

# Introduction

## **‘Community care’**

About 2.3 million people in Great Britain suffer from a disability which means that they cannot look after themselves in the normal way.<sup>1</sup> They need ‘care’.

Many live in residential care homes; some of those with the most serious problems in nursing homes. The care provided in these homes is paid for in a variety of ways: by local authorities, out of social security benefits, by the residents using their own resources, or by their relatives. There was a huge increase in the use of social security benefits to pay for residential care during the 1980s: the number of people involved rose from 13,000 in 1980 to 147,000 in 1988.<sup>2</sup> Some of the increase represents people who would have come into residential care anyway, and the Department of Social Security is paying bills which would otherwise have been met by someone else. But many people might not have been in a residential home at all if they had not been able to claim social security benefits to cover the fees.

While there is little doubt that the people in these homes need care,<sup>3</sup> this increase in support for residential care is in direct contrast to the government’s declared preference for ‘community care’. It is widely accepted that many people with disabilities could lead a fuller life if they were able to live at home, and receive care there. For most disabled people, care at home also costs the government less: this is a strong attraction for the keepers of the public purse, though the argument is naturally less impressive for those who may have to bear the costs of caring more directly.

Most care in the community is provided by relatives. But local authority social services departments have placed an increasing emphasis on provision for people with disabilities living in the community. Sometimes these services are provided to disabled people living alone without an informal carer; sometimes they are used to support relatives who cannot cope on their own. Caring and support services can also be provided by voluntary organisations, or by neighbours on a voluntary basis. Alternatively, disabled people or their relatives can pay an agency or an individual to help them.

The huge increase in social security payments to cover the costs of residential care has raised the question whether the same money might not be spent more effectively on care in the community. A series of official reports has examined the procedures by which public money should be made available to meet the costs of care. The most important of these, the Griffiths Report,<sup>4</sup> recommended that all the public resources currently available should be placed in the hands of a single agency – the local authority social services department – which would decide how much was needed by each client, and how it should be spent. A rational choice between residential and community care could be taken only if the same organisation was responsible both for assessing need and for paying the bills, whatever the decision. According to the Griffiths model, local authorities would become managers rather than providers of care services, while social security benefits would return to their original role of meeting basic living expenses.

The idea of a budget available to be spent as appropriate on the particular needs of the individual opens out a wide range of possibilities. Should the money be spent on a place in a residential home? Or should it be spent on services such as home helps, meals on wheels, day care centres or care assistants, bought-in on contract from organisations which specialise in the provision of such services? Or should an individual be paid a salary to look after the disabled person; or a team of people working a rota? One use of the money would be to allow a relative to give up work in order to concentrate on caring. A combination of these approaches might turn out to be the best package.

The Griffiths Report envisaged that when a significant amount of resources was required, the care budget would be placed in the hands of a ‘care manager’ – a social worker or other public servant. An

alternative approach would be to hand the money direct to the disabled person, or to his or her family, to spend as they think best. This might be attractive to those who see consumer choice in a free market as the best way to ensure the efficient use of resources. On the other hand, it is not clear whether the money would be spent on care, or on other important needs such as food, fuel or clothing.

Severely disabled people in need of care already receive a social security benefit – the attendance allowance – which they are free to spend on caring services, or on other things, as they choose. This report is based on interviews with 38 claimants, designed to find out how they used their attendance allowance, and what difference, if any, it made to their arrangements for care.

### **The attendance allowance**

The attendance allowance was introduced in 1971 as a benefit paid to people with disabilities who cannot be left on their own for long periods. It is payable to adults, and to children over the age of two, who require either frequent attention in connection with their bodily functions, or supervision to avoid substantial danger to themselves or others. Payment can start six months after the onset of the condition which qualifies the individual for attendance allowance.

The benefit is paid at two rates, according to whether the person requires attendance just during the day or just during the night (lower rate), or during both day and night (higher rate). For the year between April 1988 and March 1989, during which most of the fieldwork for this study was carried out, the two weekly rates were £22.00 and £32.95. The current rates (from April 1990) are £25.05 and £37.55.

