

Carers and Helpers

1 Carers and helpers

Primary carers

All of the disabled people we spoke to had someone on whom they could rely for the care they needed. It is sometimes useful to distinguish between the person who had accepted the responsibility for seeing that the care was provided, and someone who actually did the caring. In the majority of cases, the same person did both: that is, the person to whom the responsibility fell cared for the disabled person him or herself. On the other hand, as will be seen, some did part of the work themselves and arranged for other people to contribute. Another option could be to make the arrangements for, and supervise, a scheme of care provided by third parties. Some people with disabilities whose handicap was purely physical were able to take the role of care organiser themselves.

There has been a substantial body of research describing the extent of care provided by relatives at different degrees of kinship.¹ For our own purposes, it will be sufficient to describe the cases whose arrangements fell into standard categories, as background to the analysis of the more unusual packages which are of particular interest.

A number of authors² have suggested that the choice of carer follows a 'hierarchy'. Some disabled people have a single relation who will almost certainly care for them if necessary. Only if there is no-one available in that front rank might the job fall to a member of the second rank; here there might be several different relatives, and it is not clear in advance which of them, if any, will provide care. A third rank consist of people who would not normally be expected to offer care, but who might in certain circumstances. It is clear that at one end of the hierarchy people feel an obligation to care; at the other end, the

role is voluntary. Another distinction between the opposite ends of the hierarchy is that the front rank often provides full-time care, whereas the third rank is more likely to contribute part-time or occasional help. In more detail, the hierarchy appears to be as follows:

Front rank:

Spouses
Parents

Second rank:

Adult children
Siblings

Third rank:

Other relatives
Friends and neighbours

The people who cared for members of the main sample of ‘ordinary’ attendance allowance claimants followed a similar pattern (Table 2).

Table 2 Kin-carers

Living in the same household

12 husbands or wives
5 mothers
5 daughters
1 brother

Living nearby

3 daughters/daughters-in-law
1 sister

No kin carer

2 formal arrangements

15 of the 29 disabled adults were married. All but three of the *husbands and wives* had adopted the role of chief carer, even though some elderly carers were hardly in the best of health themselves. The three exceptions were elderly partners who were incapable of providing care – indeed, they needed looking after almost as much as the members of our sample did. If you asked spouse-carers how they had adopted their role, they tended to describe how their husband or wife had fallen ill; caring was so automatic that it required no explanation. Husbands and wives nevertheless felt they owed a duty to their partners, which, for the most part, they accepted willingly:

The Attendance Allowance and the Costs of Caring

She is my responsibility ... She was a woman who loved her kids ... she was cooking good food. It was wonderful ... I will look after her right to the grave.

Even so, the burden could be considerable, especially if the carer had children or other sick or disabled relatives to look after as well.

One woman had given up her part-time job to look after two severely disabled relatives. Her husband had suffered kidney failure and required regular dialysis. Her mother was a stroke victim paralysed, incontinent, partially blind and deaf, and confused.

Five unmarried young adults had been mentally handicapped since birth. They had been looked after by their *mothers* throughout their childhood, and this relationship continued after they had grown up.

So more than half of the people with disabilities were able to turn to a 'front rank' relative – a partner or parent who accepted the responsibility almost automatically.

For the remaining twelve disabled people there was no member of the front rank available. These include the three couples in which both husband and wife needed to be looked after. The interview concentrated on what did happen, without looking in detail into what alternatives might have been possible, so we do not have a full description of the family trees of each of these people.

Five people were cared for by a *daughter* who lived with them, and one by a *brother* living in the same house. Where the carer had been living with the disabled person before he or she needed much care, the change in relationships seemed to have happened without any conscious decision on either side.

An unmarried daughter had, for example, lived with her mother all her life, and had been laying plans for them both to retire to the seaside when she herself reached 60. For her, caring was as 'automatic' as if she had been a wife or mother.

When her mother was first taken into hospital, the daughter had been asked whether she would like assistance with her mother's care, such as a home help for example. But she had replied simply "I prefer to do these things myself".

The outcome was less predictable when the disabled person was not living with a relative at the time the need arose. In these cases there were two or three people in the family who might have provided

care. Sometimes either the carer or the disabled person moved home so that they could live together.

Four other disabled people had carers from the second rank (a daughter, two daughters-in-law and a sister) who did not live with them, but who visited frequently. It was clear that people with disabilities could not live without a resident carer unless they were able to look after themselves at night and do at least some household tasks. Several of the non-resident carers were also able to share the work or the worry with other members of the family who lived locally. The non-resident solution would only work, therefore, in certain circumstances.

