

## **5 Conclusions about social security and paid care**

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

We have been looking for a link between the attendance allowance and the costs of caring through a comparison of the experiences of two groups of people – ‘ordinary’ attendance allowance claimants, and the members of a special scheme in which the allowance is used directly to pay for care. We will review the findings about that scheme, before going on to draw conclusions about the impact of the allowance on the broader group of claimants.

### ***Family circumstances***

In the sample of attendance allowance claimants who were not members of the Bexley scheme, almost everyone was looked after by a close relative. It seemed likely that the majority of people with severe disabilities who did not have a kin carer had been obliged to take a place in a residential home. In the Bexley sample, members of the family often participated in the design of the care arrangements, and some of them took an active part in providing day to day care. But the majority of these relatives had assigned the lead role to paid carers.

A minority of the Bexley clients appeared to have no support from any relatives, and they were dependent on whatever arrangements could be made for them by the social services department or other agencies.

It is highly likely that members of this latter group would have been taken into a home if a community care arrangement had not been set up. For those with family support, it is not clear how many would

have gone into residential care, and how many would have been taken on full-time by a daughter or son.

### ***Care teams***

Each client of the Bexley scheme had a team of carers arranged in consultation between representatives of the family, social services, health services and voluntary organisations, as appropriate. A 'key carer' was always found. Two relatives remained the key carer, but benefited from support services. Other key carers included:

- a family who lived in the client's home, rent-free, in return for providing care;
- a home help who was asked to take on responsibility for care in addition to the housework she had already been doing for many years;
- a neighbour who was recruited through an advertisement;
- an employee of a commercial agency.

The main carer's own commitment ranged from a few hours to a full working week. But none had the 168-hour responsibility experienced by some kin carers outside the scheme. Each was supported by a regular rota of other services including domiciliary nurses, home-helps, day centres, respite care or sitters. The total added up to between 14 and 58 hours per week. Few of the carers in the sample of 29 'ordinary' attendance allowance claimants obtained anything like as much help from outside sources.

### ***Resources***

The care arranged for the clients of the Bexley scheme was paid for from a variety of sources, and it was often difficult to pin down exactly how much had been contributed by each.

Many of the disabled people benefited from caring services provided free, or at reduced cost, by the health authority or the local authority social services department. Some of them received fairly regular help from daughters, sons or other kin; a few of them were assisted on a voluntary basis by friends and neighbours. Some of the paid carers did more than they were contracted to do. In all these cases it was the provider of the care who was paying part or all of its cost, although only in the case of formal services would it be possible to assign a realistic money value to the contribution.

In spite of these hidden subsidies, the cash costs of the care arrangements ranged from £50 to £135 per week; between twice and four times the amount provided by the attendance allowance.

In two-thirds of the cases, the allowance had been topped up by a domestic assistance addition to supplementary benefit – an allowance to cover the cost of privately provided home helps which never became widely used. The smallest of these additions was as much as that claimant's attendance allowance; the largest, three times the allowance.

The domestic assistance addition was abolished in April 1988. Its nearest equivalent is the new Independent Living Fund, a charitable organisation financed by the government but administered by the Disablement Income Group. It is understood that several Bexley clients have successfully applied to the ILF over the past two years; given the importance of the domestic assistance addition, the scheme might not have been able to continue without this substitute.

One client relied on her son to meet the majority of her expenses. Two others had regular financial help from their family which met some of the costs of care, but these contributions were less important than their domestic assistance addition.

Only two clients had resources which, combined with their attendance allowance, could meet the costs of care without further help from outside the household. But their expenditure on care, over and above the attendance allowance, reduced the income which would otherwise have been available to these relatively prosperous pensioners; in one case, down to the basic level of living experienced by supplementary benefit/income support claimants. In the end, they were little or no better off than the poorer claimants who had to rely on the domestic assistance addition.

Another resource provided by two of the disabled people was their house, where their carers lived rent free.

So the attendance allowance and basic benefits were not, on their own, enough to allow people to pay for a package of care. It required the allowance *plus* some other major source. It nevertheless represented an important contribution towards the costs of care.

Although the community care scheme's aim is to provide better care for clients and/or relief from the burden of care for relatives, there are economic gains to be taken into account, as well as costs. The gainers are the people or organisations who would have borne the

direct or indirect costs of care in the absence of the scheme: relatives, statutory service agencies and the Department of Social Security.

