

4 The Bexley Community Care Scheme

The Community Care Scheme was described in the Introduction. Its clients are elderly people suffering from senile dementia, who were at risk of going into residential care. The care manager arranges a team of non-kin carers based on a preliminary assessment of need. We would therefore expect the results to be quite different from those found in the sample of 'ordinary' claimants, most of whose care arrangements had been developed ad hoc by their relatives.

Key carers

In the ordinary sample, we found that 27 disabled people turned to a close relative to take on the main responsibility for their care; the majority of them lived with that relative. Only two were cared for in a more formal arrangement with non-relatives.

Among the nine clients of the Bexley scheme, two lived with a close relative who retained the principal responsibility for care in an arrangement very similar to those found elsewhere. The distinctive feature of the scheme from their point of view was the provision of support.

At the other extreme were two clients who had no contact with any relatives. For them, there was a straight choice between paid-for care at home or in an institution.

Several members of the scheme, however, had children who participated to a greater or lesser extent in the care arrangements, but who were not principal carers. Their contributions varied: some lived nearby and visited almost daily; some contributed to the financial package; all would have expected to be consulted about any major

problem. These kin held a general responsibility for ensuring that their mothers or fathers received care, but it was a paid carer who had had taken on much of the immediate responsibility from day to day.

The scheme could be seen, therefore, to provide support for, or an alternative to, a kin carer, as well as offering care at home to the disabled person.

Apart from the two who lived with a close relative, the members of the Bexley sample had a principal carer who was not related to them, in an arrangement almost without parallel in the main sample of people who had not benefited from the scheme. Three examples are described in the boxed text on the next two pages, to illustrate the range of variation. Each case had its own particular characteristics, and it is difficult to generalise on the basis of so small a group. Indeed, the capacity to choose a different solution for each client might be claimed as one of the advantages of the scheme, though it no doubt implies a high administrative cost at the time each arrangement is being set up.

Even among the seven cases, it was possible to identify some patterns of variation:

- Variations in *the role of kin* have already been described.
- Another difference between cases was in *the location of the carer*. In addition to the two close relatives who lived with the disabled person, two of the paid carers lived with their client under a home-sharing arrangement, and were available throughout the night. But the remaining clients lived alone, with their carers coming in from their own homes nearby.
- A third feature of the cases was the *method of recruitment*. Two of the carers were experienced care-workers who helped to look after other people besides the member of our sample; two others had previously worked for the disabled person as a local authority home-help and extended their duties when the new arrangements were required. These four, then, were contacted within the existing community care network; the other three were recruited in the neighbourhood through advertising.

Mrs Cherry – care provided by homesharers

Mrs Cherry suffered from Alzheimer's Disease. She was beginning to wander out in the streets at night, when her daughter who lived nearby, but was too unwell to care for her mother herself, decided that her mother needed a live-in carer. She had the idea that it might be possible to find a family to live with her mother and supervise her at night, in return for free accommodation and a small payment. She contacted the community care scheme because she wanted assistance with drawing up a 'homeshare agreement' covering such matters as bills, shared and private areas of the house, and so on.

She placed an advertisement in the 'jobs vacant' section of the local newspaper and received thirty applications. She interviewed twelve couples, saying that they were all 'quite suitable – any one of them would have done'. Since then, several families have stayed with Mrs Cherry, and only one of them caused any problems. Her daughter described how she felt about this solution:

It's worth every penny and more. If (the family) was paid twice (what they get), it still wouldn't be enough ... My mother improves no end with the children around. It's a lovely atmosphere round there. To do that job, (the family who care for her) are lovely, loving people.

Mrs Aintree – care provided by paid neighbours

Mrs Aintree spent much of the day in bed and was incontinent. The community care scheme became involved while she was in hospital. A meeting was held, involving the manager of the community care scheme, Mrs Aintree's son (who was living away from his mother), a nurse, an occupational therapist and a social worker. It was decided to try to recruit a carer from among Mrs Aintree's immediate neighbours, to enable her to return to live in her home as she wished. A neighbour described how she came to be Mrs Aintree's carer:

A leaflet came through the door and I thought 'I don't mind a couple of hours a week shopping.' It was just something to help a handicapped person.

This 'key carer' then recruited three further members of the care 'team'. Together, they provided 42 hours a week of care and domestic assistance, paid for out of Mrs Aintree's attendance allowance and other income, with subsidies from her son.

