a home help when I wanted it, and offered me things like meals on wheels, but I didn’t want anything else...’

Some thought that people had taken enough notice of what they wanted, but that the fault lay in ‘the system’ for not delivering, like this elderly man living with his wife in the London area: ‘Oh yes, yes. C. (the occupational therapist) and A. (the social worker) have done well. It’s their superiors. Their hands are tied...’ And his view was echoed in the southern area by an elderly woman: ‘It takes time to get what you want. They promised to put lights outside, but it took ages before they arrived. The money is not always available. It’s the government’s fault. It’s not always the people who promise things’ fault – it’s the government. People are much worse off in this country. Abroad, people get more benefits. You read it in the papers...’

The question of whether people took enough notice of them was, however, a bit academic to some elderly people, like this woman in the London area who saw no problems in getting her views heard: ‘I’m a very forceful character. When I was in the military services, I got an A for my character...’

But not everyone was quite so ‘forceful’, and one third of the elderly people felt that others did not take enough notice of them, mainly because ‘they’ were not interested or did not ask them what they wanted. Some of them clearly felt intimidated, like this woman in the London area: ‘Not when it came to help in
the house. The supervisor is horrid – not a person you could talk to and ask for more. And they don’t have district nurses here you know...’ Others felt that services were difficult to get and that, in any case, professionals had other things on their minds, as this elderly man in the northern area explained: ‘They take it all down – all the circumstances – and then they go and forget it. They promise you the earth. We had a hell of a job getting the home help. There was a shortage of staff...’

Other services needed
We asked the elderly people whether there was any other kind of help they would like which would make life easier for them, and, similarly, we asked the carers whether there was anything which they would like the elderly people to have. If they wanted more help, we asked whether it was something else altogether or whether they wanted more of what they were receiving already.

Table 4.1 Other services or help needed by elderly people living in the community

<table>
<thead>
<tr>
<th>Service/Help Wanted</th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes: something else</td>
<td>28</td>
<td>30</td>
<td>35</td>
<td>19</td>
</tr>
<tr>
<td>Yes: more of service(s) already receiving</td>
<td>16</td>
<td>10</td>
<td>3</td>
<td>33</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
<td>57</td>
<td>59</td>
<td>47</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5</td>
<td>7</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

Base: all elderly people living in the community (100) (30) (34) (36)

Table 4.1 shows that 28 per cent of the elderly people wanted an additional service or services and 16 per cent wanted more of the same. Table 4.2 shows that 38 per cent of the carers wanted something new for the elderly people and 29 per cent wanted more of the same. A handful of elderly people and carers wanted something else and more of the same, which is why the columns add to more than 100 per cent.

The carers were more likely to want more services for the elderly people than the elderly people themselves. Only just over one third of the carers did not think there was a need for more services or help for the elderly people, compared with more than half the elderly people who saw no need for more services.

One third of the elderly people in the London and southern area wanted something new, compared with only one fifth in the northern area. However, one third of the elderly people in the northern area wanted more of the same, compared with far fewer in the other areas. Carers were generally more demanding than the elderly people, especially in the London area, where two-thirds of them wanted the elderly people they were looking after to have...
some kind of service they were not already receiving. The most noticeable
difference, however, was between resident and non-resident carers. Nearly half
the non-resident carers wanted the elderly people to have a new service and one
third wanted them to have more of the same, compared with around a quarter of
the resident carers wanting something new and a similar proportion wanting more
of the same.

Elderly people living with a spouse were much more likely than others to
want some kind of new service. Some of them, as we have seen, were very frail
themselves, and did not feel that they received enough help in general, like this
disabled woman looking after her spouse who had senile dementia: ‘I’d like more
help with my husband – like a little walk. Sometimes the home help takes me
out in the chair, but I could do with some help for Mr B. By 8 o’clock I try to
watch television, but he’s so fidgety. I’ll be boiling milk and he’ll call me and
won’t wait. It gets on my nerves, though he’s ever so good and cheerful. I don’t
know who to ask...’

It was some indication of the priorities of elderly people compared with the
priorities of those providing the services that a quarter of the elderly people who
wanted something new said they wanted gardening help. It is a source of great
distress to some elderly people when their gardens are untended. Anyone looking
at the homes of elderly people can see that gardens have often been their pride
and joy for many years, and when they can no longer care for them, an important
part of their lives is badly affected.

Apart from gardening, a surprisingly long list of individual services were
mentioned by one or two respondents each. They may not have been significant
on an aggregated basis, but for each of the elderly people who mentioned them
they were of importance, sometimes of overwhelming importance. They
included day centre attendance, company, a sitting service, sheltered housing,
rehousing, attendance allowance, help with a telephone, physiotherapist,
The carers came up with a similar long list of new individual services they wanted the elderly people to have. Daughters in particular were keen on more services, with nearly half of them wanting the elderly people to have something new. The anxiety of daughters who were not living with their elderly parents came through very strongly in the response to this question. The services required were mainly practical services, like home help, meals on wheels, bath nurse, gardener, occupational therapy, dental service, chiropody, night nurse, getting-up service, decorator or mobile library. There were several mentions for day care, ‘company’, short-stay care, respite care and sheltered housing, and there were three pleas for long-stay residential care.