The final two people with disabilities had no kin carer and had to rely on more formal arrangements.

Shared or delegated care arrangements

Most of the disabled people in the main sample had one person who had accepted the responsibility for caring, and who did most of it personally. In these cases, the label 'carer' could be applied without any ambiguity. There were seven cases where the basic arrangements did not fit into so simple a pattern. Four of these cases involved payment for care.

Part-time carers

Two people with disabilities were able to look after themselves in their own homes, but relied on a relative to come in at fixed times to undertake tasks which they could not manage on their own. By implication, the helpers had only a slight responsibility outside their hours 'on duty', though each was no doubt available 'on call'.

Mr Ericson was confined to a wheelchair, but was able to look after himself a lot of the time. He lived alone, and his sister came to help him three set times each week: an hour on Sunday, three hours each on Tuesday and Thursday. She brought shopping which she had already purchased, and helped with the housework. Mr Ericson had recently lost his attendance allowance, on the grounds that he no longer required constant care.

Mrs Paxton was elderly and suffered from severe arthritis. She lived alone in a large private house, which she was finding increasingly difficult to manage. She said that she would soon have to give up the house and find a place in a sheltered home.

The Attendance Allowance and the Costs of Caring

Her daughter-in-law lived nearby, and came in five and a half hours a day to provide care and domestic assistance.

Mrs Paxton paid most of her attendance allowance to her daughter-in-law who came in daily to look after her. As she said:

I've got to pay my daughter-in-law ... I can't expect her to do something for nothing.

Shared care

Three disabled people had more than one carer.

Mrs Cox had difficulty in using her arms and legs: she had problems preparing food and drink for herself, and relied on a wheelchair for getting about out of doors. She lived with her husband and a lodger who has been a friend for 20 years. Mr Cox had full-time employment, but worked double shifts three days a week so that he had four days off. He cared for Mrs Cox when he was at home, and made sure that he did the intimate tasks before and after he went to work. But the friend, who was retired, looked after her when Mr Cox was at work. "He's better than an outsider", she said. He was, therefore, the 'carer' in the practical sense for much of the time, although the responsibility ultimately fell on Mr Cox.

Mrs Cox paid her attendance allowance direct to the friend and lodger who looked after her when her husband was out.

Mrs Demetriou had been hospitalised following a stroke, and had then stayed temporarily with her son and daughter-in-law. She was able to return home with her husband, but he was very frail and confused. Between them they could live on their own, but only with plenty of support. We interviewed the daughter-in-law who seemed to have taken on most of the responsibility for the old couple, but she described a joint caring arrangement which she thought was typical of a 'Mediterranean family'. The Demetriou had four sons who lived locally, and they and their wives all visited their parents almost daily. So did Mr Demetriou's sister. They made sure that the couple were all right, brought the shopping (often paid for out of their own pockets), cooked meals and did the laundry. They were in constant touch with each other by telephone if they did not meet at the couple's flat. There was, therefore, a large number of members of the family actively engaged in caring, though it was difficult to tell how evenly the load was shared.

Mrs Ellis had serious difficulties in moving about following operations on her legs. Her husband was also seriously disabled, and required more personal care than she did herself. They both lived with their daughter and her young family. But because the daughter was fully occupied with the father and her own baby, another daughter, living nearby, came in daily to look after their mother, and also to do the daily housework. The live-out daughter was regarded as the mother's carer, but clearly the two daughters formed a team.

Care packages

The two disabled people without any relative to take on the responsibility for their care had both made arrangements with more formal sources.

Mrs Wright and her husband were both wheelchair-bound. They had moved into a specially-adapted flat belonging to a housing association, which also ran a residential care home next door. Mrs Wright needed a minimum of 30 hours of care a week, to get her up in the morning, put her to bed and help her to the toilet. The care was provided by the staff of the residential home. She welcomed the chance to live in her own specially-adapted flat after years of being 'wrapped in cotton wool' in Part 3 accommodation. "Here it is more like home."

Mrs Wright paid her attendance allowance to the voluntary organisation which ran the nearby residential home whose staff provided care.

Ms Darley was the only person who had managed to piece together a complete care package for herself using local authority services. She had severe physical disabilities and spent most of her day in a wheelchair. She had limited use of one arm, with which she was able to feed herself. She lived alone in a specially- adapted flat in a sheltered housing scheme operated by the local authority. A care attendant employed by the social services came to her for three and a half hours each day. A community nurse visited at weekends, when the care assistant did not come. She also had a home help one and a half hours a week.

Ms Darley contributed £10 per week towards the cost of her social services. This was the minimum fee, determined by the fact that she was on income support.

