Meeting the costs of disability
4. Meeting the Costs of Disability
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It is widely agreed that many disabled people have to spend money on things which they need specifically because of their disability. Some social security benefits are designed to help them meet those needs. This chapter is in two main sections: the first is concerned with identifying what the extra costs of disability are, the second with existing and potential policies for dealing with them.

Identifying extra costs
What do we mean by ‘costs’?
There is a whole series of ways in which we might describe the financial ‘costs’ of disability. One is the loss of earnings which many disabled people experience, or which their relatives face if they have to give up work to provide care. A second is the cost to public or voluntary organisations of treatment, care, training or other specialised services provided free to disabled people. A third is the extra cost of living faced by disabled people.

This chapter is about the last of these elements. How much more does it cost a disabled person to maintain the same standard of living as an able-bodied person? Clearly the answer depends a lot on the other two financial issues: on the effect of disability on the income of the disabled person and his or her carer; and on the provision of free or subsidised goods and services to meet special needs. But the question of extra costs can be addressed most clearly if we assume that these other factors are fixed: given current public services, what is the effect of disability on the way in which people spend their current income?

What people actually spend will depend partly on their personal preferences, and partly on the social and economic framework within

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which they live. It might be possible to discuss what they ‘ought’ to be able to afford. Do they really need a washing machine? are they spending more than they should on cigarettes? should they not spend more on healthy foods? On the other hand, it might be argued, people ought to be able to travel about town as freely as anyone else, even though a car and driver might be required for them to do so; they should have the means to hire care assistants rather than depend on the good-will of their families; and so on. These are all important questions to be taken into account in the debate about disability and public policy. But they are moral and political questions which do not yield directly to empirical research. This chapter will focus on what disabled people do spend their money on, rather than on what might happen if individuals or the government changed their priorities.

**Types of cost**

It is useful to think of four ways in which the costs of disability should be analysed.

- **Needs versus costs:** For the most part, the end-products which a disabled person requires are similar to those of anyone else. He or she needs to get up in the morning, go downstairs, keep warm and go shopping. But the disabled person may need to spend money on a carer, a lift, extra fuel and a car in order to achieve these things.

- **One-off versus recurrent costs:** Adaptations to the disabled person’s home, or the cost of purchasing and moving into more suitable accommodation, can be regarded as capital items which would not need to be repeated. Expenditure on fuel, food and clothing are recurring costs which would have to be met out of current income. A borderline category consists of durable goods such as wheelchairs, washing machines and so on which impose costs from time to time when they need to be replaced.

- **Special versus additional costs:** Some goods and services might be purchased solely because of disability; other people would not need them at all. Examples include domestic and caring services, medicines, travel to hospital. In principle these costs ought to be relatively easy to identify. Other items are required by everyone, but disabled people might need to spend more than others. Examples include fuel, food, clothing and transport. The
additional cost is difficult to distinguish from what would have been spent anyway.

- **Extra versus reduced costs:** Disability probably increases the expenditure needed on some goods and services, but might reduce it on others. It is difficult to choose examples without sounding heartless, but it might be assumed that deaf people would have a very low expenditure on radios. Negative costs would be particularly difficult to identify; it might be argued that (in practice) they are small and/or rare. But it is important to think about them, at least as a theoretical possibility.

**The income constraint**

The most important problem in identifying extra spending on the needs created by disability lies in the fact that expenditure is constrained by income – you can’t spend what you haven’t got. Supposing we know for a fact that Mr and Mrs X spend exactly £10 every week on heating their home; and that if Mr X did not have a heart condition they would spend exactly £5 per week. The Xs must have cut down their spending on other things somehow, in order to make their books balance. So what does ‘extra’ cost mean? On the other hand, the shortage of income may have prevented them from spending, say, £15 on fuel, which is what Mr X’s condition really demanded. In that case, does extra spending measure the true extra cost?

An economist’s definition of what people ‘need’ is the goods and services which they buy even if their income is low; in contrast, ‘luxuries’ are things which people buy only if they have a high income. Needs are therefore items like food, housing and fuel which, in the diagram on the next page, have a flat relationship with income (they are ‘income inelastic’); those with low incomes spend a relatively high proportion of their limited resources on these needs.

If someone needs extra heating (for example) because of their disability, we would expect them to spend more on fuel, and we would expect that extra expenditure not to be very sensitive to the level of income available. Both of these expectations flow from the definition of a need as an item which people buy in spite of a restricted income. Because total expenditure in the long run has to equal total income, the extra money spent on fuel will mean that the disabled person will spend less on other goods and services which are evidently slightly lower in his or her hierarchy of needs. He or she will experience a
lower general standard of living than other people on the same income, 
because part of that income has been diverted to higher heating bills. 
Looked at in this way, we might identify the ‘cost of disability’ as 
lying not so much in the extra spending on fuel, as in the reduced 
consumption of other items.

This way of looking at extra costs is particularly appropriate if we 
think about what would happen if disabled people were given extra 
income. There is no point in giving the money in order to allow them 
to spend it on the additional costs (the heating costs of our example); 
those extra costs can only be identified because disabled people pay 
them anyway, before they are offered the extra income. Extra income 
will, however, allow them to buy the other items which had been 
displaced by the specific disability-related expenditure. So, again, it 
is the effect on the other costs which is crucial to the argument.