It was perhaps surprising that there were no more calls for long-stay residential care, considering the picture some carers painted of the lives the elderly people led. There was evidence of considerable frustration on the part of carers with the lack of suitable services in the community. A daughter in the northern area summarised the anxieties of many in her situation: ‘She needs a nurse to go again. She needs help with the bath as she gets out of breath. She also needs a home help who helps and doesn’t just sit down and drink tea...’

The living conditions of some of the elderly people were clearly quite unsuitable, and it sometimes appeared that sheltered housing at an earlier stage could have relieved some of the pressure to enter residential care that we found among our sample of elderly people in residential homes. This elderly wife was looking after a very frail husband in the London area: ‘We need sheltered housing to get out of the eating, sleeping and toileting in the same room. If we had a ground floor flat, he could get to the toilet – and I wouldn’t have to empty the commode – and he could get a bath. We could sleep together as well and have a cuddle, rather than being on two settees...’

When we asked which services the elderly people and their carers wanted more of, there was absolutely no question in the minds of the elderly people themselves. Nine out of ten of them wanted more home help, while one wanted meals on wheel at weekends and one wanted a night sitter every night. Some of the elderly people were resigned to the probability that they would not get the services they required, like this woman in the northern area who lived with her son: ‘I’d like just more time from the home help – even one hour. I could ask Mr M. (the DCO), but it’s no use. There aren’t enough of them...’ Some of the elderly people did not even know how they would go about getting more home help, like this elderly woman living with her equally elderly spouse: ‘I’d like the half hour back that I lost. They didn’t give a reason. They just sent a letter to say I now only got one hour. I’m not sure who I’d ask. Maybe if I asked the home help, she’d know...’

The carers too were keen on increased home help, and it was mentioned by half of those who wanted more of the same for the elderly people they were looking after. Sometimes the carers wanted the home helps to do more for the elderly people and sometimes they wanted the home helps to be more reliable...
and better organised, as this son in the northern area pointed out: ‘She needs her home help regularly and more often – perhaps twice a week – and definitely a replacement if one is away. I think it’s awful to go three weeks without one...’

We asked the elderly people who said they wanted more help how they would go about getting it. They gave a variety of responses, again indicating that there was no one recognised source which people felt they could call upon to discuss services which might help them at home. One quarter said they would ask the home help or the domiciliary care organiser, one fifth said they would ask the social worker or social services and three said they would ask their GPs, while again there were individual mentions for the sheltered housing warden, occupational therapist, day centre, building society or electricity board. However, one third of those who wanted more help said they did not know how to go about getting it, reinforcing the general impression of a substantial minority of elderly people who did not have the information to participate in decisions about their services, let alone make any kind of active choice about them.

We also asked those who did not want more services how they would go about getting them if they wanted them. Around a third said they would ask the social services or social worker, just over ten per cent said they would ask the home help or domiciliary care organiser, around one in ten said they would ask their GP and the usual list of individual statutory service workers were mentioned. Around one in six said they would ask their carer or a relative, but one in six did not know whom they would ask. Again there was evidence that, although some elderly people were well-informed and independent with good support networks, others were not, and the organisation of services did not offer them one reliable source of information and advice.

**Services asked for and services refused**

If elderly people are to exercise choice in the services they receive, they might expect to have their wishes satisfied. It could be argued that a needs-led service should respond to the needs of the customers. On the other hand, the customer should also have the right to refuse a service if it is inappropriate or is not what they think they need. There has been evidence of a certain mismatch of services to need among elderly people, and this has been reinforced by evidence from carers, so we asked both elderly people and their carers for their views and experience.

Eighteen per cent of the elderly people said they had asked for or tried to get a service which they did not actually get, and 17 per cent of the carers said this was true of the elderly people they were looking after. There was quite a marked difference in the areas, with far fewer elderly people in the southern area saying they had been refused services compared with the other two areas. The carers gave similar evidence.

Nearly one in five is quite a high proportion to be refused services, particularly among such a relatively frail and elderly set of people. What were these services and whom had they asked for help? Was there something about
The familiar list of services had been refused, with home help or more home help being mentioned most often by both elderly people and carers. A few of the elderly people and carers mentioned benefits. Again the list of people from whom help had been sought covered the whole gamut of professionals, with social workers and social services being mentioned by about one third of the elderly people and rather more of the carers. The local council or the civic centre were also mentioned, along with the GP, the hospital, the warden, the home help, the nurse, the housing department, the DSS, the day centre, the residential home, the health visitor, the health centre and Age Concern.

Why had they not got the service they asked for? A variety of reasons were put forward by the elderly people and carers. They had been assessed by social services or social security and turned down, they had savings and had been turned down, the services were short-staffed, there was no transport, there were no vacancies, the services were no longer available, they were not disabled enough, they were waiting to hear, or the doctor had refused to help. One fifth of the elderly people did not know why they had been refused the service.

Few complained about it, and most took it as a matter of course that services would be refused. Some elderly people who had been refused benefits were less content, like this woman in the London area: ‘I asked the council about a rent rebate. You have to take all the papers. I’ve got a bit of money saved up and it’s with the interest that I make the ends meet...Not everyone want handouts. They want to paddle their own boat and not take handouts. But they make you spend your savings so that then you have to ask for help. You save up, so they won’t help you out. So you spend your money and then they have to help you. Other people never save and so they’re helped out. They get everything...’