Mrs Binney – care provided by home help who extended her duties

Mrs Binney lived alone in a block for elderly people, but her behaviour had been causing uproar among her neighbours. Mrs Binney already had a devoted home help, who wanted to do more. With the agreement of the home help organiser, the home help's role was extended to that of carer, the extra hours of work being paid for out of the benefits obtained through the community care scheme. The home help's daughter also helped out as a carer, and even, on occasion, the home help's husband.

The neighbours were soon reconciled to Mrs Binney's living near them, and some of them popped in to see her with cups of tea. As the community care manager put it:

It's what it ought to be and it very often does happen like that, where the whole family becomes a surrogate family to this old lady and they love it.

In the words of the home help:

I just got roped in and got on with it sort of thing. It's not put me out as such or anything.... It's just worked out that I've got myself that little bit more involved than I intended.

One striking feature of the arrangements was the extent to which many of the non-relatives had developed a 'family' type relationship with the person they looked after. Mrs Cherry's daughter commented on the 'lovely atmosphere' created by the homesharer's own family. Mrs Binney's home-help shared the work with her own daughter, and asked her husband to help out on occasions, in a relationship which the scheme organiser described as a 'surrogate family'. Another carer sometimes invited her 'client' for Sunday dinner. A social worker commented:

(She) is very fond of him but incapable of asking for money ... She has gradually stepped into the daughter role and now makes all decisions and copes with personal care, bills, working and cleaning.

Support for key carers

An important point about the role of the principal carer within the Community Care Scheme was that no-one had to look after a disabled person 24 hours a day, seven days a week. Although at first sight the most distinctive feature of the scheme is the assignment of

**Table 4
landscape**

responsibility to a non-kin carer, it is also striking how much help and support the carers received. The same was true whether the leadership lay with a relative or a paid carer: the principal carer did some of the work, and arranged for other people to do some of it. One principal carer was acting as an agency, hiring staff to provide the care, and acting as a supervisor rather than as worker. At the other end of the spectrum, one live-out carer put in a forty hour week, and the live-in carers would have had long periods of duty; but all of these could also rely on other people to take regular turns. No-one was put under the continuous strain accepted by some of the kin carers in the sample of ordinary attendance allowance claimants.

Table 4 summarises the care and support received by each of the nine disabled people in the Bexley sample. Each arrangement was set up ad hoc, depending partly on the availability of kin, as well as on the needs of the individual client. Support came from four separate sources: from members of the disabled person's family; from additional non-kin carers paid directly; from the local authority social services department; and from the local health authority. But while some disabled people benefitted from officially-provided services, others did not.

The five clients whose carers did not live with them received between 26 and 57 hours of care per week. The four live-in carers could not estimate how many hours they put in each week, but they had other forms of help and support totalling between 14 and 47 hours per week. It can be imagined how glad the carers of disabled people who were not members of the scheme would have been to have received support on anything like that scale.

'Teams'

These arrangements whereby a number of different people and organisations combine to deliver care to one person are often referred to as 'packages', although the organisers of the scheme prefer to emphasise the links between their members by calling them 'teams'. Compared with the patchwork of statutory services that some disabled people had received previously, respondents in Bexley often said that the one-to-one cover supported by statutory and paid services provided a much more flexible and satisfactory arrangement:

It's the best because you're buying what you want, when you want it. You're not getting it put on a plate saying 'this is what

there is; that is what you've got to have'. That may not suit what you need. And most of the people it doesn't suit their needs. They don't want to be got up at 10 in the morning by a district nurse, because they are used to getting up at seven or eight in the morning ... They don't want to be put to bed at 6.30 at night. They want to stay up and watch Dallas!

It crosses over the rigid lines that have been made by the social services. A home help can only do a, b, c, d. The district nurse will only do the other bit and don't you tread on my patch. It creates atmospheres and you get people wrangling.

Many of these arrangements seemed to work well:

We work together ... It's sticking together and working together that keeps us all sane.

On the other hand, complex schemes involving the coordination of several different carers did not always operate perfectly. Some of the specialist services could not be fitted in at the times which would have been ideal from the carer's point of view:

In the morning I waste time ... I'm hanging around waiting (for the District Nurse) ... I can't get the washing on the go until they've been, because I don't know if there will be any wet sheets.