### ***Advantages***

All of those associated with the Bexley community care scheme seemed to be pleased with the result.

The prime advantages were seen to be to the clients themselves. Residential care was perceived as an impersonal environment within which disabled people were looked after too much or too little: either way, it led to rapid decline. The home care arrangements were based on individual assessment, providing sufficient care and protection, but at the same time stimulating the client to make as much use of his or her faculties as possible.

Another potential advantage lay in the variety of types of service put together to meet particular needs, instead of selecting from the range of standard services provided by existing agencies.

Some respondents also thought that paying for care provided disabled people with a greater degree of independence than if they relied on the goodwill of their relations, and greater control than if they relied mainly on statutory services.

The scheme was also valued by relatives on their own behalf. They were relieved of the difficult choice between looking after their elderly kin themselves, and 'putting them in a home'.

Some paid carers had not previously found a job which fitted in with their own domestic commitments, and were glad of the employment opportunity provided by the scheme.

### ***Drawbacks***

The research was not designed to evaluate the effectiveness of the care provided through the scheme. In principle, it might be argued that the cover might have been less than the client needed. But no-one we spoke to mentioned any problems of that sort.

Some of the care arrangements were largely financed from the personal incomes of the clients or their families. The cost represents a disadvantage to them if the alternative might have been care provided free. All of the members of the scheme had committed their attendance allowance to pay for care, so it was not available for the basic goods and services which most other claimants chose to spend it on.

Some of the potential disadvantages were concerned with the people who were employed as 'carers'. They were taking on a heavy burden not only of work but also of responsibility, in return for modest wages and the poor conditions of service typical of ad hoc employees. While some of them achieved a welcome degree of autonomy, others were not clear who they answered to.

### ***Assessment***

There is little doubt that the clients of the Bexley scheme, and their relatives, preferred it to residential care. It was also cheaper. For those whose adult children might have provided care, the benefits of the scheme are at least as important to the family, as to the client him or herself.

Compared with the services available to 'ordinary' people with serious disabilities, clients of the scheme have four advantages:

- the scheme's core staff: a clinical psychologist to assess their particular needs, and a care manager to coordinate services and claim benefits;
- benefit income specifically aimed at care expenditure;
- care services secured in the open market; and
- (in some cases) a significant input of support services provided by formal agencies.

It is unlikely that care arrangements could be built without the combination of these, and it is therefore difficult to decide which are the crucial ingredients.

The Bexley scheme has emerged both to cope with and to exploit the particular combination of public programmes which happens to exist at a particular time. It is important to analyse its components:

**The objective:** is to enable people suffering from senile dementia to be cared for in their own homes, without placing excessive strain on their daughters or other kin.

**The strategy:** is to hire people in the open market to play roles which would otherwise be taken by relatives and/or the employees of social services departments.

**The tactics:** are to obtain resources wherever they can be found – from statutory services, social security benefits, the client or the family.

There is wide agreement about the desirability of the community care objective. The Bexley strategy is one of the options for delivering care which will have to be considered in the development of post-Griffiths<sup>1</sup> care management; it is possible that some local authorities, or perhaps all local authorities, might follow the Bexley example of hiring individual carers. But the scheme could not be replicated on a larger scale without a clearer set of rules about resourcing. The ad hoc tactics only highlight the current division of responsibilities between different national and local government agencies, between the public and the private sectors, and between formal organisations and the family.

### **‘Ordinary’ claimants**

Most of this report has concentrated on the attendance allowance claimants who were not members of the Bexley scheme. Although there were only 29 of them, selected from two small areas of London, they are our only guide at this stage to the circumstances and behaviour of the majority of attendance allowance claimants up and down the country. Further research is in progress, at PSI and elsewhere, which will provide a more complete assessment.

### ***Spending the attendance allowance***

The great majority of them were not spending their allowance on care – certainly not in any direct sense. Unlike the mobility allowance, which was often allocated specifically to meet the costs of transport, the attendance allowance was usually added to general income; indeed, it was often paid by the DSS in a combined order book including their pension, invalidity benefit or income support. So people could not directly distinguish between it and their other sources of income when they described their expenditure.