In 1971 54,000 people received attendance allowance, whereas in 1988 it was received by thirteen times as many: 425,000 at the lower rate, 287,000 at the higher rate.<sup>5</sup> As the figures below show, many claimants are very old, but the benefit is nevertheless important to disabled people of working age, and children.<sup>5</sup>

|      |            |         |
|------|------------|---------|
| Aged | 2 to 15    | 71,000  |
|      | 16 to 59   | 193,000 |
|      | 60 to 74   | 153,000 |
|      | 75 or more | 337,000 |

The OPCS report on the financial circumstances of disabled adults confirms that the attendance allowance tends to go to those with the severest disabilities.<sup>6</sup> Using a ‘severity’ scale from one (lowest) to ten,

it was found that those receiving attendance allowance were concentrated in categories nine and ten. Thus 54 per cent of adults in category nine received attendance allowance and 74 per cent of those in category ten, whereas none of those in category one received the allowance.

An important feature of the attendance allowance is that entitlement depends on need and nothing else. Unlike income support, the benefit is not means-tested; indeed it is not regarded as income for the purposes of calculating income support. Neither is the benefit taxable. It therefore provides a genuine increase in resources for people receiving it. Unlike the invalidity pension or invalid care allowance, it does not depend on either the claimant or the carer being unable to work, and it is therefore not an earnings replacement benefit. The allowance does not have to be spent on care; indeed in principle it is payable even if the claimant does not receive the attendance which qualified him or her for the benefit.

It has never been clearly stated what the attendance allowance was for. A common assumption is that it was designed as a payment towards the costs of care. An alternative assumption is that it was intended to pay for the extra expenditures faced by many people with disabilities, and that the attendance criterion is simply used as an indicator of the extent of disability.

Whatever governments may have intended, another question is what the attendance allowance is spent on in practice. Social Policy Research Unit studies of families with severely disabled children have suggested that the attendance allowance tended to go towards general living expenses and/or specific items like hospital visits or compensatory 'treats', rather than on care services.<sup>7</sup> A National Institute for Social Work study of elderly people suffering from dementia<sup>8</sup> also touched on the question, and found the allowance being used in a variety of ways to cover the extra expenses which arose from the person's illness; in some cases this included services such as domestic help and 'sitting'.

### **Other social security benefits**

The majority of people with disabilities rely on social security benefits for most of their income.<sup>6</sup> These are usually classified either as 'income maintenance' benefits or as 'additional costs' benefits.

Income maintenance is provided both through benefits especially for disabled people, and through mainstream social security benefits.

- The *state pension* or *invalidity benefit* are part of the national insurance scheme.
- A *disablement pension* is available to people whose disability was caused by an industrial accident or disease.
- People without an entitlement under national insurance can claim the *severe disability allowance*, paid at only 60 per cent of the rate of the contribution-based benefits.
- Those whose benefits or other income are insufficient for their basic needs can claim *income support* -- formerly supplementary benefit -- and *housing benefit*.

All these benefits are designed to provide claimants with the ordinary necessities of life; apart from housing benefit, they are available only to people who are not able to earn their own living.

Three benefits are designed to provide for the additional costs faced by people with disabilities.

- The *attendance allowance* has just been described.
- *Mobility allowance* is available to people who are unable or virtually unable to walk; it is explicitly intended to help them with the additional costs of transport.
- People with disabilities who claim income support or housing benefit can receive a *disability premium* which allows their minimum needs to be assessed at a higher rate than that of other claimants.

It is open to question whether the attendance allowance is designed to meet the costs of care or not. But other social security benefits are more explicitly aimed at care.

- Income support will meet the *fees of residential care or nursing homes*, up to certain limits, if the claimant's own income does not cover them; this arrangement will, however, be phased out as the responsibility is transferred to social services departments over the next few years.
- Other benefits provide income maintenance for informal carers who are prevented from working. The *invalid care allowance* is solely for that purpose, but carers can also claim *income support* if their other resources are inadequate. An

income support *carers' premium* will be introduced in October 1990.