If we focus on how people’s patterns of expenditure would respond 
to changes in their income, it seems unlikely that the costs of disability 
would be a fixed amount, independent of income. As income rises, 
some of the extra will be spent on goods and services which were 
required only because the individual was disabled, but which did not 
take precedence over basic needs while income was short. This does 
not at all imply that the extra costs incurred at higher levels of income 
are not legitimate; it simply suggests that the demand for 
disability-related items is subject to budgeting constraints just like any 
other form of consumption. On the other hand, it would be false 
reasoning to suggest that the ‘true’ costs are those incurred by people 
with very high incomes. The true cost is the one actually experienced 
by this person with this income.
Measurement
There are three possible ways of measuring the additional costs of disability.

- The first involves asking disabled people how much extra they spend on the relevant items. The comparison is with how they would spend their money if they had no disability. People can also be asked whether there are any specific items on which they spend less as a direct result of their disability, but the reduction in spending on other, non-disability-related, items is simply assumed.

- The second method involves taking detailed measurements of all expenditures of a sample of disabled people, and comparing the results with similar data from a sample of non-disabled people. Here the comparison is with other people. The findings show both increased and decreased expenditure within a fixed total, and it is difficult to interpret in terms of a net additional cost.

- The third method looks for evidence of a reduction in the standard of living which disabled people can support from a given income. It therefore turns away from specific additional costs to focus on the secondary effects discussed earlier.

Each of these three approaches will be examined in turn, as they affect disabled adults. The findings for disabled children will be summarised at the end.

Measuring costs: 1 – direct questions
This is in many ways the most straightforward approach. A disabled couple say, for example, that they have had to make alterations to their home to adapt it to their needs; they have to pay someone to do the decorating which they used to do themselves; they have to wash their sheets daily; they have to keep the central heating on all the time. They can estimate the additional costs of each of these four items, and the total represents their extra spending.

While this method is conceptually accessible, it may not be very accurate. People would have to give an accurate report of their normal spending on particular goods and services; many people might be able to do this for items which are paid for separately (such as fuel), but few could do so for items which are included in the general housekeeping budget (such as detergents). These are at least facts
which are ascertainable in principle; but the method also requires people to report what they would have spent in other circumstances. The estimate might be fairly accurate if the disability was of recent origin, and little else had changed. But for people with long-term handicaps, or who had changed their life-style significantly, the ‘what if’ expenditure would be little more than conjecture.

Nevertheless, this method gives a clear indication of the sorts of cost which disabled people are conscious of.

- In 1975, Mavis Hyman interviewed 56 wheelchair users of working age in central London (Hyman, 1977). They reported extra costs on transport, diet, heating, clothing, laundry, telephone and chemists’ supplies. The totals ranged from 75p to nearly £60 per week – £14 on average, or 24 per cent of their incomes, representing about £39 per week at 1985 prices.

- Richard Stowell and Felicity Day found that in 1983 ‘the shopping’ cost disabled people an extra £3.36 per week (Stowell and Day, 1983).

- Judith Buckle’s study of people with a mental handicap provided an estimate of £19.50 a week at 1981/82 prices, or about £23.70 at 1985 prices (Buckle, 1984).

The OPCS survey

All but one of the attempts to measure the extra spending of disabled adults by direct questioning have been based on intensive interviewing of small samples of severely disabled people. The exception is the OPCS survey carried out in 1985 (Martin and White, 1988). The OPCS survey beats all rivals out of sight for the size, accuracy and representativeness of its sample. Its questions are well-framed and neutral. On the other hand, the people being interviewed would not have thought precisely about these questions beforehand, and would not have had an answer ready. It is arguable that a series of extra-cost questions reeled off in the middle of an hour-and-a-half interview would not allow respondents time to work out their true situation. The responses might, therefore, provide a conservative estimate.

The average extra cost reported by the OPCS survey was £6.10 per week. However, this is not a very meaningful figure since it is an average covering a wide range of disabilities from very severe to relatively minor. What we are really interested in is how much
disability can cost, among those experiencing the most disabling handicaps. Chart 4.1 shows how the total additional costs rose from £3 per week in severity category 1 to £12 in category 10. The impairments most associated with additional expenditure were locomotion and digestion; people with hearing difficulties reported relatively low additional costs.

Chart 4.1  Average extra expenditure, by severity of disability (OPCS survey of disabled adults, 1985)

Although some disabled people reported extra costs above the averages shown in the chart, there were few very high figures. Our own (PSI) re-analysis of the OPCS data shows that the estimated numbers with above-average costs are as follows (McKay, 1990):

\[
\begin{align*}
\text{£10 - £20} & \quad 840,000 \\
\text{£20 - £30} & \quad 190,000 \\
\text{£30 - £50} & \quad 70,000 \\
\text{£50 or more} & \quad 30,000
\end{align*}
\]

The OPCS questions distinguished between special items needed only because of disability, and extra spending on standard items
which everybody needs. In the former category the most common cost was chemist’s items, required by three-fifths of seriously disabled adults; but the most expensive was home services, costing £11.30 per week for those severely disabled adults who used and paid for them. Among normal goods and services the most common extra need was for fuel, reported by four out of five of the severely disabled people; the most expensive was extra food, costing £7.00 per week for those affected.