One theory is that the attendance allowance was originally designed to (help) meet the direct costs of ‘attendance’; another is that it was designed to contribute to the higher cost of living faced by people with disabilities, of which payment for care was only a part. Whatever the underlying intention, there is no doubt that claimants are entitled to spend it as they like, with neither a legal nor a moral obligation to allocate it to certain approved purposes.

Most people described some aspect of their household budget which was affected by their disability – extra heating, laundry, diet,

travel costs and so on. We did not attempt to measure the total amounts involved. Two other studies have produced inconsistent estimates. Severely disabled people taking part in OPCS's large scale survey reported that they were spending around £11 per week on extra expenses – about half the lower rate of attendance allowance.<sup>2</sup> A small sample interviewed by the Disablement Income Group averaged £70 per week – twice the higher rate of the attendance allowance.<sup>3</sup> Many claimants and carers said that they spent the attendance allowance on these extra basic costs, though few had a very clear conception of exactly what difference the benefit had made, or how the additional money was allocated.

Other people, though, were confident that they would have met the essential extra costs of disability anyway – that was what they meant by the word 'essential'. But the costs placed a heavy strain on basic budgets, so the attendance allowance provided the element of discretionary income to spend on the modest luxuries which made life tolerable.

### *Paying for care*

Either way, the attendance allowance was seen by most claimants as a component of their general income, aimed at maintaining or improving their standard of living, rather than as a direct contribution to the costs of caring. There was another group, however, who paid for some care. Among the 29 in our sample:

#### *Primary care, formal services*

- two did not have a kin carer; they paid formal services for the care which enabled them to remain in the community;

#### *Primary care, informal relationships*

- two paid their attendance allowance to the relative or a close friend who looked after them;

#### *Support, formal services*

- one paid for a weekly overnight stay in a hostel;

#### *Support, informal relationships*

- two paid a relative or friend who helped with the housework;

#### *Therapy, formal services*

- two paid for therapy to alleviate the physical problems associated with their disability.

The cash cost of these arrangements ranged between £10 and £30 per week (compared with between £50 and £135 in the Bexley

scheme). Only two – the therapy sessions – were paid for at the full rate in a transaction which reflected the influences of supply and demand observed in most markets. All the other seven ‘charged’ well below the full cost of their services; it is not unlikely that they would have continued their side of the arrangement even if the payment had stopped.

- The formal services were organisations committed to service provision, which derived most of their funds from other sources. For them, charging was probably seen as a way of maximising the number of people who could be helped out of a restricted budget.
- The other carers and helpers were relatives or friends who were not doing it for the money. Payment had generally been offered, rather than asked for, and was seen by both sides as a token in recognition of the kindness provided, rather than as an economic exchange.

Some carers and helpers were paid the exact amount of the claimant’s attendance allowance, and the name of the benefit helped to legitimise the payments which might otherwise have been a source of embarrassment. In other cases, it was not the attendance allowance as such which was being used to pay for care, though it may have been the allowance which enabled the payment to be made. On the other hand most of the people with disabilities who paid for services had other sources of income, as well as basic benefits, and it can be argued that the attendance allowance on its own would not have left people with enough money to divert from basic needs for this purpose.

### ***Financial support for unpaid carers***

Several carers had suffered a substantial loss of income when they took on their responsibilities, and this represents a ‘cost of caring’ just as real as the cash cost involved in paying a carer. One possibility was that the resources of the disabled person, including the attendance allowance, were contributing some financial support to the carer – at least to the extent of reducing the carer’s losses. This might be seen as an indirect form of ‘payment’. Another way of looking at it would be to ask if the existence of the benefit helped to establish the financial viability of an arrangement in which a relative gave up work, or incurred other costs, in order to provide care.

The issue is complicated by the fact that there are other social security benefits which carers can claim in their own right – the invalid care allowance and income support. The attendance allowance is important in triggering carers' entitlement to the invalid care allowance; but the attendance allowance itself is intended to meet the needs of the dependant, not the carer. If, on the other hand, a share of the attendance allowance was sufficient to persuade someone to care who otherwise would not have done, that might be seen as a legitimate use of the dependant's income.

Certainly several claimants and carers thought of the attendance allowance in that light – as a form of payment to the carer to take on a job which would have cost the state much more to meet directly.