What about services refused by elderly people? There had certainly been indications that some elderly people were quite fussy about services, partly because they wanted to remain independent, even if they were not, and partly because they did not care for what they had heard about some services. 21 per cent of the elderly people said they had refused services they had been offered, but as many as 41 per cent of the carers said the elderly people they had been looking after had refused services. Again the non-resident carers were more concerned than the resident carers, with more than half the non-resident carers saying the elderly people they were looking after had refused services.

There was a difference between the two samples in that the carers were looking after elderly people who had carers, but nevertheless there were indications that elderly people tended to minimise the extent to which they had turned down services, sometimes to the despair of the carers, like this daughter in the northern area: ‘I say, ”Mother, you are just plain bloody awkward”, and she is. She refused meals on wheels and the day care centre after she’d been told about it in hospital. She also refused to go to physiotherapy one week...’

We thought there might be a pattern to the services refused by the elderly people, but, although meals on wheels, luncheon clubs and day centres were
mentioned more often than other services, there was still quite a long list of services that elderly people had turned down. The carers confirmed the elderly people’s reluctance to have meals on wheels or day care, but a quarter of them also mentioned that the elderly people had turned down home help.

The elderly people put forward a number of reasons for refusing services, ranging from a wish to stay independent, not needing the services, an unspecified dislike of the services, transport difficulties, not wanting to go out, not wanting to leave their spouse or their dog and a worry about the expense. The carers gave a similar list of reasons, although more of them said that the elderly person just did not want the service. It sometimes appeared that the elderly people were just digging their toes in, much to the frustration of the carers, as this daughter explained: ‘It was meals on wheels and now it’s this day care business. She won’t go any more, but they’d still have her. It would be a good break for me...’

There was little doubt that refusing a service was a way of demonstrating choice, and some of the elderly people were quite clear about this, as this elderly woman in the southern area explained: ‘We did try meals on wheels, but we like lunch at 12 and they came at half-past one and it was cold. I think it was scraping from the pot...’

Sometimes the circumstances of the elderly people hardly seemed to have been taken into account, as was clear from an elderly woman in the London area: ‘Last week social services asked me if I wanted to go on a shopping trip. It was ridiculous. I need two ambulancemen to get me downstairs and strapped into the ambulance...’ It was not perhaps surprising that elderly people refused some services, as illustrated by another elderly woman looking after her even more disabled husband: ‘They told me about a church hall for dinner, but my husband couldn’t go so I wasn’t thrilled. I’d have to pay someone to sit with him...’

But if the elderly people were refusing services, what could the carers do about it? We asked them if they had ever tried to persuade the elderly person to receive any help or service or to go anywhere. 46 per cent of the carers said they had. The non-resident carers, as might have been expected from the account given above, were more likely than the resident carers to have tried, and there was a marked area difference, with over two-thirds of the carers in London having tried persuasion, compared with over half the southern county carers but only a quarter of the northern carers.

What had they suggested? Two-thirds of them had tried to persuade the elderly people to have day care of some kind. Daughters in particular were very concerned about this. Around a third of the carers who had tried to persuade the elderly people to have a service mentioned short-stay care, one fifth had suggested meals on wheels and nearly one fifth had suggested home help. A handful had tried to persuade the elderly person to consider day trips, a residential home, a district nurse, the doctor or physiotherapy.

Many of the suggestions had fallen on deaf ears, as this daughter explained: ‘We tried to get her to go to a day centre to get her out to meet people, but she said she would not go and sit with all those old people...’ Some of the carers were concerned not only about the elderly people but also about themselves, and it
often appeared that day care would have given them great relief. However, many of the elderly people simply refused, and no amount of pressure from the carers was going to budge them. There were some fairly desperate comments from carers, like this daughter: ‘I’ve tried to get her to go to a dinner club. I’ve tried to persuade her to stay in a home, but she won’t go. It’s for her, but it’s for me as well. I worry about her...’

There was no doubt that these elderly people were exercising choice, if only in a negative way. But their choice not to receive a service or even to give it a try was a source of great concern to many carers. The choice of the elderly person did not coincide with the choice of the carers, and there were often clear signals that continued refusal to contemplate services on the part of the elderly people would put a considerable strain on their relationship with their carers.

### Dissatisfaction and complaints

If elderly people are to act as consumers they should naturally have the rights of consumers to express concern and to complain if services are not delivered to their satisfaction. To what extent did the elderly people we interviewed feel confident that they had these rights, and what did they do about them? If they did not feel able to express concern or complain, what did their carers feel?

We asked both the elderly people and the carers what they would do if they were not happy about the help and services being received. The elderly people differed from the carers in the action they would take, with 10 per cent saying they would tell their social worker, 10 per cent saying they would tell the domiciliary care or home help organiser and 12 per cent saying they would tell their carer or relatives. Only five said they would ring social services or the civic centre and four said they would contact their doctors.

