

## 2 Sources of income

### **Claimants' and partners' incomes**

Some social security benefits, including the attendance allowance, are paid to individuals without regard to their family circumstances. Entitlement to other benefits, including the retirement pension and invalidity benefit, is based on the individual, but the amount paid can be influenced by his or her commitments to support a spouse and/or children. A third group of benefits, including income support, assumes that husbands, wives and children share their income and expenditure, and entitlement is based on the family unit. Because of the importance of income support in setting a baseline income against which other resources should be compared, this section considers the combined incomes available to disabled people and their partners.

The growth in the number of two-earner families makes this view of married couples as a single income unit increasingly out of date in many social groups. But the married couples in this sample were not two-earner families, and retained the traditional assumption that the income of either was available to be spent on the needs of both. They operated a common purse, usually handled by the caring partner.

Some members of the sample had close kin who lived with them, or in the vicinity, who might add to the resources available to the disabled person. The British social security system treats the incomes of adults who are not married to each other as almost entirely independent of each other. The incomes of caring kin, and the financial relationships between carers and people with disabilities will therefore be treated in a separate section.

The analysis of disabled people's income needs to be set in the context of the baseline provided by income support. The scheme offers

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a minimum income to people not in full-time work which can be augmented by premiums based on age and disability. (Children are left out of this description; only a few claimants in the sample had any.) The weekly income (excluding rent and rates rebates) guaranteed to a single person with the attendance allowance (at 1988 rates) was:

	Single person	Couple
Income support basic	£33.40	£51.45
Severe disability premium	£24.75	£24.75
Attendance allowance (higher)	£32.95	£32.95
Total	£91.10	£109.15

(Mobility allowance, if paid, would be in addition to this.) These amounts compare with the basic level of income support (for single people without disabilities) of only £33.40 (single) or £51.45 (married). The extras reflect an official view that the minimum needs of seriously disabled people are considerably higher than those of people who are unable to work for reasons other than disability. The income base for people relying purely on social security benefits is therefore higher for attendance allowance claimants than for the rest of the population, but only part of this extra consists of the allowance itself.

A corollary is that someone entitled to attendance allowance would be highly likely to qualify for income support and housing benefit. Pensioners, for example, would need independent means of at least £15 per week to add to their basic state pensions in order to lift themselves clear of income support; more to be clear of housing benefit.

For these reasons, incomes of attendance allowance claimants can be simplified into three categories: those who relied (almost) entirely on state benefits and would therefore have qualified for income support; those with fairly substantial pensions from former employers, or with other resources of their own; and those with an income from employment. This small sample is not suitable for describing the levels of income available to disabled people in detail. The OPCS disability survey provides information which is fuller and more accurate.<sup>1</sup> We will simply compare the experience of claimants in each of the three categories.

Among this sample of 29, none of the people with disabilities was in employment. Only one member of the sample had worked in the

recent past; none of the others considered going out to work as an option.

However a working husband or wife could have made all the difference to their level of income. In fact, only three partners worked – all husbands, all of them full time. Two had sole care of their wives. They were kept exceptionally busy as they struggled to fit their caring and domestic duties into their working day. Their lives were among the most exhausting and physically stressful of any of the carers.

On the day Mr Joseph was interviewed, he had been up at 7am to get his wife out of bed and his teenage son off to school. He was due to start his eight hour shift at work at noon. His school-age son would help look after his mother when he returned from school at 4pm, and an older son would look in when he finished work in the early evening. All the time Mr Joseph was being interviewed, he was busy washing pots, tidying and making his wife drinks.

Mr Joseph regretted that he was unable to work overtime or at weekends, because the family needed the money to pay the mortgage on their terraced house. He suffered from a stomach disorder which he put down to having to eat too fast and at irregular intervals. However, he was reconciled to his lot, and felt that he owed it to his wife to care for her.

One full-time worker had arranged to share his caring duties with an old friend who lived with him and his wife – Mr and Mrs Cox, described in Chapter 1. He had had to alter his hours of work to allow time to undertake his share of the caring, but the arrangement appeared to be working reasonably well.