While the question is easy to discuss in principle, it is difficult to analyse in practice. Most carers lived in the same house as the disabled person, and the housekeeping was run jointly. With all income going into a common budget, it was not possible to work out which members of the household had the use of which money. In some households the carer had a higher income, and was clearly contributing to the support of the disabled person. This was not very common, though, and in most households it would not have made much difference whether income had been pooled or kept separately.

People usually discussed the process by which they became carers without reference to financial considerations. If money was mentioned at all, it was usually to point out the costs. Nevertheless some people mentioned that it was their disabled relative's attendance allowance which had enabled them to reduce their hours of work, or to take early retirement, and so had contributed to the costs of caring.

### **The prospects for paid care**

Although several members of the sample of 'ordinary' claimants were using their attendance allowance to meet part of the cost of their care, not one of them had adopted the Bexley solution of paying someone to look after them as a form of employment in direct competition with other jobs. No doubt there are cases somewhere in Britain where this has happened without the support of a scheme such as the one in Bexley, but it is certainly not a common feature of care in the community. The OPCS survey of people with disabilities<sup>2</sup> reported that nearly one fifth of the most severely disabled adults were paying extra for 'home services', and that the average amount spent on these

was £11. But most of these payments were probably contributions towards the costs of home helps provided at subsidised rates by social services departments. Only one in twenty reported 'private domestic help', and one in forty 'private nursing help'.<sup>4</sup>

This form of care has not developed naturally, but it is worth asking whether it would be a good thing to encourage it to grow. There is no doubt of its popularity among the small group of people in Bexley who have tried it, and that is a good enough reason for taking the idea further.

### ***Substitutes or help for kin carers***

Some disabled people have no relative who could care for them, so a paid carer in the community would be the only alternative to an institution. At the other end of the spectrum, there are some degrees of kinship in which the assumption of caring responsibilities is so automatic that the question of a substitute scarcely arises.<sup>5</sup> In between there are many people with disabilities who have two or three relatives – probably daughters or sons – who might care for them themselves, but who would be happy to let someone else do it if appropriate arrangements could be made. Several of the Bexley clients were members of this intermediate group in which a paid carer had taken over from a daughter or son. Depending on what would have happened in the absence of the scheme, it could be argued that the daughters and sons were the principal beneficiaries. Some of them were contributing to the cost.

The cost of full substitute care, however, was commonly £100 per week or more, even though free and subsidised services were often available as well. This is undoubtedly cheaper than residential care, but it is unlikely that public resources would normally be found to pay for care if a relative might provide it for free. There is the prospect of a game of chicken between the state and the family in which each threatens to abandon the disabled person in an attempt to blackmail the other to accept the responsibility; there is little doubt that the state would usually win this game with ease.

It is not necessary to think in terms of a stark choice between a kin carer and a paid carer. One of the striking things about the Bexley care arrangements was that no paid carer was expected to deliver the 168 hours per week of unremitting supervision which some of the carers in the main sample had to provide. It is unlikely that anyone would

have been found to take on so great a burden, even for ready money. All the key carers in Bexley had support from paid helpers, or from formal services, or both. If kin carers had had anything like as much help, their problems would have been reduced at a stroke. Few enjoyed substantial regular assistance from official services, perhaps because the latter concentrated their resources on people without a family to look after them. Most of them had no paid helpers either. But the idea of hired help for kin carers might be more successful than the suggestion that paid carers should take over from relatives altogether.

### *Sources of money*

The higher rate of attendance allowance would scarcely stretch to as much as two hours per day, even at the low wage rates available to part-time female workers. This would be little enough support for a 24 hour carer, though it would no doubt be welcome. But carers running household budgets consisting just of basic benefits and the attendance allowance did not feel able to divert money from basic necessities to pay for services. One reason for this was the extra expenditure on such things as heating, laundry and so on which were required to maintain the health and comfort of the disabled person. Whatever the reason, people who depended on social security benefits for all or most of their income felt too poor to spend money on services which, when it came to it, they could undertake themselves.

Payment for care out of their own resources became a possibility only if they had other sources of income to take them above the basic benefit line. Such sources might be earnings, an occupational or private pension, or, perhaps, support from a member of the family. People with these extra resources might be in a position to pay for care, though they could impoverish themselves in the process.