- Under the old supplementary benefit scheme it was possible to claim extra money to pay for privately provided *domestic assistance*. Additions of this sort have been replaced by the disability premium mentioned above, but the government has also set up an *Independent Living Fund* which can meet the costs of domestic assistance and other care. This scheme, which did not exist when our research was being planned, can play an important role in meeting the costs of care for a few thousand people with disabilities, though its future will be reviewed as other aspects of community care policy develop.

### **The Bexley Community Care Scheme**

Although there is no national policy on the use of social security benefits to pay for care at home, several local schemes have been set up to employ 'paid carers' for people with disabilities. One is the Community Care Scheme which has been operated in the London Borough of Bexley since 1984. The scheme aims to develop alternatives to residential care for elderly people suffering from multiple disabilities. The scheme currently has 60 clients, most of whom suffer senile dementia. It was inspired in part by the Kent Community Care Project which had carried out pioneering work in supporting frail elderly people in the community.

The scheme seeks to arrange packages of care tailored to an individual's needs through coordinating the contributions of public agencies, relatives and paid carers. Each client has a case manager who organises the programme of care arrangements.

Much of the money to pay for carers is provided by social security benefits. Assuming that basic benefits such as the state pension, invalidity benefit or income support are designed to meet ordinary living expenses, the case manager ensures that the client has claimed the attendance allowance at the appropriate rate. Until April 1988, the domestic assistance addition to supplementary benefit was of great value to the scheme. Since then, many of the scheme's members have successfully applied for support from the Independent Living Fund.

Members of the scheme are people who were at risk of going into residential care, but wished to remain in the community. A different package is arranged to suit each case: carers may be individually

recruited paid neighbours, private agency carers, care attendants or home sharers; their services are sometimes combined with statutory services such as home helps, meals on wheels, bath attendants and district nurses.

Every member of the scheme has a 'key carer' who takes the overall responsibility for ensuring that the elderly person's needs are met. But no-one is expected to take on the whole of the task without regular help from others. Sometimes the 'key carer' is a close relative of the disabled person, but in the majority of cases no relative is available to take on the task, and the 'team' is led by a paid key carer.

A clinical psychologist is available to assess the needs of the client in terms of therapy as well as care. The scheme is run by three care managers, who put the packages of money and carers together in collaboration with relatives, statutory services and other interested parties. These packages are described in Chapter 4.

### **Aims of the research**

This study examines the financial circumstances and care arrangements of 29 'ordinary' claimants of the attendance allowance, plus 9 members of the Bexley Community Care Scheme. The research was designed to find out what role, if any, the attendance allowance played in bringing together the package of care suited to each individual, and about the actual or potential role of paid carers in support of, or as substitutes for, kin carers.

This was an exploratory survey of a specific question about the link between one benefit and one form of care. It aims to add one or two pieces to a jigsaw, large areas of which have already been filled in by other studies.

- A series of surveys of people with disabilities conducted by the Office of Population Censuses and Surveys has provided a definitive analysis of the *prevalence of disability*,<sup>9</sup> analysed by the cause, nature and severity of the handicap. The same surveys offer a wealth of information about disabled people's *financial circumstances*,<sup>6</sup> *use of services*<sup>1</sup> and so on.
- A large volume of research on *informal carers* has been undertaken during the 1980s. Recent major studies include those by Janet Finch<sup>10</sup> and by Hazel Qureshi and Alan Walker;<sup>11</sup> a full review of this literature has been undertaken

by Gillian Parker.<sup>12</sup> Caroline Glendinning<sup>13</sup> has studied the financial costs of caring, and the views of carers.