Because most of the disabled people in this group were very confused, we did not consult them directly, but the constant rotation of faces and voices may have unsettled them, and, perhaps, added to their confusion. There were some signs of irritation with a member of the care team:

The girl she's got at the weekend ... she's very very nice but she's one of these people who tend to patronise old people. It's "is that all right, love, are you sure that's all right?" and of course Mrs Whates that, like a lot of old people do. It's getting on her nerves a bit. (Principal carer.)

And of course the principal carer was not always happy with every member of the team:

Her daughter gets terribly neurotic and worries constantly about her ... she has to be kept at arm's length.

Problems of this sort are probably inevitable when many different people are trying to cope with a situation which was difficult in the first place. None of the care teams in this study had fallen out so

seriously for care cover to break down; it can be assumed that if they had, the care manager who had helped to make the arrangements in the first place could have intervened and put things right.

Opinions about the scheme

It was emphasised in the introduction that this exploratory research was *not* set up to perform an evaluation of the Bexley scheme in terms of the content of what was done. We are concerned only with the economic and administrative questions about how it was arranged for a given number of hours care to be delivered; a much more intensive inquiry would be required before judgements could be passed as to whether the right kind of care was being offered, or whether it was the best solution for the client. We can, however, pass on the comments of some of the people who were involved.

The relatives and carers of the nine clients of the Bexley Community Care Scheme whom we interviewed described the situation prior to the involvement of the scheme as being unsatisfactory or distressing for the elderly person concerned. Relatives were often desperate when they first came into contact with the scheme, and in most cases, there was a real possibility that the disabled person would have to go into a residential home or hospital.

The scheme was seen as having made a considerable improvement to the situation of the disabled person. The scheme organisers' skills in obtaining benefits and coordinating services were much admired. Carers and relatives thought the arrangements were flexible, reliable, and designed to meet the particular needs of the elderly person.

Care arrangements were usually developed after an initial assessment of the client's needs, including advice from a clinical psychologist. This often meant that relatives and/or principal carers could be told what to expect of an old person suffering from dementia. Second, it was sometimes possible to include a programme of rehabilitation, rather than simply taking over certain activities. Sometimes it might be decided, for example, that the disabled person should be expected to take responsibility for the shopping and housework themselves, rather than rely on a home help provided by the social services department.

The following account of an old lady's transition from hospital to the community by her key carer illustrates some of the advantages of rehabilitation in the community:

I did an assessment visit in the hospital... I said 'Hello, I'm Frances', and started the conversation by saying 'Have you had your lunch?' 'No. Yes. '; 'Well what did you have?' 'No. Yes.' There was no conversation at all...

Now she can make a cup of tea for herself and she does her washing up. She gets undressed and into bed and she gets herself up in the morning ... So her whole life has changed and it's opened up again. She's gained confidence ... and she's enjoying it, being at home.

One of the objectives of keeping elderly people in the community was to ensure that they continued to exercise a degree of responsibility and control over their own lives. One elderly woman was given a budget out of which she was obliged to provide for her homesharer's and her own food and keep:

She's got to feel that she's looking after someone ... If you remove him ... she hasn't got a reason to live. (Daughter).

The same woman had to be retaught how to go out to the shops. Her daughter describes her first trip on her own:

We gave her her trolley and her purse and said 'away you go'. I drove round Bexleyheath shadowing her. People must have thought I was crazy. I was hiding in shop doorways. She was absolutely over the moon, she was brilliant. She was dodging about in shops and beaming from ear to ear. It was a joy to see her.

Another group of people affected by the Bexley arrangements consisted of the clients' relatives. Some relatives continued to take a direct part in care management, while others played a background role. Either way, they found their responsibilities stressful, particularly if they were elderly or unwell themselves. Many said that, without the help of the scheme, they did not know how they would have coped:

I would have had a complete nervous breakdown ... I just ... thank God that I've got a job that pays me enough money that I can buy in care. (Daughter of woman suffering from dementia.)

Relatives often spoke in glowing terms of the carers who took on so much responsibility for the elderly people with disabilities. One said 'I trust her implicitly', another, 'I can't speak too highly of her'. Several relatives spoke of the reliability of the care that was provided;

for example, some carers arranged cover over Christmas and other public holidays.

There could, on the other hand, be tensions in the relationships between kin and paid carers. One daughter described her difficulties in transferring responsibility to a stranger:

I can't let go of Mum now, because if there is anything wrong I want to deal with it. I can't get used to sending notes to Jill saying so and so ... I keep being told that Jill is responsible for mother, not me.

In other cases, the non-kin carer felt that she was in conflict with her client's next of kin:

The daughter would love desperately for her to be in a home, so it's a peace-keeping job the whole time with her ... The least little thing upsets her.