Carers, on the other hand, were rather more focused in their actions, with nearly 30 per cent saying they would ring social services or the civic centre, nearly 20 per cent saying they would contact the social worker, over 10 per cent saying they would contact the domiciliary care organiser or the home help organiser and a similar proportion saying they would tell the ‘person in charge’. Over ten per cent said they would contact the elderly person’s doctor.

Nearly 10 per cent of the elderly people said they would keep quiet and do nothing, a similar proportion said they were quite happy and had nothing to complain about, and seven said they had no services in any case. Apart from this, elderly people named a number of people they might contact, including one intrepid widow living alone who said she would write to her MP. A handful of people said they would get rid of the services or do the job themselves. However, over 10 per cent of the elderly people said they did not know what they would do.

The carers were less likely to opt out of the situation and named a number of other actions they would take if they were unhappy about the services, including contacting the CAB, Age Concern, the MP or a solicitor. Some of them described their tactics, like this nephew: ‘I’d speak to the supervisor to ask if something could be done. I wouldn’t go red in the face and thump the table. I
know their shortcomings, but I don’t know what their problems are. Maybe they’re overloaded with work...’ A son in the London area took a rather more formal approach, but said that he would be less understanding if things were not put right: ‘I suppose I’d follow the chain of command with the complaint. I’d go through the appropriate department and follow up along those lines. Then I’d thump the table and demand satisfaction...’

The elderly people were a lot more reticent about ‘thumping the table’. They might know what they ought to do if they were unhappy about a service, but some of them feared the consequences, like this elderly woman in the London area: ‘I’d jolly well keep quiet. Every time you say anything you get told off. The home help organiser is dreadful...’ Others thought they had little choice, like this elderly woman in the southern area: ‘I’d do nothing – grin and bear it. Some of the home helps have broken things and not told me. But I think I’m lucky to have what I have...’

But other elderly people thought they might be a bit more active, like another elderly woman in the southern area: ‘I would be very worried. I would be tempted to write to my MP and I might contact Douglas Hurd...’ (He had evidently impressed her as a man who might take up the cudgels on her behalf, even though he was not her MP or even connected with the Department of Health.) And men were rather more likely to express their concern than women, like this elderly man in the southern area: ‘I’d tell them to clear off!’

Some of the carers were not afraid of expressing their displeasure, like this daughter in the southern area: ‘I would jolly well say something about it. About six months ago there was a meals on wheels lady. She said “Your meal” – no “Good morning”. This made me very cross and I made a comment for her to hear. She said, “I am voluntary”. I was very angry...’ But other carers were afraid of upsetting the elderly person, while others thought there was little point in making a fuss, like this son in the northern area: ‘I have not done anything. She has not had home help for three weeks, but if you phone they just say they are short-staffed – you cannot get one anywhere...’

We were concerned about the extent to which elderly people were worried about complaining about the help or services they received. After all, if they were to have any choice or influence over the type of care they were getting, it might seem appropriate for them to feel secure in complaining if things were not satisfactory.

Over a quarter of the elderly people said they would be worried about complaining about the help or services they were receiving. There was quite a marked difference between the men and women as Table 4.3 shows, with one third of the elderly women saying they would be worried about complaining, compared with only one in ten of the men. It was also clear that those living alone would be more worried about complaining than those living with others. Over one third of those living alone said they would be worried about complaining, compared with 13 per cent of those living with a spouse or other relatives. As Table 4.3 shows, those living in the London area were more worried about
complaining than those in the northern area and certainly their comments indicated greater anxieties.

What were the problems about complaining? A number of elderly people were clearly not used to complaining and did not feel it was in their character: ‘I’ve never been a complainer. I wouldn’t unless I had a real grievance. But otherwise I wouldn’t complain...’ Others were concerned that their complaints might affect the jobs of the people supplying the services. This came up quite frequently in relation to home helps, as this woman in London said: ‘I don’t like grumbling. I feel I’m being disloyal. But she’s so unreliable and I am paying...’

There did seem to be a reluctance among some of the elderly people to complain about services which were in short supply or which they were not paying for. Complaining was also seen as something which might backfire, according to elderly people in all areas – ‘If you say anything they clamp down on you. It’s better to shut up...’ – a view echoed by another woman in the same area – ‘I wouldn’t be entirely happy – they wouldn’t like it. I wouldn’t like to complain...’

The carers were not so concerned about complaining, and only 17 per cent said they would be worried about doing so. Northern carers were much less concerned about complaining than those in the London area or the southern area. Both elderly people and carers seemed to be less diffident about sticking up for their rights in the northern area.

Like the elderly people, a number of carers said they would only complain if they had a real grievance. Some were concerned that complaining would not achieve the desired effect, like this son in the southern area: ‘I would complain, but I’d be worried they’d take (the services) away. But if there were grounds for complaint, I would complain...’ Others thought the complaint might rebound on the elderly person, like this daughter: ‘You would lose out and we wouldn’t get anyone else. Home help – that is all she has...’