One or two relatives of Bexley clients were conscious that their earnings enabled them to pay for care which they might otherwise have had to provide directly. Only one of the carers of 'ordinary' claimants was using his earnings to pay for support. But in general the idea of paying a carer or helper in order to enable the responsible relative to remain in employment was not well developed.

The care arranged under the Bexley community care scheme depended heavily on the old domestic assistance addition, and now on the Independent Living Fund. Since these sources were directly linked

to the provision of care and/or support, there was no question of diverting money out of the limited budgets of the disabled people themselves. The costs were genuinely borne by the Department of Social Security. On the other hand a benefit provided on the condition that it should be spent in a particular way limits the independence which might be considered one of the advantages of the attendance allowance. In effect the DSS is saying 'you must spend the money on care, even though you might prefer to spend it on electricity.'<sup>6</sup>

The DSS supports care costs in another way, by providing the invalid care allowance and/or income support to people who are unable to combine work with caring. Not everyone is entitled, and the income on offer is scarcely attractive, but the rules of entitlement can nevertheless provide more support for unpaid carers than for services.

The new disability allowance which the government announced at the beginning of 1990 will incorporate the current attendance allowance with very little modification.<sup>7</sup> A new, lower, level of benefit will be available to people with disabilities not quite severe enough to qualify for the attendance allowance. The government was not specific about what either payment was intended to cover, referring in general terms to 'needs'. If the attendance allowance was not sufficient to allow people to pay for care, it must be assumed that the new allowance of £10 will have even less effect. One of the disappointments of the twin white papers on community care<sup>8</sup> and disability benefits is the absence of any direct consideration of the role of benefits in promoting care, in either policy.

### ***Care management***

The government is determined that care costs should not be seen as a social security responsibility. That is why the charges for residential homes currently met by income support are being transferred to social services departments under the 'Griffiths' arrangements.<sup>1</sup> Similarly, the DSS hived off the Independent Living Fund to a charity, rather than ask its local office staff to make judgements about disabled people's needs for domestic assistance. The question arises whether support for paid carers might not be sought from local authority social services departments. Hitherto they have usually provided home helps, care attendants and other services directly, using their own employees. After 1991 their primary role will be to provide the resources and the case managers to ensure that care is provided,

without necessarily supplying the services themselves. They might decide to spend some of the budget allocated to each client on paid care – that is someone recruited directly to work for the particular client, rather than an employee of a care-providing organisation.

Those disabled people and relatives who had experience of paid care, or had thought about it, liked the flexibility of the arrangement. Directly-hired carers and helpers were thought to be more responsive to the consumer's needs and preferences than the staff of a larger organisation would be. This advantage might be reduced if the paid carer was hired by the social services department, using its own money; at least partial control would revert to the bureaucracy; the carer would be uncertain whether her employer was the disabled person or the social services department, and might feel answerable to neither.<sup>9</sup> One option might be for the social worker to allocate a sum of money to be spent on care, but to leave the client or the family to hire and supervise the carer. That is how the Independent Living Fund operates.

On the other hand, one of the main lessons to be learned from a comparison between the Bexley clients and 'ordinary' attendance allowance claimants is that there is no longer a natural market in which personal service is exchanged for wages. Several members of the main sample discussed the question of paid care as a mere hypothesis: if they wanted help of this sort, they would have had no idea how to obtain it. The market did not operate at all until the Bexley scheme was set up to act as a broker. The scheme could also act as a regulator: protecting vulnerable clients against the obvious risks of poor service and/or exploitation; ensuring that the carers themselves were properly paid and well-treated. It may be concluded that paid care in the community is not viable without care management. That is precisely the role that the new social services departments will be in a position to adopt.

Any discussion of future development of paid care will, however, have to be explicit about the source of the money. The attendance allowance currently makes a contribution, but is insufficient on its own. The social services department will have a budget, but it will be under immediate pressure to target resources on people who have no other means of meeting their needs. This will tend to be disabled people with no independent income and no kin. There is therefore the prospect that care and support will be subject to a triple or quadruple

test: of the disabled person's needs; of his or her income; of the availability of kin as carers; and perhaps of the incomes of kin. Relatives will still be under pressure to accept the duty of care unaided.

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