The third group of people whose interests have to be considered are the workers – especially those who had taken on the responsibility of being a key carer. More detailed studies of the motivations and rewards of paid carers have been carried out by Diana Leat.¹ Most of the non-kin carers who were interviewed for our own research were happy with their work. For some of them, it provided an good opportunity for part-time employment close to home, which could be combined with their own domestic responsibilities. Several felt 'involved' in their work in a way which was not possible in many low-skill occupations.

There are lots of lonely old people and there's lots of people that would like to help. But they can't get together ... There are people that this little job is ideal for. They don't want to earn a fortune. They don't want to pay tax on anything, but they could do with a few bob extra. (Paid neighbour caring for elderly lady.)

It's giving people a job and a home ... It's a lovely idea. (Daughter of woman with a homeshare arrangement.)

The scheme aimed to achieve a one-to-one relationship between the disabled person and their carer as a 'surrogate daughter'. The scheme supported the key carer with advice, a newsletter, information about carers' groups they could join, courses on medical problems such as dementia, and sometimes counselling. Carers were encouraged to gain the confidence to take decisions about the different

kinds of needs of the person they are caring for. 'The whole ethos of the scheme', according to its manager, is to ensure that carers become 'the boss of their own situation'.

But some carers said that the level of responsibility for the elderly person they cared for weighed heavily on them. One felt that this was affecting her own family:

If I was a nurse with geriatric patients in a hospital, I would walk away from it to my own family. But I don't ... I do get tired sometimes because I get calls out during the night as well. That affects my husband because he comes with me at night. He won't let me go up there alone ... Ray is like a Dad to us all now. He spends Christmas with us ... It's not a situation I would get into again, but as I've got into it, I can't walk away from it. You accept it, don't you, and make the best of it.

One woman reflected the potential problems for carer's families when she pointed out that it was only acceptable to her now that she was a widow – 'he wouldn't like me being called on any minute of the day'.

Most carers felt under considerable moral pressure to do what was asked for or needed by the person they cared for. One daughter said that her mother's carer 'does an awful lot above and beyond what she's paid for', and several other relatives and carers echoed these words. One woman had previously worked as a home help for the person she cared for, and it was discovered when she came onto the community care scheme that she had been cooking meals for the disabled person, but concealing this from the home help organiser because it was against the rules.

Many of the informal carers carried out both domestic and 'nursing' tasks (such as bathing the elderly person and changing light dressings and incontinence pads), yet they had received no 'nursing' training. One carer, for example, had not spotted the symptoms when the person she was caring for developed a bladder infection which required hospital treatment: she felt that there ought to have been weekly check-ups from a qualified person, such as a nurse, in addition to the care she provided.

If carers had taken on responsibility for personal finances, there were potential risks of impropriety on either side. One carer, concerned to protect herself against the possibility that she might in the future be accused of theft or misappropriation of funds, took the

trouble to formalise her financial responsibility through a solicitor. Another carer had been left the disabled person's house in his will, and the community care manager worried that the carer might be open to exploitation by her client.

Some of the elderly people depended on quite complicated care arrangements, and this could cause problems of coordination. One carer had in effect three bosses: the home help organiser, the community care manager and the elderly person she cared for. The different members of the care team needed to work together, or there could be problems.

Carers could also suffer as a result of the informality of their employment contract. Their hourly earnings at the time when the research was carried out were quite low – around £3.50 per hour – although against this has to be set the probability that many of them did not have to pay any tax. More important, perhaps, the carers were not afforded the usual protections of employment legislation such as protection from unfair dismissal, rights to holidays and sick leave, and so on. Carers would have had no redress, for example, if they had injured their back while lifting the person they were caring for, since they were not covered by health and safety legislation. Some were insured against this sort of risk, but others were not.

Paying the costs

Although several of the 'ordinary' attendance allowance claimants were paying for care in some way or another, they were buying relatively small quantities, or obtaining it at preferential or non-market rates. None of them was paying more than the amount of their attendance allowance. Among the members of the Bexley community care scheme, on the other hand, we have seen that much larger amounts of outside care were being provided; and most of it was paid for at a rate of between £3 and £4 per hour – about the average for part-time female workers. The cost of this care was therefore much higher.