<table>
<thead>
<tr>
<th>Table 4.3 Whether elderly person was worried about complaining about help or services received</th>
<th>column percentages</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
</tr>
<tr>
<td>Yes</td>
<td>26</td>
</tr>
<tr>
<td>No</td>
<td>56</td>
</tr>
<tr>
<td>Don’t know</td>
<td>13</td>
</tr>
<tr>
<td>Not applicable/no help</td>
<td>5</td>
</tr>
</tbody>
</table>

Base: all elderly people living in the community

<table>
<thead>
<tr>
<th></th>
<th>(100)</th>
<th>(27)</th>
<th>(73)</th>
<th>(30)</th>
<th>(34)</th>
<th>(36)</th>
</tr>
</thead>
</table>

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Complaining is one thing, but getting redress is another. What did the elderly people and carers think would happen if they did complain? Perhaps it was some indication of the diffidence of the elderly people that nearly 30 per cent of them said they did not know what would happen. It had simply not occurred to many of them that they might complain, either because they were quite happy with the services and help, or, perhaps, because they did not really recognise that they had the right to complain.

For just under a quarter of the elderly people, there was no problem. They thought if they complained the authorities would put it right, as this elderly woman in the north said: ‘Things would improve, hopefully. They are supposed to give a service after all...’ But around one in ten of the elderly people thought nothing much would happen if they complained – ‘In one ear and out the other...’ was the comment of an elderly woman in the southern area.

It was perhaps more worrying that over one in ten of the elderly people thought that complaining would bring nothing but trouble, as this elderly woman in London explained: ‘You’d probably get thought of as thorough nuisance. I think you’d get less. They’d cross you off the list...’ Her concern was shared in the northern area: ‘If I complained about the home help I suppose I wouldn’t get even the one hour...’

It was not only the fear of being ‘crossed off the list’ that concerned some of the elderly people, like this woman in the northern area who was worried about the reaction of those delivering the services: ‘They might get told off and then they might not like me...’ The vulnerability of elderly people in this situation cannot be underestimated, and some of them were not going to put themselves in the position of finding out what would happen if they complained, like this elderly woman in London: ‘They’d think me very ungrateful, I suppose. I don’t suppose they’d like it. I don’t think I’ll try it to see. I’d best keep in their good books...’

In some cases it almost appeared that the elderly people felt they were receiving charity – ‘I wouldn’t want them to think I wasn’t grateful,’ said a woman in the northern area. Others were very cautious about the effect any complaint might have on their reputation – ‘They might talk among themselves and I like to play for safety...’

There was a very strong impression given by some of the elderly people that they were made to feel lucky to get services which were in short supply and should not be complained about. There was little evidence that many of them felt free to say what they really felt about the services they were receiving. They were happy to grumble to the interviewers, but were certainly not happy to complain to anyone who might do anything about their complaints, some of which were clearly of great importance to them.

If there was little evidence of an active consumer movement among the elderly people, was there any evidence that carers were more vociferous on their behalf? They were much more likely than the elderly people to think that their complaints would lead to some kind of action, with well over half saying that ‘the authorities’ would rectify the action which had caused the complaint, or
would at least look into it. Nearly one in ten said that they would make sure that something was done. But over ten per cent said they did not know what would happen if they complained, while one in six said they did not think anything would happen.

Male carers were more likely than female carers to think that something would be done if they complained, and elderly husbands looking after their wives were often quite confident that something would be done: ‘I dare say somebody would come out and want to know all the ins and outs. They would speak to us separately to get the story to see what we both said.’

The acceptance that some kind of arbiter would be introduced in the case of complaints provided an interesting commentary on how the system of providing care services is not seen as really comparable to that of providing other services. If a consumer employs, say, a window cleaner or television repair man or some other service provider in the home, there is an assumption that they are there to do a job for which there is a contract, written or unwritten, and they do it to the satisfaction of the customer or the customer has a right to complain. With care services for elderly people, the contract did not seem to be as clear, and there was a general impression among both elderly people and their carers that the service had to be negotiated in a way which made it difficult for the customer to complain. One of the main problems was that the service provider was usually clearly acting as a rationer of scarce services, and complainers were not regarded in a favourable light.

A son from the London area explained the processing of his complaint, which illustrates the way in which a certain amount of power was removed both from elderly person and carer:

> When I spoke to the supervisor, we just made a compromise. I did say mother feels the home help is unreliable and not really obliging. I asked if there was list of what they can and can’t do. I mentioned that she would not shake the mat or wash the plates or the glasses. I know old people have their own way of doing things and nothing else is right, but still... She said, ‘I don’t think your mother realises she pays the same however long she comes to her – and she comes as long as we can spare her, but sometimes there’s a greater need elsewhere’. And I can appreciate that...

But other carers were not so understanding and felt aggrieved, like this neighbour in the same area, who had been trying to find out how much time the elderly person had been given for home care: ‘Not a lot would happen if I complained. They’d get their knuckles rapped for five minutes, and then it’s back to normal. They cover up for each other. I tried to get out of the social workers how long she’s allowed, but they wouldn’t say. They can’t say. But it’s all poppycock. I then feel anger and guilt...’

There was no doubt that carers often felt more than anger and guilt, but felt unable to complain too much. There was certainly evidence of frustration in trying to get appropriate services for the elderly people, as this son in the London area explained: ‘The advice from the carers’ group is that you have to press hard...’
to get services. That was true when she needed nursing help. The situation then seemed to improve. I’m not sure “complain” is the right word – it might be "badger"…

**Carers’ views about the choice of elderly people**

We wanted to establish whether the elderly people had had enough choice in the services they received and how satisfied they were with what they were getting.