All of the figures in the previous paragraph refer to severity categories 9 and 10 – the two most severe categories. For them, the total broke down as follows:

- Disability equipment*  
  - 70p
- Hospital-related expenses  
  - 20p
- Home services/treatment  
  - £2.30
- Chemist’s items, prescriptions etc.  
  - £1.00
- Fuel  
  - £2.20
- Food  
  - £2.10
- Laundry, clothing  
  - £1.20
- Travel  
  - 80p
- Other extras  
  - £1.60

*Purchases over the past year of disability equipment such as special furniture are not included in the OPCS total, but are shown separately.

It was suggested earlier that the costs of disability might not be fixed; that people with a higher income would be able to release a proportion of it to disability-related needs which poorer people could not afford to meet. The OPCS survey shows a link between costs and income, so that among the small number of very severely disabled people with an income above £120 per week the total extra spending averaged more than £20 (Martin and White, 1988).

**The DIG survey**

These findings caused some consternation when they were published: they suggested that the extra costs of disability were less than the disability organisations expected, and less than the attendance allowance and mobility allowance already being paid to disabled claimants. The Disablement Income Group (DIG) immediately undertook a small-scale telephone survey which suggested much higher levels of extra cost (Thompson, Buckle and Lavery, 1988), and followed this up with a more detailed enquiry of their own (Thompson, Lavery and Curtice, 1990).
The DIG survey differed from the OPCS survey in two ways. The sample consisted of 87 disabled people selected from two lists: one of people who had written in to DIG to ask for an information pack following a TV programme; the other of people who had applied to the Independent Living Fund (ILF) for support. Respondents’ average incomes were far higher than those of the OPCS sample. The DIG sample is therefore small and unrepresentative. Peter Large reviews a number of differences in the next chapter. It seems clear, however, that the differences between the results are not due to the compositions of the samples. Our own re-analysis of the OPCS survey shows that if it exactly matched the DIG profile in severity of disability, age and income, it would still only set the additional costs at £12.80 per week, compared with DIG’s average of £50 (McKay, 1990).

The interview was longer and more detailed – or rather, it was the same length as the OPCS interview, but almost the whole time was spent probing the extra costs of disability. The interviewers were specially knowledgeable about the topic, as opposed to the generalist professional interviewers employed by OPCS. These features of the interview are likely to increase the amount of extra costs reported, but it is not clear what interpretation should be placed upon them. On the one hand, more detailed and more leisurely questioning should reveal costs which respondents to the OPCS survey did not have time to consider properly. This is an advantage. On the other hand, persistent questioning by interviewers keen to establish a high figure could suggest responses and exaggerate the true effect. We are not suggesting even the slightest dishonesty; the problem is that answers are always highly sensitive to the form of questioning when the respondent has not thought about the issue in detail beforehand.

The figures overleaf show the extra costs reported by the DIG sample of people in disability categories 9 and 10, compared with the OPCS findings for the same categories.
Methodological difficulties do not allow us to interpret the DIG findings as anything like a precise estimate of the true cost of disability, still less to analyse its components more finely. The survey has, however, succeeded in throwing dust in the eyes of those who might have concluded on the basis of the OPCS survey that the average costs of the severest disabilities were only about £12 per week. The OPCS survey was always going to produce a conservative estimate; in this light, it looks like an underestimate. But be careful: read the next instalment of the saga before you reach a conclusion.

**Measuring costs: 2 – expenditure diaries**
The direct questioning approach asks disabled people to work out how much they currently spend on particular goods and services, and compare that with what they think they would spend if they had no disability. The second approach measures how much disabled people actually spend on all goods and services; the analyst then compares the answers with similar data on the spending patterns of non-disabled people.

In principle this is a more reliable method, since both sides of the comparison are based on facts, not guesswork about how someone would have behaved in different circumstances. A criticism commonly lodged against the expenditure comparison is that extra spending on some items is necessarily offset by lower spending on others, because of the income constraint. While the constraint imposes difficulties of analysis and interpretation, this should actually be seen as an advantage of the method. The constraint is a real one, and the expenditure comparison method allows us to examine its implications in a way which is not possible with the direct questioning method. Remember that we are not trying to measure what spending on
disability-related items would be without an income restraint; extra costs do not mean an excess of spending over income, they mean a reduction in resources available for other goods and services.

The method is nonetheless difficult to analyse and interpret. What we are looking for is goods or services on which disabled people spend significantly more than similar families with no disability. We would expect the resulting shortage of money to show up as slightly reduced spending on all other goods and services. The picture would look something like the pattern on the left of the chart below.

If, on the other hand, there were goods and services which disabled people did not need so much as others, we would expect a dip in their spending to be compensated by a slight increase in the allocation to other categories – like the pattern on the right of the chart.