In principle, one option might be for people to continue working and use their earnings to pay for someone else to care for their disabled relative. The arrangement between the Coxes and their friend has some similarities with such a plan, but no-one in the main sample of attendance allowance claimants had a straightforward substitute carer paid for out of earnings.

None of the worker/carer husbands was able to draw a high wage. But at least they were better off than those reliant on ordinary state benefits.

Some husbands or wives were unable to work in their own right; they had retired or had a disability themselves. Others had given up work in order to care for the disabled claimant. So very few families (3 out of 29) combined the attendance allowance with earnings. All

the others were more or less dependent on other social security benefits.

Among claimants without earnings, some of them were confused, and it was not easy to sort out what they were getting from which sources. But some of them were retired people or widows who had an occupational pension or other resources which, when added to their state pension or invalidity benefit, lifted their income clear of the basic benefit zone.

Mrs Ling had a war widow's pension of £63 per week, plus an occupational pension of her own of about £50. She reckoned that interest on her savings added about £20 per week to her regular income.

But the majority of people with disabilities had little or no income derived from previous employment. These included some who had retired without an adequate occupational pension, as well as those who had become disabled before they could build up pension rights. The latter group included, of course, the five young people who had been handicapped from birth, who relied on income support for their basic benefit.

The combination of an income guarantee rather higher than is paid to unemployed people and lack of independent resources means that the incomes of attendance allowance claimants filled rather a narrow range, with few very low, and none very high. The same narrow band is revealed by the much larger sample studied by OPCS: compared with the national distribution of net incomes, many severely disabled people were in the middle of the range; few were found at the top or the bottom of the range.<sup>1</sup>

Indeed the categorisation between those with earnings, those with occupational pensions and those with neither meant a lot in terms of the composition of people's incomes, but did not make all that much difference to the total amount. The crucial point for claimants was receipt of the attendance allowance and/or the mobility allowance. Up to £80 per week could hang on that pair of assessments.

### **Incomes and contributions of relatives**

It was shown in Chapter 1 that, apart from the 12 people with disabilities who were cared for by their husband or wife, a further 11 were cared for by a close relative who lived in the same house, but who formed a separate 'income unit' as defined for social security

purposes. Most of them were women – the mother or the daughter of the attendance allowance claimant.

In principle relatives might be able to combine work and caring in a marital partnership: one person caring, the other working full-time to provide an income for the whole household. In practice though, only three of the eleven live-in kin carers were married. The husbands of two of them were in full-time work with good earnings. The other was as disabled as the member of our sample, so the daughter cared for two people without any earned income.

Some non-married carers worked part-time, having adapted their working hours to suit their double responsibilities. Another source of income was an occupational pension drawn by a carer in her own right.

So several live-in carers had some income from employment, either directly or indirectly. But others had to rely entirely on social security benefits.

The question about whether live-in carers contributed to the financial support of people with disabilities was rather academic in most cases: those on social security, and many of those with part-time earnings, were no better off than the disabled person they cared for. Their financial contribution took the form of the loss of their own earning power, rather than adding to the resources available to be spent on goods or services.

Most of the live-in carers operated joint household budgets. The mothers who had been looking after mentally handicapped children from birth simply carried on with the housekeeping as they always had done, and the one handicapped child with a working father benefited from his earnings in much the same unquestioned way as she would have done when she was younger. Some of these mothers were conscious of spending the child's income, including the attendance allowance, on items specifically for the child; but they had no concept of their own income, *not* to be spent on the child. All of these young people had a mental handicap, and their mothers took most decisions on their behalf; perhaps a different relationship would have developed if the handicap had been physical.

The daughters who lived with their disabled parent all ran joint household budgets. If the parent's disability was purely physical, the supervision of the housekeeping money tended to be shared between them; if the dependant suffered from dementia, the carer tended to take complete charge. A distinction might be made between 'my' money

and 'your' money, but a good deal of it was pooled, and there was no sign that either member of the household preserved income in order to maintain a higher standard of living than the other. Few of them had the resources for a high standard of living anyway; but where they did, it was shared.