Table 5 itemises the cash cost of the services paid for by each of the nine respondents. The minimum cost was £50 per week – more than twice the amount of the attendance allowance claimed by the people concerned. The average was £90. Three claimants were spending £130 or £135 per week – not far short of £20 per day. These figures refer only to the cash costs met directly: services given for free by relatives or friends are not counted; nor those provided without

**Table 5
landscape**

charge by the social services or the NHS; services provided at subsidised rates are counted at the rate charged, not at full cost. Two of the disabled people contributed an implicit payment to their carers in the form of rent-free accommodation, but again this is not counted.

The same table shows the 'available' income of each person. It is assumed that the basic social security benefits (state pension, supplementary benefit/income support and housing benefit) are intended to meet people's basic living costs, but that any other sources of income might be considered to be 'available' to be spent on other things, such as care. (The mobility allowance is not counted since it is supposed to be earmarked for transport costs.) It was not always possible to obtain exact amounts, and one or two of the figures have been inferred on the basis of indirect evidence. All the figures (including the attendance allowance) have been rounded to the nearest £5 to indicate that the calculations are not precise.

In spite of some inaccuracies, the table shows clearly that another source of income was always required in order to meet the costs of care in the community.

- In two cases, the claimants themselves had sufficient resources to meet the costs of care. Mr Meredith had a pension from his former employer, and a sizeable nest-egg of savings, from which he was able to pay £135 for care and still have a little left over for everyday expenditure. Mr Sergeant had a smaller pension, but his wife's earnings from part-time work were also available. In both cases the attendance allowance plus their own resources were sufficient to cover the costs, although buying in care transformed what could have been a comfortable standard of living to near-poverty.
- In one case, most of the additional income was provided by the disabled person's family. Mrs Aintree's son worked in a bank and felt he could afford to support his mother in this way, though he could not have managed the full costs of residential care.
- In the remaining six cases, the costs of care in excess of the attendance allowance were met, or largely met, by the Department of Social Security through the domestic assistance addition to supplementary benefit. Two of the budgets also included a subsidy from daughters; two of them included small but regular contributions from charities.

The interviews with Bexley claimants were undertaken at just about the time when supplementary benefit was being replaced by income support. Under the former scheme, claimants were entitled to additional benefit to pay for domestic assistance, if this was provided privately, not by the local authority. Very few of these additions were paid, but they were clearly vital to the Bexley scheme; among these nine claimants, the domestic assistance addition contributed as much to the costs of care as the attendance allowance.

The domestic assistance addition was abolished in April 1988, and replaced by income support disability premiums which would not have provided anything like so much. The people who were already claiming the addition would not have lost it all immediately, because their benefit was maintained in cash terms by transitional protection. The more direct replacement for the domestic assistance addition has been the Independent Living Fund. We understand that several members of the Bexley scheme have successfully applied to the Fund for support.

In the sample of disabled people who were not members of the Bexley scheme, it was suggested that the attendance allowance was not spent on care unless there was some other source of income which released it. Among the Bexley sample the conclusion is reinforced: the attendance allowance on its own was nowhere near enough to support a viable package of care. On the other hand it always made an important contribution. The scheme relied on the attendance allowance plus... In three cases the plus came from the client and/or the family; in six, from the domestic assistance addition.

It has already been said that the scheme's organisers are important: first, to assess the needs of each disabled person; and second to help put together a team of workers. A third role, almost as important as the other two, is to assemble the financial resources.

In several cases, the attendance allowance had been applied for and obtained by the scheme organisers on behalf of their clients, expressly for the purpose of paying for care. The scheme manager admitted that it would be difficult to persuade people who had been receiving attendance allowance for some time to consider using that money to start paying for care. However those who had not previously received the allowance, did find it acceptable to spend the money in this way.

The Attendance Allowance and the Costs of Caring

She is one of the people who have had a hard life, like they all did then, and they like their bit of money ... She would never pay for help herself (before she received the attendance allowance) even if she could afford it. (Paid neighbour caring for woman suffering from dementia.)

This money is hers ... She knows she is paying her way. She doesn't want hand-outs from the family ... She's worked all her life and she's earned it. (Daughter of woman suffering from dementia.)

In addition to the attendance allowance, the scheme's manager had shown considerable ingenuity in negotiating a domestic assistance addition for so many people, and has continued to take the same line with the Independent Living Fund. As she said:

There's always enough money if you're prepared to really study to get it. But you've got to go all out to get it.

References

1. D. Leat, *Paying for Care*, PSI, 1987; *For Love and Money*, JRMT, forthcoming, 1990.