We had found in piloting the questionnaire that elderly people found it very difficult to answer any questions about ‘choice’ as such, so we explored the concept by asking them about the extent of the discussion they had had about services and whether they had refused any and whether they felt able to complain about services. We tried to establish some indication of whether they felt they had participated in decisions about their services by asking them whether they felt people had taken enough notice of what they wanted.

As we have seen, two-thirds of the elderly people thought that others had taken enough notice of their wishes. We asked the carers directly whether they thought the elderly people had had enough choice in the help or services that had been offered to them. Over 70 per cent of the carers thought the elderly people had had enough choice, but nearly one fifth thought they had not had enough and just over one in ten did not know.

Carers who thought the elderly people had had enough choice did not always amplify their answer other than to say that the elderly people had got what they asked for or had got what was on offer. Some thought the elderly people had had enough choice as far as it had gone, in that services had been offered and accepted, as this daughter explained: ‘I don’t think choice really came into it. We were grateful for whatever has been offered…’

However, some carers thought that, although the elderly people had had choice, the choice had been very limited, often to one or two services. These carers’ views were often shared by people who thought the elderly people had not had enough choice, like this daughter: ‘If we don’t know enough about them, she hasn’t been able to make a choice because she hasn’t had the information to do so…’

The question of choice was related to information and knowledge of what services might be available, and carers often recognised that it was related to whether elderly people or their carers were prepared to ask for services. There sometimes appeared to be a ‘conspiracy of silence’ about available services, and throughout these interviews with elderly people and their carers, there were signs of frustration at the lack of information available on services which might help elderly people to live more comfortably in the community, as this son explained: ‘She’s not really able to cope, as she is 88. She could have had more help. She hasn’t asked, so she hasn’t got, apart from the home help…’
Satisfaction with services

One of the aims of this study was to explore in detail what elderly people felt about the services they were receiving from all sources. One of the most common features of surveys of clients of health and social care services is the high level of satisfaction which emerges when people are asked to say how satisfied they are with their services. The measurement is usually based on a standard ‘satisfaction rating’, which is a common market research tool.

People answering questions about their overall satisfaction with health and social care services often appear to apply rather different rating standards from those they use when describing their satisfaction with other goods or services. They may well complain about various aspects of the care or service they receive, but when asked to give the service an overall rating, they seem peculiarly reluctant to criticise it. This has been shown in studies of health care. There is plenty of evidence that satisfaction with GPs is not universal, and yet every study of GPs shows a very high level of satisfaction with GPs and the services they offer.

It does appear that people make allowances for shortcomings in the provision of health and social care services and apply different standards in rating them, partly because they are seen to be operating under financial constraints which may lead to rationing and a rather poorer service than might otherwise be offered, partly because they are supplied by ‘dedicated’ hard-working people who are ‘serving the public’, and partly because they are usually ‘free’. It could be argued that education would satisfy the same criteria, but people seem much less inhibited about criticising the education service, often it appears because the ‘healing’ or ‘caring’ aspect of the education service is not as marked as that found in health and social care.

The high level of satisfaction recorded in the satisfaction ratings used so frequently in surveys of health and social care services is often interpreted as meaning that people are satisfied with the services and that little needs to be done to improve or change them. We were able to explore in more detail than is usually possible what people really felt about their services. We were aware that a high satisfaction rating often conceals very real dissatisfaction with certain aspects of services.

We were not surprised to find that, when we asked elderly people and their carers how satisfied they were in overall terms with the services and help received, there was a generally high level of satisfaction recorded, as Tables 4.4 and 4.5 show.

One third of the elderly people and a quarter of the carers said they were very satisfied with the services and a further 41 per cent of the elderly people and one third of the carers said they were satisfied. A high level of satisfaction was therefore recorded for three-quarters of the elderly people and nearly 60 per cent of the carers, a rating which should be pleasing to the service providers. There were area variations, borne out by the comments made in the interviews, with over 80 per cent of the elderly people in the southern area saying they were satisfied or very satisfied, compared with three-quarters of those in the northern
area and just over 60 per cent of those in the London area. Elderly people in the northern area rarely said they were ‘very satisfied’, but over 60 per cent said they were ‘satisfied’. Elderly people living with a spouse were generally less likely to express satisfaction than those living alone or with others, again suggesting a certain inadequacy of services among these frail elderly couples.