- There has been much less research about *paid carers*, but Diana Leat<sup>14</sup> has looked at a variety of ways in which ‘ordinary people’ are paid, usually by the local authority social services department, to care for people in need. Much of her interest has been in the motivations and rewards of the paid carers; our own study tends to look at paid care more from the point of view of the disabled person, and/or their family.
- A number of other local *community care schemes* have been evaluated, notably that in Kent.<sup>15</sup> We should emphasise that our own look at the scheme in Bexley is intended simply to cast further light on the link between benefits and care, and is *not* an evaluation of the care provided by the scheme. This report analyses the number of hours of care delivered, and its cost, but a much more intensive enquiry would have been required to compare the quality of the care received with that available from other sources.
- The experience of claiming the *attendance allowance* has been examined in a recent report by Judith Buckle,<sup>16</sup> but she did not look at way in which it was spent.
- Although our particular interest is in the relationship, if any, between the attendance allowance and care, an alternative use of the benefit is to meet the *additional costs of disability*, including special diets, extra fuel or laundry costs, and so on. The OPCS surveys, mentioned above,<sup>6</sup> estimated these on the basis of a set questionnaire, but the Disablement Income Group has published much higher estimates based on more intensive questioning.<sup>17</sup> Sally Baldwin used a direct comparison of expenditure patterns to estimate these costs for children with disabilities,<sup>7</sup> and a similar analysis for adults is currently being undertaken by the Department of Social Security.

The research is intended to contribute to the development of two important areas of government policy, both of which are currently under consideration. One is concerned with the development of care in the community; the other is concerned with the reform of disability benefits.

The government's policy on community care has been under review since 1984. The Griffiths report, recommending the allocation of all responsibility to local authority social services departments was published in March 1988.<sup>4</sup> The government announced its broad acceptance of the proposals in July 1989, and published a detailed white paper in November.<sup>18</sup> The new policy is intended to be implemented in 1991.

When the Government announced major reforms of the structure of the main social security system, it said that decisions about benefits for people with disabilities would be made when the results of a series of major surveys of disability, carried out by the Office of Population Censuses and Surveys, were known. The reports on those surveys have now been published. In addition, the Social Security Advisory Committee, which advises the Government on social security matters, published its recommendations about how the system of benefits for disabled people should be changed.<sup>19</sup> The government's plans for disability benefits<sup>20</sup> were announced in January 1990 – after this research had been completed. Among other changes, it proposes to introduce a new 'disability allowance' incorporating the current attendance and mobility allowances, but adding a new, lower, rate of payment for people who do not qualify at present.

### **Research methods**

The Department of Social Security supported the study by selecting a sample of attendance allowance claimants. This will be referred to as the 'main sample'. The Department selected 40 cases at random. Half received benefit at the higher rate (requiring attendance both by day and by night); the other half at the lower rate (either by day, or by night, but not both). Within each category, half of the claimants selected were adults of working age (18 to 59); the other half over pension age (65 or more).

The DSS used information about the Post Office where the benefit was cashed to confine the sample to two areas: a district of North London overlapping the Boroughs of Haringey, Islington and Hackney; and a district of Southeast London approximating to the Borough of Bexley.

The Department wrote to each of the 40 claimants informing them of the proposed study, explaining its purpose, and giving them the opportunity to have their name and address removed from the list.

Seven of the claimants were deleted by the DSS after responses to this letter: three had died, three did not wish to take part and one could not be traced. A researcher then visited each of the remaining claimants in their homes to carry out an interview. Three more declined to do so at this stage, two of them because of language difficulties. One of the claimants who gave an interview had already moved into residential care, and his circumstances were not relevant to the enquiry.

29 of the original 40 claimants therefore contributed to the study. Two of them had been reassessed for the attendance allowance, by the time they were interviewed, and had been told that they no longer fulfilled the conditions of eligibility. These two cases may not strictly fit into the sample, but information about them has been referred to in this report where it has seemed relevant.

The aim was to interview the disabled person, the main carer, and preferably both. The interviews were carried out in one or other of their homes, and frequently both individuals were interviewed together. Some of the claimants was physically unable to communicate, or were prevented through mental ill-health from carrying out a full interview, and in these cases only the main carer was interviewed. Most interviews were recorded on tape and afterwards transcribed; where the respondent asked for the tape recorder not to be used, the researcher took detailed notes.