Payment for primary care

None of the one-for-one carers who had taken on the full responsibility for the care of their disabled relatives were directly paid for their services, whether out of the attendance allowance or not. In practice, most of them had direct access to the attendance allowance money because they ran the household budget, but in no case was there any suggestion that it represented payment.

Nor, in the four cases involving payment, was there any suggestion of a strictly economic transaction, still less that the amount paid represented a fair evaluation of the work done.

- In the two cases where the payment was made to a friend or relative (Mrs Paxton's daughter-in-law and Mrs Cox's lodger) there is a strong presumption that the service might have been provided anyway. The transfer of the attendance allowance was a voluntary gesture of reciprocation on the part of the disabled person. It is nevertheless clear that the opportunity to offer payment made both Mrs Paxton and Mrs Cox feel happier about their relationship with their helpers, neither of whom was within the degrees of kinship bound by a caring obligation.
- In the two cases where the payment was made to an agency whose paid staff provided care (Mrs Wright's voluntary organisation, Ms Darley's social services department) both organisations were motivated by a commitment to service rather than by commercial considerations. The amount of the payment was, again, a token determined by their ability to pay, while the agency bore most of the financial costs of the arrangement from its central funds.

Help from organisations

All of the disabled people had received assistance or support at some time or other from the local authority social services department, and the local health authority. The most common forms of service, each mentioned by between a third and two-thirds of the sample, were:

- Advice about services from a *social worker*;
- *Physical aids*, such as wheelchairs, household gadgets and so on;
- Assistance with *transport*, including bus passes, taxi services;
- *Holidays* organised and/or subsidised by the council;
- *Home deliveries* of meals on wheels or incontinence pads.

Each of these services was valuable. Some of them, especially the home deliveries, effectively reduced the amount of work which had to be undertaken within the home. But they did not contribute directly to the claimant's regular need for care.

Mrs Wright and Ms Darley were receiving substantial domiciliary services from the local authority and a voluntary organisation respectively, because they had no informal carer. Only two other members of the sample were receiving any support services in the form of a helper who came into their home.

Mrs Joseph's main carer was her husband. He remained in full-time work and was exceptionally busy trying to fulfil both roles. The social services department provided a home-help two hours per week, and a care assistant came one afternoon per fortnight.

One other respondent was visited by a community nurse three mornings and seven evenings every week.

So only four people had domiciliary care in the sense of regular visits of personnel who helped care for the disabled person, or shared the housework. The OPCS disability survey showed that home helps were easily the most commonly available home service, provided to about a quarter of the most severely disabled people (severity grades 9 and 10) living in the community. Home-help provision varied according to the domestic situation of the person with a disability:

Single and living alone	75%
Married	25%
Single and living with others	10%

If these figures applied to our own small sample, we would have expected six or seven respondents to have been in receipt of domiciliary services; four is therefore on the low side. Either way, it is clear that the great majority of disabled people with kin carers had no support of this kind. The carers were left to do the work on their own. For some of them, of course, the job could be managed by one person without too much difficulty, and no help was needed. But for others, the burden of care was heavy, and some relief might have made all the difference.

Support services can also be provided outside the home, and this allows a measure of relief to carers. Five members of the sample were affected:

- Four of the five young adults with mental handicaps were attending training centres; one of them also stayed one night a week in a hostel, primarily to prepare her for the possibility of living apart from her parents when they could no longer look after her. Her mother paid £10 per week to the hostel.
- One woman went to hospital for two days and nights each week, to give her husband respite from his caring duties.

The remaining 20 people with disabilities did not have any regular caring services from official organisations, although they did have access to the other forms of support outlined at the beginning of this section.

Views about helping services

Some carers felt that caring for their relative was their own responsibility, or that the disabled person preferred kin to strangers.

I was a funny man myself. I didn't want nobody to help ... She's not easy to get on with. I felt I wanted to do it myself. (Husband of woman with mental illness.)

A relatively small amount of help from the formal services could be exactly what was wanted:

She is my responsibility ... I don't phone them and ask them anything ... But a little bit of help here and there, it's just wonderful. Thank the Lord for it. (Husband who cared for wife who is a stroke victim.)

However, others were critical of the level of support provided by the formal services. Several relatives remarked that while they were available and physically able to act as carers it seemed impossible to persuade the formal services to take on more responsibility.

My GP actually said to me when I was at breaking point ... "Go away and leave your mother"... But I couldn't do that ... leave her unattended in the house ... She's a human being ... I couldn't have driven off ... (Daughter of woman suffering from dementia.)