Unfortunately we are hampered in our search for peaks (and perhaps troughs) in the patterns of disabled people’s expenditure by a process of averaging. Because everyone’s spending is influenced by their personal preferences as well as by their circumstances, it is not possible to look for individuals whose spending exhibits particular patterns; the comparison has to be between groups of people. But suppose that one set of disabled people had to spend extra on (say) food and fuel, and were forced to spend less on (say) transport and services to make the books balance. Suppose another group needed to spend extra on transport and services, and less on food and fuel. Among disabled people as a whole, the two effects would tend to

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cancel each other out, making it appear that there was no special need associated with disability.

The analyst also faces a host of technical difficulties.

- Expenditure can only be measured for households, not for individuals; some of the extra costs faced by the disabled person may be cancelled out by reduced consumption among other members of the household.

- Expenditure is an accurate indicator of consumption only if it is assumed that disabled and non-disabled people buy at the same prices. In practice disabled people may sometimes have to pay more for the same goods or services. A trip to the shops, for example, might require a taxi fare instead of a bus ride. The high prices faced by disabled people might lead to an increase in expenditure; or to a reduction in expenditure, if the price is more than they can afford.

- Normal expenditure patterns are strongly influenced by household composition and by levels of income; it is necessary to allow for the fact that disabled people do not live in typical households with typical incomes.

- Goods and services are coded into detailed categories, which are traditionally summarised in eight groups. If extra spending on one category results in reduced spending on another category within the same group, analysis by group will smooth over the real pattern of variation. But very large samples would be required to identify the detailed sources of variation, category by category.

- The normal range of variation between households is so wide that it is hard to see distinct patterns.

For all of these reasons the samples of disabled people and ordinary households used in these comparisons have to be either very large, or restricted to certain tightly defined groups.

**The DSS survey**

The Department of Social Security (DSS) has recently published the results of an expenditure comparison designed to complement the OPCS survey discussed in the previous section (Matthews and Truscott, 1990). The Family Expenditure Survey (FES) is the standard source of data on households’ expenditure patterns. For one year, the
FES interviewers identified disabled members of the sample, and followed up the standard expenditure interview with a second questionnaire – a cut-down version of the OPCS survey. While this provided a mass of data for analysis, the design based on the Family Expenditure Survey necessarily limited the number of people in the sample in important groups: out of 7,000 households, only 63 people in disability severity categories 9 and 10; 150 in categories 7 and 8. For some purposes, it is important to distinguish between people above and below pension age, but there were only 80 non-pensioners in the sample in the top four severity categories combined. These small numbers in key groups severely hampered the scope of an analysis which would have been difficult enough even if there had been plenty of interviews. It should also be borne in mind that the response bias normally associated with the FES might affect the comparison between disabled people and the control group.

As a result, it is difficult to form clear conclusions on the basis of the findings of the expenditure comparison. Chart 4.2 shows how much more and less households containing disabled people were found to spend, compared with a sample of non-disabled households, matched for income and household composition. The extra housing costs are probably best ignored, as rather sensitive to the exact calculations on which the graph is based. But the findings provide fairly stable evidence that disabled people require additional expenditure on fuel and durables, and also on tobacco and services. In contrast, households with a disabled person tended to spend less than expected on clothing and transport.

Because of the income constraint, this method does not naturally produce an estimate of the total extra costs of disability. We have argued, however, that the true cost of disability lies in the reduction in expenditure on other items. If we assumed that the negative elements in Chart 4.2 all represented losses (rather than reduced needs), adding them up would produce an average cost of £5.40 per week – not far short of the average of £6.10 reported by the main OPCS survey. Remember that both figures offer an average for all disabled people, covering the complete range of severity from categories 1 to 10. Since the averaging effect described above would tend to understate the influence of disability on expenditure patterns, it is likely that the true effect is larger than that.
Similar estimates of the total effect of disability on different spending groups in the DSS sample suggest that the cost rises with income, as indicated by the OPCS figures.

Analysis of the small number of severely disabled people captured by the FES tends to confirm that their main additional costs were durables, fuel and tobacco, plus health services and domestic services. But they were too few for any clear picture of the influence of severity on extra costs to be drawn.

**Measuring costs: 3 – standard of living**
Because people’s spending is governed by their income, we have suggested that the best way of looking at the overall costs of disability is to consider the reduction in the general standard of living enjoyed by disabled people, as a result of having to divert scarce money to the things they need because of their disability.

Suppose we could measure households’ standard of living in some way which was not just a statement of their income, and which was not directly influenced by their disability. The chart below shows in

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**Chart 4.2** Extra and reduced expenditure by households with a disabled adult (DSS expenditure comparison, 1985/86)
outline what we would expect. For people with no disability, standard of living would rise with increasing income, as shown by the solid line. For any given level of income, disabled people would be expected to have a lower standard of living; thus the dashed line lies below the solid line.

The dashed line in the chart is drawn below the solid line. But look at it again, and see that it also lies to the right of the solid line. Disabled people could enjoy the same standard of living as others, but they would require a higher income in order to do so. We could therefore define the cost of disability as the extra income required by a disabled person to bring his or her standard of living up to the same level as other people.