As far as live-in kin carers are concerned then, income and resources tended to be pooled, but this involved few transfers between income units because the carer's income was usually almost as low as the disabled person's. Nevertheless, most live-in carers would have seen it as their responsibility to purchase something that the disabled person needed, without considering whose money it was.

When kin carers lived separately from the people they looked after, household budgets were much more likely to be kept separate from each other. In this category we identified:

A daughter who had given up work to look after her mother, while her sister looked after their father; although the sister's husband had a job, both families felt very poor, as described below;

A team of sons and daughters-in-law, apparently led by one of the latter, all of whom had jobs. The carers were spending a lot of their own money on things for the old couple, without any regular arrangement for doing so.

A daughter-in-law with a working husband. Since she was paid for her services, it is unlikely that much income flowed in the other direction.

A sister who came in to help her brother, who was confined to a wheelchair, at set times each week. This man was among the least dependent members of the sample, and, again, the two households kept their money separately.

So only one of the live-out kin carers seemed to be using some of their income to contribute to the welfare of their disabled relative.

Apart from their immediate carers, several people with disabilities had other relatives, often a son or daughter, who might have contributed to their income. In this sample, there were no kin who had made a regular arrangement to pay so much per week or per month to top up their social security benefits. But several kin were 'very good to me' with occasional support – paying electricity or phone bills, bringing food or other gifts when they visited and so on.

*Our daughter works for a butcher: she brings in meat every week ... My brother bought us the video ... we wouldn't have that otherwise ... If I said 'now I'm short of continental quilts' ... the children would help out.*

But other relatives, close both in kinship and in travelling distance, appeared to make no contribution of this sort.

*Do our children give us money? ... Our children would take money from us if they could!*

It cannot be said that a clear picture of relatives' financial contribution to disabled people's welfare has emerged. We are just starting a larger scale study which is designed to examine the question in more detail. But, in summary:

- no relatives had assigned a fixed slice of their income to support a member of this sample; this is in contrast to the Bexley sample, where regular payments from kin were an important source of money.
- most relatives who lived with the person they cared for had blurred the distinction between their own money and the disabled person's.
- this could lead to implicit transfers; but most of the kin who had accepted the main responsibility were little better off than the disabled person they cared for.

### **Feelings about benefits**

The people with disabilities in this sample, and many of the relatives who cared for them, were unable to go out to work to earn a living; so they did not feel that they had any choice but to rely on benefits as their main source of income. Some of them, especially those who had been disabled for many years, or who had relied on their pensions long before their disability affected them, were so used to the idea of relying on social security that they did not comment directly. But others were unhappy about the experience.

Some people said that it hurt their pride to have to live on benefits.

One woman, who had first applied for attendance allowance and been refused when her mentally handicapped daughter was a baby, had been dissuaded from applying again by her husband:

*My husband was that type of man. He said 'well it's charity, forget it'.*

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As a result she had only applied again for attendance allowance (successfully on this occasion) six years ago, and consequently missed out on up to 12 years of potential attendance allowance payments.

Some carers and disabled people said that they spent hours on the telephone or queuing at their local social security office if they needed advice, or had a problem; and then often, as one carer put it ‘everyone passes the buck to a different department’.

One woman recalled how she and her husband had had ‘a terrible job’ getting on to social security when they lost their job managing a shop as a result of her disability: ‘We waited months. We went through nearly all our savings.’

Others were just confused:

*Benefits is a jungle ... people understand their bit of it, but there's no way of overall understanding it.*

Some disabled people wanted benefits advice from someone outside the DSS. On the other hand, some of the social workers we interviewed felt that they did not know enough about the complex system of benefits available to disabled people to give good advice. They might pass on enquiries to specialist welfare rights workers. But this meant that a disabled person had to go to one person to find out about care and another to find out about their financial position, even though the two were closely inter-related.