Originally it was intended (with the permission of the disabled person) to interview the social worker dealing with each individual's case, so that we could get a clear measure of the role of formal services in support of informal carers. In the event only seven of the 29 respondents in the sample of 'ordinary' allowance claimants had an individual social worker who regularly dealt with their needs. Instead, representatives of the social services departments of each of the boroughs where the research was carried out were interviewed about the services offered to disabled people, without going into the details of particular cases.

Nine members of the Bexley Community Care Scheme were selected, and their agreement (or that of their main carer) to participate in the study obtained, with the assistance of Bexley Social Services Department. All the individuals in this sample were suffering from some form of mental ill-health or dementia, and interviews were carried out with their main carer and, in some cases, either a second

carer or a close relative. The files relating to each case were consulted, and the Community Care Manager was interviewed about each case.

Table 1 provides some basic information about the members of the two groups of respondents. Although some members of the main sample of ordinary attendance allowance claimants lived in the same borough, the word 'Bexley' is always associated with members of the Community Care Scheme whenever it is used in this report.

**Table 1 Details of the samples**

|                          | 'Ordinary'<br>claimants | Bexley<br>clients |
|--------------------------|-------------------------|-------------------|
| <b>Age</b>               |                         |                   |
| 18 to 34                 | 5                       | nil               |
| 35 to 60                 | 11                      | nil               |
| 65 or over               | 13                      | 9                 |
| <b>Sex</b>               |                         |                   |
| Man                      | 7                       | 2                 |
| Woman                    | 22                      | 7                 |
| <b>Location</b>          |                         |                   |
| North London             | 22                      | nil               |
| South East London        | 7                       | 9                 |
| <b>Condition</b>         |                         |                   |
| Mental handicap          | 5                       | nil               |
| Mental illness           | 6                       | 9                 |
| Physical disability only | 18                      | nil               |
| <b>Rate of allowance</b> |                         |                   |
| Lower                    | 14                      | 4                 |
| Higher                   | 15                      | 5                 |

The Bexley clients were very similar to each other: all were over pension age, and all suffered from senile dementia. Some of the main sample were also old, and also suffered from senile dementia or other conditions which affected their ability to take decisions for themselves. But the main sample was broader, including five young adults with mental handicaps, and many people with disabilities which required physical assistance, but who could take their own decisions about income, expenditure and care.

On the other hand, the samples had two things in common: all members of both samples received the attendance allowance, and they

all needed care. Although their particular needs were often different, each sample could throw some light on the main question facing the research, about the relationship between the attendance allowance and the costs of caring.

The research was based on extremely small samples in two areas of London, and it is not possible to draw general conclusions with any confidence. The objective of the study was simply to explore the issues surrounding the use of social security benefits to pay for care, on the basis of a small number of examples. A larger scale and more structured enquiry would be needed to provide an accurate measure of the patterns which seemed to emerge.

### **Plan of this report**

The next chapter describes the care received by members of the main sample of ordinary attendance allowance claimants, either from their family, or from other sources. We concentrate in particular on arrangements which did not fit into the standard patterns described by other studies, and on the relationship between primary carers and alternative sources of support.

Chapter 2 describes the main sample's sources of income. One focus is on the impact of the attendance allowance on a household's total resources; another is on the incomes of carers.

Chapter 3 concentrates on expenditure. It is here that the first two chapters' analyses of care and cash are linked, in an attempt to assess the impact of one upon the other.

The sample of clients of the Bexley Community Care Scheme is analysed in Chapter 4. Some of the care arrangements are described in detail, and it is possible to trace a much more direct link between the costs of caring and sources of income than could be found in the main sample.

The concluding chapter includes a summary of the findings, and a preliminary discussion of possible relationships between social security benefits and paid care.

All quotations are taken from the transcripts of tape-recorded interviews. To preserve the anonymity of the thirty-eight disabled people and their carers who took part in this study, fictitious names have been used throughout.

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