All this depends on our finding an indicator of people’s standard of living which is positively related to income and is not directly influenced by disability, but which responds to the extra costs of disability in the manner just outlined. The main OPCS survey contains a number of questions which can be used to indicate how well-off people are. They concern: possession of consumer durables, budgeting difficulties, and participation in ‘normal’ activities. We are working on the survey data to combine these questions into indicators of people’s standard of living. We have not yet been able to reach firm conclusions, but preliminary findings suggest that the cost of living is about £40 per week higher in disability categories 6 to 10 than in category 1 (McKay, 1991). This indicates that the effect of disability on living standards is greater than the direct measurements in the OPCS and DSS surveys would indicate, but less than the very high estimates reported by the DIG survey.
**Disabled children**
All of the estimates referred to so far cover disabled adults.

_The OPCS survey_
OPCS undertook a detailed survey of (the parents of) disabled children in parallel with the survey of adults already quoted (Smyth and Robus, 1990). It included direct questions about the extra costs which the parents incurred as a result of their child’s handicap.

The method was virtually identical to that applied to adults, and need not be discussed again. The average extra expenditure came to £6.50 a week. For the top two severity categories, extra costs were reported at £12.50. Both these figures are strikingly similar to those for disabled adults, though children’s costs came out slightly higher.

_The SPRU expenditure comparison_
The recent wave of disability surveys did not include an expenditure comparison of families with disabled children. But a similar study was carried out in 1978 by Sally Baldwin of the Social Policy Research Unit (SPRU) at York University (Baldwin, 1985). The SPRU study was based on interviews with 480 families selected from the records of the Family Fund; all of them received the attendance allowance, and were probably in OPCS severity categories 9 or 10. The families were matched with a sub-sample of otherwise similar families from the normal Family Expenditure Survey. The study was therefore much more tightly focused on a particular category of severely disabled children than the DSS expenditure comparison could be. This was an advantage in that the SPRU analysis could discount extraneous sources of variation; it was a disadvantage in that the sample of Family Fund applicants was not necessarily typical of all families with severely disabled children.

Baldwin’s detailed comparison of the spending of disabled and non-disabled families is shown in Chart 4.3. Extra costs appear to have been mainly transport and food, followed by durables, tobacco and clothing. The most noticeable difference from the DSS findings on adults is that transport heads the list of extra costs for children, whereas it headed the list of reduced expenditure for adults. The extra spending on tobacco even among families with children suggests that some of the additional costs may be incurred by carers, rather than by disabled people themselves.
The SPRU assessment of the total cost of disability was based partly on the fact that the disabled group spent more each week than the comparison group, even after allowing for income. This is the opposite of what the DSS analysis of adults found, and the implications of the difference need to be considered. Baldwin suggested that the total cost to middle-income families was about £12 a week at 1984 prices; and that the cost was greater among families with either higher or lower incomes. Note that these estimates all refer to severely disabled children, and are quite close to the OPCS figures at that end of the severity scale.

Conclusions about extra costs

What are we to make of this mixture of estimates of the cost of disability?

The OPCS direct questions and the DSS and SPRU expenditure comparisons all yield results which are broadly consistent with the conclusion that:
disability costs increase with severity, up to about £12 per week at 1985 prices for the people who are most severely affected; 
the costs are not fixed, but rise with income.

Both of these methods, while sound, have an in-built tendency to understate the true effect on people’s spending.

Two other methods – the DIG enquiry and the PSI standard-of-living analysis – are more speculative. But neither of them can be dismissed out of hand. Both suggest that the true cost of disability may be substantially higher than the conservative estimates based on the other approaches.

Benefits to meet extra costs

Objectives of extra-costs benefits

Benefits aimed at meeting the additional costs faced by disabled people include the non-means-tested attendance and mobility allowances (soon to be replaced by the disability living allowance); certain aspects of the means-tested supplementary benefit/income support schemes can also be seen as extra-costs benefits. (Peter Large argues in the following chapter that the higher rates of benefit available under the war pensions and industrial injuries schemes should also be regarded as at least partly aimed at the additional costs of disability.) Current benefits and proposals will be reviewed in detail in the following sections, but it is valuable to start by considering the criteria against which the performance of these benefits might be judged.

Proposals for a comprehensive disability income scheme have been canvassed at least since the early 1970s (DIG, 1987). The Social Security Advisory Committee’s report on disability benefits recommended the phased introduction of such a scheme (SSAC, 1988). A comprehensive benefit would contain two elements – one concerned with basic income maintenance, the other with meeting the extra costs of disability. In principle it would be possible to design either of these without the other, and it is with the extra-costs element that we are concerned here.

There are three main questions: how to assess the extra needs of each disabled person; how to decide between support in cash or in kind; and how much benefit should actually be paid, bearing in mind the other resources available to that person.
Assessing need

One option would be to measure the actual extra costs faced by each individual: do you need extra heating? extra diet? extra clothing? and so on. How much do you need for each of these? That was, in effect, the procedure available under the old supplementary benefit additional requirements regulations, discussed later. Bearing in mind the difficulties we have already experienced in the measurement of the extra costs of whole groups of disabled people, the chances of designing a measure accurate for each individual seem slim. People’s actual costs are constrained by their income, but there would be no automatic limit on the things which they might reasonably request if offered. Intrusive questions would enquire whether they really needed each item. At least by implication, the claimant would be required to spend the money on specific approved items.