Some felt that the formal services had almost conspired to force them to take on the full burden of responsibility for their disabled relative:

(When my husband came out of hospital) they said I could have all the help and support that was possible. But I didn't have

anything other than a nurse come in every Wednesday to give him a blanket bath. (Wife of man suffering the effects of a stroke.)

They all tell me I look after her so well that I don't really need help. (Daughter of woman who has suffered severe strokes.)

Some people complained that the range of duties home helps were allowed or were willing to do was too narrow for their purposes. One disabled person complained that home helps would not 'cross the barrier' to do 'nursing' tasks, such as emptying commodes or giving a person a bath. Another felt that they were unreliable:

They don't turn up or they change ... I've been about five weeks without anybody ... They are not particularly over-enthusiastic, some of them, to help ... Some of them are just plain lazy. (Woman confined to a wheelchair.)

Mr Andrews said his greatest difficulties were first thing in the morning, and when school closed at 3.30pm – which was when his children needed looking after as well as his wife. Finding it impossible to cope alone, he investigated ways of bringing in another helper to share the care. He discovered that the health authority nurses were fully stretched, and unable to help his wife. He considered private nurses, but had to abandon the idea on the grounds of cost. Then he approached the local social services to see if it would be possible to get a home help from 8 to 10am and from 3.30 to 6pm each day. But he was told that, because he was in employment, his case did not have high priority, and therefore he would only be able to get a home help between 10am and 3.30pm – precisely the time when he did not need one!

Mr Andrews observed that the level of support provided had always seemed to be the minimum necessary to sustain him in his role as carer. For example, it was only when he himself became ill that his wife was offered two nights a week of care in hospital, to give him a break: 'If you don't do this', his GP said, 'you are ... going to crack up completely, and that wouldn't do either of you any benefit'. On another occasion, when he slipped a disc lifting his wife into the bath, he said that the hospital ...

... gave me top priority for hydrotherapy and all the rest of it to get me fit. With a smile, if you like, they said "the quicker we get you fit, the quicker you can look after your wife again".

On the other hand, others had a higher opinion of these services:

The home help is marvellous, and most of them are. (Carer of woman with dementia.)

One of the features of the new arrangements for community care following the Griffiths Report will be ‘care managers’ – people who would assess the client’s needs, and put together a package of services and benefits, and act as a source of advice and back-up. Several people recognised the need for a single point of contact with public services; and wanted to feel that someone was keeping an eye on their needs.

Nobody comes to see if you’re cracking up ... There aren’t enough social workers ... If you feel suicidal, no-one would know. (Daughter of woman suffering from dementia.)

One partially paralysed woman felt that she had been able to take the care manager role herself; but she recognised that not every one could be expected to:

I had lots of people in the beginning – lots ... I (sorted it out) with the central care people ... I’m lucky, I can do that. Some people can’t ... I know what to do.

But others had not been successful in their attempts to obtain help from official organisations. They felt that they should not have to ask – they should be told:

I think that a social worker should come and assess the whole situation and tell you what is available for you. You shouldn’t be asking, because half the time you don’t know. (Daughter-in-law, working part-time, of elderly disabled woman.)

For those who did ask for help, securing support was often a laborious and frustrating experience.

You can apply and apply (to social services) and in the end you are talking about waiting for six months to get something done. So you end up doing it yourself. (Daughter-in-law of stroke victim.)

One carer was so upset by the way she felt she was treated by officialdom that she assumed that our request to talk about her mother’s attendance allowance would be some sort of check that she was not ‘pocketing the money’:

You've got no back-up of any sort. You feel like you are on your own ... and you are clawing for everything that you can get. And you don't even know what you are allowed to get anyway ... You feel like you're being treated like some sort of gold-scrounging criminal ... The incontinence service called and said 'Why are you using so many?' and I was just thinking, well this is terrible ... that you should be accused of stealing incontinence pads!

Help from informal sources

We have already described the arrangement whereby the role of 'key carer' had been shared more or less equally between an elderly couple's four sons, four daughters-in-law and a sister. In that case, clearly, there was plenty of mutual support within the family. Another family, already described, had arranged for one daughter to care for the mother, and another for the father; again, this was an arrangement where mutual support was built in.

Other carers received regular, perhaps daily, assistance with caring from relatives living in their home or in the area. Several elderly couples, the one caring for the other, had help with their daily chores from a daughter who lived nearby. Where a live-in carer had a family of her own, her teenage sons or daughters might provide a 'sitting' service for the disabled member of the household when she went out. It was normal, however, for intimate care to be the responsibility of the main carer alone.