### Table 4.4 Overall satisfaction rating by elderly people in the community of services and help received

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>33</td>
<td>33</td>
<td>53</td>
<td>14</td>
</tr>
<tr>
<td>Satisfied</td>
<td>41</td>
<td>30</td>
<td>29</td>
<td>61</td>
</tr>
<tr>
<td>Fairly satisfied</td>
<td>10</td>
<td>13</td>
<td>3</td>
<td>14</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>6</td>
<td>--</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Fairly dissatisfied</td>
<td>2</td>
<td>3</td>
<td>--</td>
<td>3</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>2</td>
<td>7</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>3</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Not applicable/no help</td>
<td>5</td>
<td>10</td>
<td>6</td>
<td>--</td>
</tr>
</tbody>
</table>

*Base: all elderly people living in the community (100) (30) (34) (36)*

### Table 4.5 Overall satisfaction rating by carers of services and help received by elderly people in the community

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>London area</th>
<th>Southern area</th>
<th>Northern area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>24</td>
<td>--</td>
<td>50</td>
<td>14</td>
</tr>
<tr>
<td>Satisfied</td>
<td>33</td>
<td>39</td>
<td>15</td>
<td>46</td>
</tr>
<tr>
<td>Fairly satisfied</td>
<td>22</td>
<td>22</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>6</td>
<td>11</td>
<td>--</td>
<td>7</td>
</tr>
<tr>
<td>Fairly dissatisfied</td>
<td>4</td>
<td>11</td>
<td>--</td>
<td>4</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>3</td>
<td>6</td>
<td>4</td>
<td>--</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>1</td>
<td>--</td>
<td>--</td>
<td>4</td>
</tr>
<tr>
<td>Don’t know</td>
<td>4</td>
<td>11</td>
<td>4</td>
<td>--</td>
</tr>
<tr>
<td>Not applicable/no help</td>
<td>3</td>
<td>--</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

*Base: all carers of elderly people in the community (72) (18) (26) (28)*
Carers too were far less satisfied generally in the London area than in the southern area, where over 90 per cent expressed a high level of satisfaction, or in the northern area, where 60 per cent did. In London, none of the carers said they were very satisfied, and under 40 per cent said they were satisfied. Again, the evidence from the ratings was reinforced by the comments made by the respondents.

Two-thirds of the resident carers expressed a high level of satisfaction with services compared with less than half the non-resident carers, again reflecting the level of worry suggested throughout these interviews on the part of sons and daughters in particular, who were not living with their elderly relatives but undertaking the caring role.

Ten per cent of the elderly people and over one fifth of the carers said they were fairly satisfied with the services, which often disguised a considerable level of dissatisfaction with at least one service. Six per cent of each sample said they were neither satisfied nor dissatisfied, while 4 per cent of the elderly people and 8 per cent of the carers said they were dissatisfied to a greater or lesser extent.

Dissatisfaction with services was often related to dissatisfaction with the home help, which was not really surprising since this was the main service received by most of those interviewed, and in many cases was the only service received. We heard comments again about the poor timekeeping of the home helps, the restricted service they offered and the general unreliability of some of them. Apart from the comments on the home help service, there was some dissatisfaction related to money and benefits, some dissatisfaction with the GPs’ services and some dissatisfaction related to a lack of services in general, but the overwhelming impression was one of satisfaction among the elderly people, often tempered, it must be added, by a fairly low level of expectations, as summarised by this elderly woman in the southern area: ‘I’m satisfied. I don’t expect a lot in life...’

The carers were much more likely to relate their dissatisfaction to the home help service, with one in six of all carers expressing some dissatisfaction with it, mainly regarding the limited amount of home help time available for the elderly person. Few of the carers related to services as a whole, again, it appeared, because most elderly people were getting so few services. There was little awareness that a ‘package of care’ might be available or might even be provided, and there were few comments from carers suggesting that they realised there might be more services available than they knew about or the elderly people were receiving. This son was unusual in his assessment, and even he appeared to be feeling his way into unknown territory:

Within the limitations the services are OK. We’re not able to assess them yet, but they’re turning up and she likes them. But we feel she could slip through the net. The GP and the social worker are now visiting regularly. But she’s not getting regular attention. There have been no suggestions of visits in the evening or a bed-time visit from the social services department...
Views on private community care

The huge increase in the private sector in residential and nursing home care over the last few years has led to much speculation that there might be a similarly large market in private community and domiciliary care. The government has sent out many messages encouraging an increase in the use of the independent sector in community care, but, without the impetus offered by money from the social security budget, there has been little evidence of much growth in the provision of this kind of care by either private or voluntary organisations.

We were interested to hear the views of elderly people and their carers about what they saw as the advantages and disadvantages of private care in helping elderly people to manage at home. Very few of the elderly people we interviewed had any private care, and it often seemed that it had never occurred to them that private care might be available. It certainly did not seem to have been suggested to them by anyone. Similarly, carers rarely mentioned private care. There seemed to be a general assumption that it was only available in a very limited form and was very expensive.

We wanted to explore people's views on private care as such, leaving aside the question of whether money was a problem. We wanted to know whether there were any factors which made the idea of private care more attractive or less attractive to frail elderly people seeking help in their own homes.