The alternative approach would be to derive an estimate of individuals’ needs from factual information about the nature and severity of their disability. Relatively simple arrangements of this sort already provide entry to the attendance and mobility allowances. There is some administrative advantage in clean cut-off points between those who do and do not qualify for benefits, and it should not be forgotten that claimants as well as administrators prefer easily understood rules. A more sophisticated attempt to align benefit rates with individual needs would be a sliding scale based on a series of detailed questions – a ‘points system’ (Mitchell, 1986). The OPCS severity scale might be considered a prototype for such a scheme.

It seems likely that the government was prepared to consider a points-based extra-costs benefit in the review which led up to the 1990 White Paper *The Way Ahead*, and expected to use the OPCS findings as the basis for a new proposal. Unfortunately, the OPCS survey suggested that the great majority even of the most seriously disabled people had extra costs of less than £20 a week. Those of them already receiving attendance or mobility allowances were therefore getting more than they ‘needed’, if need is based on the OPCS measure. As *The Way Ahead* commented, an attempt to replace the existing allowances with a costs allowance aligned with OPCS-based needs would have meant losses for those already receiving attendance and mobility allowances (DSS, 1990a). Our own re-analysis of the OPCS measure shows the problem (McKay, 1990): a new benefit paying ‘OPCS costs’ would have led to losses averaging more than £30 a
week for people currently receiving the higher rate of attendance allowance combined with mobility allowance; 89 per cent of those claiming one or other of these benefits would have been losers.

This explanation for the government’s policy depends, however, on acceptance of the OPCS measure as the best indicator of the true costs. If a new benefit was based on the PSI standard-of-living analysis, most people on attendance and mobility allowance would stand to gain (McKay, 1991).

**Benefits or services?**
The first half of this chapter discussed attempts to measure the extra costs of disability in cash terms, on the assumption of a fixed supply of free adaptations, equipment or services from local authorities or other agencies. It was also assumed that the present arrangements would continue, under which the great majority of caring is undertaken by close relatives. But support services and physical aids are sometimes paid for directly by disabled people. They were part of the extra costs revealed by the OPCS, DIG and DSS surveys.

Should social security benefits attempt to meet the cash cost of support services? One of the government’s principal anxieties about the use of supplementary benefit to pay for residential care (see below) was the difficulty social security staff would have in assessing individuals’ needs for care. On the other hand, the idea of placing the money to pay for care in the hands of the consumer has many attractions (Berthoud, 1988). The Independent Living Fund (also see below) has demonstrated that there is both a demand among disabled people, and a supply among potential care workers, for personal support arrangements of this sort. But we are a long way from sorting out what the proper relationship in the provision of care should be between family, social services and directly-paid carers.

It is outside the scope of this chapter to try to resolve that question. But it is relevant to point out that the potential cost of care – in excess of £100 per week – greatly exceeds all other estimates of the extra costs of disability. Policy decisions about an extra-costs benefit are, therefore, very sensitive to assumptions about the proper relationship between cash and care.
Assessing resources
Discussion of social security benefits is often confused by the word ‘need’ meaning two quite different things. So far in this chapter it has been used to refer to the goods and services which disabled people have to buy. But it is also used to mean lack of income; in fact, that is its more common usage. These two types of need are independent of each other. It is common to discuss the first in terms of ‘horizontal equity’ and the second in terms of ‘vertical equity’.

A benefit designed to meet extra costs is clearly addressed to the ‘horizontal’ issue – equalising the standard of living of people with varying requirements. One might combine horizontal and vertical considerations in a single benefit, which would be paid when both types of condition were met: extra costs and shortage of income. That is the line which the Conservative government has tended to favour in its policy on support for children. However, the case for income-testing the extra-cost element in disability benefits is probably even weaker than it is for families. Most of the severely disabled people who would qualify for an allowance do not work anyway, so that the savings to be derived from a means test would be small. Given the size of the benefit entitlement, and the limited earning capacity of disabled people or their spouses, the introduction of a means test or a work test for the extra-costs benefit as well as for income replacement benefits would create a disincentive cliff which few could hope to scale.

There is therefore a strong case for a benefit which varies with severity of disability, but which does not vary with income. That is how the current attendance and mobility allowances work. Effectively the government would be underwriting the financial costs of disability, leaving disabled people to spend their earnings on the same goods and services as other people.

The OPCS survey and other evidence suggests that expenditure on disability-related costs may increase with income. It is difficult to imagine a social security benefit positively related to income. It would depart too far from all the other principles of the system. (The state earnings-related pension scheme is linked to previous income; no benefit is positively linked to current income.) But the fact that true costs rise with income at least strengthens the case against a means test. A flat-rate benefit would contribute much less to the extra costs of a disabled person with a high income than to the poor.
On the other hand, the tax system could easily be adapted to meet this point. Severely disabled people qualifying for the flat-rate disability-costs benefit could be offered a reduction in their income tax rate. Not a tax allowance, but a reduction from 25 pence to (say) 23 pence in the tax paid per pound.

**Needs-based benefits**
A series of special disability benefits was introduced during the 1970s, including two directly concerned with extra costs.