Other carers said that they had some irregular but valuable assistance from the wider family. For example, a relative might take care of the disabled person at weekends from time to time.

The brother of a woman caring for their arthritic mother came each year from Cornwall to take the mother back to his family, to give the main carer a break.

But other carers had much less help from the family. In these cases, the only involvement seemed to be paying social visits and perhaps contributing gifts. Relatives who lived away from the disabled person's home and had homes and families of their own to look after did not appear to be expected to contribute significantly to the task of caring.

Even members of the family living locally could not necessarily be relied on to help more than occasionally.

Mrs Eldridge had arthritis and lived with her husband. Their daughter came in regularly to help with housework. But their

The Attendance Allowance and the Costs of Caring

son, who also lived locally, had always been fairly distant from his parents. He visited only occasionally, and provided little help.

Help was not always available even from people living in the same house. While some carers described the contributions provided by their husbands or teenage children, others commented wryly that their own sons and daughters did little to help beyond preparing drinks, or occasionally sitting in in the evenings. One carer remarked about her children that, 'you can't put upon them too often.'

Friends were less likely than relatives to provide significant assistance to the key carer. However, there were some notable exceptions to this generalisation:

The friend who lodged with Mr and Mrs Cox regularly looked after her when her husband was at work. In fact the family described him as her 'carer', though the husband seemed to us to have retained the principal role.

An elderly couple had a friend who came in two hours a week to help the caring husband with the housework – 'she keeps us all nice and clean and tidy'.

A frail elderly woman relied on a younger friend for the kind of domestic assistance that some other disabled people received from home helps.

Another friend regularly 'sat in' one afternoon a week, so that the disabled woman's husband could have a break.

Mr and Mrs Wright, whose basic care needs were provided by the workers from a nearby old person's home, had friends from their local church who provided the additional essential assistance that allowed them to remain in the community. These friends accompanied Mrs Wright on her regular hospital visits and on shopping trips, when she needed assistance with her wheelchair.

A few other disabled people said that they received assistance with their care needs from friends, though on an occasional rather than a regular basis. In some instances, the disabled person said that they liked to give a small payment or gift to their friends when they helped in this way: they felt awkward about 'imposing' on their friends too much, or exploiting their goodwill.

Payment for help

We have seen that a few people with disabilities paid their principal carer, usually a sum which bore no direct relation to the extent of the work the carers did. A few attendance allowance claimants paid for smaller amounts of help.

Mrs Bull paid her daughter £25 per week to help her caring husband with the domestic work – shopping, cleaning, ironing and so on.

Mr and Mrs Miston paid their friend who helped with the housework, but there was ‘no set amount’; they seemed to give her what they could each week, sometimes ‘in kind’.

This latter case was the nearest we found to a paid neighbour, but it was clearly an informal arrangement.

Two people paid for regular treatment to help alleviate their physical disability: one woman had weekly instruction from a yoga teacher and a man paid for weekly visits from a physiotherapist.

Some people hired help on an occasional basis. A husband who worked full time recently paid a cleaner to do two days spring-cleaning, and said that he would like to buy in more domestic assistance or care in this way, but could not afford it. Other bought-in services included gardening, household repairs and decorating.

In spite of the scarcity of paid support, disabled people and their carers could identify some potential advantages. Payment could make the arrangement acceptable to the disabled person and carer alike – ‘you can’t take advantage’, as one disabled person put it. Disabled people who relied on friends to do ‘odd jobs’ around the house, or to accompany them when they went shopping, similarly felt more comfortable if they could give their friend a small payment or ‘treat’.

Few people with disabilities could rely on regular, unpaid assistance from friends and relatives other than their key carer. Payment might have enabled the disabled person to ask for help without feeling so dependent on people’s sense of duty or generosity because they are giving something in return. One disabled person felt that, without paying the helper, ‘the commitment will fizzle out’.

Some people with disabilities recognised that paying for care could give them more control over the kind of services that were provided to them. One disabled couple who were unhappy about the service they received from home helps said that they wished they could pay directly for domestic help:

The Attendance Allowance and the Costs of Caring

You have to just accept whoever comes ... Because they are not paid by you, they are only ... answerable to their governors -- who never come and see the work they do. So there's no control ... A few weeks ago I asked the lady to wipe the window sill. -- 'I am not supposed to wipe paint work.' -- I couldn't believe it ... it's ridiculous really.

References

1. Reviewed by G. Parker, *With Due Care and Attention*, Family Policy Studies Centre, 1990.
2. H. Qureshi and A. Walker, *The Caring Relationship*, Macmillan, 1989.