Some claimants felt bitter when they compared their lot with that of other people on benefits:

*I'm not mentioning no names, but it really annoys me when they can say they go out this day and that day -- ‘Oh, I bought a dress for myself. I bought a pair of shoes for myself.’ I can't keep on doing that. (Mother of mentally handicapped girl.)*

Because of all these problems with claiming and living on benefits some people simply chose to close off their mind to the possibility that there might be other benefits which they could claim:

*Right now I think there is even a little more one could get. But ... I just get on with what I have and don't worry about these things. (Man caring for his wife who is a stroke victim.)*

For people with little cash to spare who depended on benefits, every review of their allowances, or every change in government policy could be frightening.

When the benefits system changed in April 1988, one disabled woman was panicked into thinking that she would lose half her benefits, and phoned up her social security office 'in a terrible state'.

Another disabled woman who was receiving income support said that she secretly maintained a small savings account in order to protect her against the insecurity of living on benefits. She argued that if she didn't do this, then if her benefits were ever cut, she might be unable to pay her telephone bill, for example. She did not want to risk having her telephone cut off – she depended on it too heavily.

### **Claiming attendance allowance**

There was no single method by which the disabled people in our sample had found out about the attendance allowance. In most cases, there had been a delay between the onset of a person's illness or disability and their application for the allowance; and in some cases the interval stretched to many years.

Many people who had spent time in hospital had been informed about the attendance allowance (and perhaps other benefits) by the hospital welfare officers or by other medical staff. Sometimes it was the nurse who visited the disabled person at home when they were discharged from hospital who had told them about the allowance.

Households who lived mainly on state benefits tended to have intermittent contacts with welfare rights officers, social workers, or citizen's advice bureaux; and information about attendance allowance had often been passed on through these sources. Mothers of mentally handicapped children tended to rely on the schools and day centres their children went to, and the network of other mothers of mentally handicapped children, for their initial information about attendance allowance and their advice about benefits generally. Other people had learned about attendance allowance through friends or other relatives, by picking up a form at the Post Office, or from a television programme.

Most claimants had applied for the attendance allowance as soon as they found out that it existed. However, some people had been more reticent, either because they were not sure whether they qualified or because they were generally reluctant to claim benefits.

Mrs Staines received industrial injuries benefit in addition to her old age pension and her daughter had a pension from her

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former employer. The daughter felt that they could manage fairly comfortably on their income, but felt sorry for disabled people who had only the minimum level of state benefits to survive on: 'they must be in dire straits sometimes'.

Mrs Staines's daughter was persuaded to apply for attendance allowance for her mother by the local geriatric welfare officer. The first time he gave her the form and told her that she should apply, Miss Staines felt unhappy about claiming benefits, and had put the form away in a drawer. When the welfare officer visited again, some time later, he was firm.

*At the time there was quite a furore raging in the local press which had publicised a story about a disabled person getting two agency nurses to look after her, which was costing the council £800 a week. 'You've seen that piece in the paper', the welfare officer said, 'you're saving the council £800 a week looking after your mother the way you do. You apply for it!'*

There was also pressure on Mrs Staines' daughter from other people she knew:

*(They) said 'you really should apply'. I wouldn't have bothered with it in the first place but for them all ganging up on me!*

On the other hand, a few people had had what one carer called 'a fight on my hands' to get the attendance allowance, having to apply more than once before getting the allowance. Some people objected to the way the medical examination had been carried out by the doctor who came to assess them.

One disabled woman, who had applied four times before she had got the allowance, said that she had got 'fed up' with doctors coming and hitting her feet and knees with hammers.

The daughter of one frail old woman had been reluctant to apply for the attendance allowance at first, simply because she knew that her mother found medical examinations a strain.

Two disabled people in our sample had just had their attendance allowance cancelled following a medical review, or had been informed that it soon would be cancelled. They could not understand the inconsistency between the assessments made by the different doctors who had come to see them, since neither of them felt that their health had improved.

**Reference**

1. J. Martin and A. White, *The Financial Circumstances of Disabled People Living in Private Households*, HMSO, 1988.