**Attendance allowance**
The attendance allowance was introduced in 1971 for disabled people who cannot be left on their own for long periods. It is payable to those who require either frequent attention in connection with their bodily functions, or supervision to avoid substantial danger to themselves or others.

Claims for attendance allowance are decided on the basis of a medical assessment carried out by a local doctor employed on a freelance basis. These assessments have attracted much criticism (Buckle, 1988; NACAB, 1990). At a policy level:

- It has been asked why a separate assessment is necessary when the claimant’s own GP, specialist or social worker may know more about his or her needs than could be learned in the course of a new examination. On the other hand, there are arguments in favour of a separate assessment by an expert in the attendance allowance criteria.

- Another complaint is that claimants are invited to demonstrate their inability to perform tasks, when they ought to be encouraged to minimise the extent of their disability. This seems an inevitable feature of any benefit limited to people with particular disabilities; the conflict between targeting and incentives is familiar from other areas of social security policy.

At a practical level:
- A proportion of claimants complain that their assessment is too superficial or too detailed; that the doctor was curt or rude, did not appear to be interested in or understand their conditions, and generally lacked a satisfactory bedside manner. It is arguable that any assessment of incapacity is potentially humiliating. The signs
are that while many of the doctors carrying out the attendance allowance assessment understand how to minimise this risk, others – perhaps a minority – make little attempt to do so.

Claimants who are refused the attendance allowance at the first attempt can ask for their case to be looked at again. As many as a quarter of them do so, and nearly two-thirds of the reviews are successful (DSS, 1991). These figures suggest that the dividing line between those who do and do not qualify is very hard to define clearly.

Payment can start six months after the onset of the condition which qualifies the individual for attendance allowance. This delay no longer applies to people with a terminal illness. The six-month qualifying period was probably intended to distinguish between long-term disability and short-term sickness, but many conditions are known to be long-term from the start and it is far from clear what purpose the six-month wait serves. Absurdly, claimants of supplementary benefit (before 1988) were entitled to receive the equivalent of the attendance allowance during those six months, as an ‘additional requirement’; this is no longer available under income support.

The benefit is paid at two rates, according to whether the person requires attendance during the day or during the night only (lower rate), or during both day and night (higher rate). The rates from April 1991 are £27.80 and £41.65 per week. People receiving the attendance allowance automatically qualify for the disability premium in the assessment of income-tested benefits, and in certain cases for the severe disability premium. The allowance also triggers entitlement to invalid care allowance, and the carer’s premium for people who are unable to work while caring for the disabled claimant.

As the figures below show (DSS, 1991), many claimants are very old, but the benefit is nevertheless important to disabled people of working age, and to children. Until 1990 there was a lower age limit of two (on the assumption that young babies needed constant attendance anyway) but that has now been lifted.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged 2 to 15</td>
<td>72,000</td>
</tr>
<tr>
<td>16 to 59</td>
<td>160,000</td>
</tr>
<tr>
<td>60 to 74</td>
<td>161,000</td>
</tr>
<tr>
<td>75 or more</td>
<td>369,000</td>
</tr>
</tbody>
</table>
Chart 4.4, based on the OPCS survey, confirms that the attendance allowance tends to go to those with the severest disabilities. It has been questioned whether anyone in the highest disability category would not qualify for the benefit. In fact, our more detailed analysis shows that nearly half (46 per cent) of the OPCS respondents with the maximum disability rating on personal care were not getting the attendance allowance (McKay, 1990), even though the group is described as ‘cannot feed self without help, cannot go to and use toilet without help’. The questions in the survey are not a substitute for the full medical assessment, but the *prima facie* evidence of incomplete take-up is supported by the results of welfare rights campaigns identifying unclaimed entitlement among a significant proportion of disabled people (Bennett, 1990).

**Chart 4.4 Receipt of attendance allowance, by severity of disability (OPCS survey of disabled adults, 1985)**

The number of people receiving the benefit has risen from less than 300,000 in 1971 to 760,000 in 1989 (Chart 4.5). There is no evidence to suggest that the number of severely disabled people grew at anything like that rate, and it is clear that take-up has improved
dramatically. Until the trend starts to level off, however, it has to be assumed that there are still many people who have not yet claimed.

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

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

Whatever governments may have intended, another question is what the attendance allowance is spent on in practice. The evidence suggests that the majority of claimants use it as a general contribution to the basic cost of living (Buckle, 1988; Horton and Berthoud, 1990); they do not feel that they can afford to use it to pay for care. Some claimants, perhaps those with a better basic income, give part or all of the allowance to their carers as a gesture of reciprocation, especially if the carer is not very closely related to them. For others, the contribution of the attendance allowance to the household income has enabled a carer to give up or reduce her hours of work. The benefit on its own is not sufficient to pay anything like the full costs of care.

A number of schemes have been set up in which the attendance allowance is combined with other resources to pay for non-kin carers in the disabled person’s own home. Many local authority social services departments have their eye on the benefit as a resource to contribute to the community care packages to be set up after 1993 (see Hazel Qureshi’s chapter in this volume). While these arrangements may be desirable in their own right, it should be remembered that the attendance allowance is a general extra-costs benefit: far from earmarking it for care, the majority of claimants feel they need it to pay for the ordinary extra costs identified in the first part of this chapter.