The elderly people found it difficult to comment on the advantages of private care and nearly one third of them said they really did not know, while one fifth could not think of any advantages, even if money were no real object. However one in ten of the elderly people thought that with private care they could say when they wanted the service to come and others said the service would be better and they could stipulate what they wanted to be done. There was no doubt that most of the elderly people were thinking only or mainly in terms of a home help service, and this elderly woman’s comment was typical of those who thought a private service had its advantages: ‘You can get done what you want doing, when you want it. There are some things home helps won’t do…’

This question of choice about time and duties was not the only advantage of private care mentioned. A handful of elderly people thought that paying privately for care might mean that the general service would be better and not so dependent on other calls on the time of the service providers, as this woman in the London area said: ‘I think in a way you would be able to rely on them more. Often home helps are meant to come and don’t because they’re sent on a more “urgent” case. If it was private, they’d come I suppose…’

Some elderly people thought that paying for private care would mean that they could get things done which the statutory services did not provide, like window cleaning and gardening. But the main advantage of private care in their minds hinged around the freedom to choose the time, the duties and the way in which the task was done. This was something which many of them felt they lacked at the moment, as this elderly woman in the northern area found: ‘You could tell them what you wanted doing, not just what they think needs doing. They are always in a hurry now and don’t have time to do any extras...’
It was the question of choice about time which was the most attractive thing to carers. Like the elderly people, some found it difficult to comment on the question of private care, and over a quarter could see no advantages in it. However, nearly 30 per cent of carers said that the main advantage of private care was that the elderly person could say when they wanted it. Carers also pointed out potential advantages of choosing the person who delivered the care, getting the service more quickly when it was needed, stipulating what needed to be done and getting services not provided by the council. Some carers felt that elderly people had little choice in their present services, and that private care would provide more choice, like this daughter: ‘You’ve got choice of who is going to come, whereas normally they just arrive. You could tell them what you would like them to do, instead of them telling you...’

There was a strong undercurrent of feeling among some carers that paying for care meant that the customer would have rather more power than most elderly people had at the moment, a view expressed by this son in London – ‘I suppose like anything you buy you dictate the terms. You possibly have more control over what happens...’ – and this nephew in the same area – ‘You get greater efficiency. You’re paying the going rate and you’re buying a commodity from them. If it’s a public funded service they’re less motivated and less efficient...’

Again the non-resident carers were more likely than resident carers to mention advantages of private care such as choosing the time and the person and what was done. Their anxiety about the variability of the services provided to the elderly people they were looking after was expressed in these interviews in a variety of ways, and this daughter in the southern area summarised the views of a number of non-resident carers: ‘You get exactly what you want if you pay. You get continuity and no swapping of home helps and the day you want them. Gardeners are easier to find privately and chiropodists are as well. If you pay for taxis you don’t have to wait for social transport. It makes life more comfortable...’

What about the disadvantages of private care? Although we had stressed that we were asking this question with the proviso that money would be no real problem, over a fifth of the elderly people still thought that private care would be too expensive and so did one third of the carers. There were indications that private domiciliary care was thought to be very expensive, so that the question was irrelevant. But the cost alone was not thought to be the main disadvantage. A number of the respondents pointed out the disadvantage of paying for something which they did not regard as value for money, as this daughter-in-law said: ‘It’s paying out a lot of money for nothing. A lot of people do jobs for financial benefit only and not for the welfare of the person they are helping. People often do the least work they can. For example, they get paid for an hour and leave after half an hour...’

The cost was a matter of great concern to some of the carers in the northern area, some of whom also felt that elderly people should not have to consider private services, partly because of fairness, as this son pointed out – ‘Why should someone who has saved all their lives have to pay, while those who do not save get everything...’ – but often because elderly people were seen to have
contributed to these services, as this daughter pointed out – ‘You shouldn’t have
to pay for services or help after a lifetime of contributions. I think after the age
of 75 people should get everything free...’

The carers were much more likely than the elderly people themselves to say
that the services should be freely available and that elderly people should not
have to pay. There was stress on the contributions that the elderly people had
made, and a much more acutely developed sense among carers of the rights of
elderly people to have reliable services which were accountable to ‘the
authorities’, and in which the workers had been ‘vetted’. There were definite
fears among carers of elderly people being exposed not only to ‘cowboys’, but
also to exploitation or worse. Some of the elderly spouses were particularly
worried, like this husband: ‘You do not always get the best by paying for it. You
hear of old people getting robbed by conmen saying they will do jobs for them...’

Elderly people themselves were more likely to say that they would not know
how to go about getting or choosing private care. Many of those we interviewed
were very frail and dependent and certainly did not feel capable of making the
arrangements to employ private care. Even if they did, they often thought they
would feel insecure about doing so, as this elderly woman in the northern area
pointed out: ‘You would have the job of choosing, and you might choose
unwisely...’ There was a sense of security among some of the elderly people in
feeling that statutory service workers were accountable to someone, as elderly
woman said: ‘I would not like to have strange people in my house who I don’t
know and who are not official like the home helps...’ Her views were echoed by
another in the same area: ‘I suppose the council people are reliable and if anything
goes wrong you contact them. If you pay for people you don’t know them...’

The question of private domiciliary or community care was clearly not one
which had exercised the minds of the majority of elderly people and carers we
interviewed. The cost was thought to be prohibitive, they did not know how to
go about getting it, they were worried about accountability and being exploited.
On the other hand, some carers and elderly people thought that private care might
provide greater flexibility of time and hours, and that it might also provide elderly
people with more control over what was done for them. Statutory authorities
should take careful note of these comments in their attempts to provide a service
which is more needs-led. There were plenty of indications in this study that
services, particularly the home help services, were often thought to be designed
round the needs of the service providers rather than the needs of the elderly
customers.