**Mobility allowance**

The mobility allowance was introduced in 1976, replacing a series of lesser schemes offering vehicles or tax allowances to certain classes of disabled people. The benefit is available to people who are unable to walk; who are virtually unable to walk; or for whom the exertion involved in walking would constitute a danger to life or health.

Medical assessments for the mobility allowance have attracted some of the same criticisms as have been levelled at the attendance allowance assessment (Buckle, 1988), but the problems do not seem quite so serious in this case – perhaps because only a single test is required. Many claims are awarded for a limited period, and a proportion of these are not renewed. Naturally the prospect of re-examination causes anxiety for those whose condition has improved but not been cured. The rate at which disappointed mobility
allowance applicants request reconsideration, and the success rate at the second stage, are both lower than for the attendance allowance (DSS 1991); this suggests that the distinction between those who are and are not entitled is easier to make.

The 1991/92 rate is £29.10 per week. It was originally set at £5.00 – £15.50 at 1990 prices. Most of the increase in value occurred between 1976 and 1982, and there has been virtually no change since then. Like the attendance allowance, the mobility allowance confers automatic entitlement to the income support disability premium; but it does not give access to the severe disability premium, nor to the invalid care allowance.

Chart 4.6 confirms that the mobility allowance, like the attendance allowance, tends to be paid to more severely disabled people. But the OPCS survey also showed that one-fifth (21 per cent) of those with the maximum disability rating for locomotion – who ‘cannot walk at all’ – were not receiving it, even among those within the qualifying age range (McKay, 1990).

Chart 4.6 Receipt of mobility allowance, by severity of disability (OPCS survey of disabled adults, 1985)
Perhaps the most controversial aspect of the mobility allowance is the age limit. People with limited mobility may claim up to the age of 65. If successful, they may then receive benefit for the rest of their lives, subject to reassessment if the original award was for a limited period. At first, it was intended that no-one should receive the allowance after the age of 75, but this limit was extended before anyone reached it, and will be abolished altogether with the new disability living allowance. But those whose disability arises after the age of 65 cannot claim at all. One explanation for this may lie in some of the scheme’s precursors, which were explicitly concerned with helping disabled people to travel to work. The great cost of extending the allowance to all elderly people with restricted mobility was and remains one of the main objections. But the rule appears to imply that old people have no need to move about.

The mobility allowance was introduced in stages. In 1979, there were more than 100,000 people receiving it (DSS, 1991). By 1989, there were 575,000 (Chart 4.7). Part of this increase is caused by the extended period on benefit of those who claimed before their 65th

Chart 4.7 Number of mobility allowance claimants, 1979-89 (Social Security Statistics)
birthday. If the comparison is based on those under 65, however, the numbers have trebled since 1979 – a rate of increase even higher than that for the attendance allowance. Since the number in every age group continues to grow more rapidly than could be explained in terms of increased incidence of disability in the population, we have to assume that there remain more people entitled to mobility allowance than have so far claimed it.

Although there is some doubt about what the attendance allowance is ‘supposed’ to be spent on, it is clear that the mobility allowance is intended to be spent on transport. That is not an obligation on the claimant, but the intention of the policy. A number of surveys of claimants suggest that the majority of them do spend the allowance on the costs of buying or running a car, though some spend it on other things (Cooke and Staden, 1981; Buckle, 1988).

The new disability living allowance
In The Way Ahead the government announced that the attendance allowance and mobility allowance would be retained in roughly their present form, but incorporated in a single extra-costs benefit called the disability living allowance (DSS, 1990a). There will be two main changes to the existing benefits. They will have a single claim form and assessment procedure. And there will be a common qualifying period of three months; at present attendance allowance claimants have to wait six months, mobility allowance claimants not at all.

The new element in the disability living allowance will be a lower rate of payment – about £10 – for people in need of care or with restricted mobility, whose handicap falls short of the criteria providing access to the existing allowances. The government argues, on the basis of the OPCS survey, that the existing allowances are fully adequate for the most seriously disabled people, but that there is a group with significant extra costs who do not qualify for anything. The new scheme can be seen as providing an intermediate step for fairly severe disability. Indeed it could be seen as a crude ‘points system’ providing access to a range of allowances between £10 and £70 a week. The decision to base the new allowance on the two old ones is both a strength and a weakness: a strength because it builds on practical experience of existing schemes, a weakness because it confines the assessment to only two elements – care and mobility – and might exclude people whose disabilities impose costs of other kinds. The
OPCS survey indicated that digestive disorders created the greatest need for additional spending (Martin and White, 1988), but such costs are simply ignored by the new scheme.

The government estimates that about 140,000 disabled people will qualify for the new care component, and 150,000 for the new mobility component (DSS, 1990a). Those who qualify for both will receive both.

*The Way Ahead* says that one of the arguments in favour of the disability living allowance is that ‘people who become disabled early in life are particularly disadvantaged because they have less opportunity to make financial provision to enable them to meet disability-related expenses’. Since this is an income-maintenance point, it looked at first as if this paragraph had strayed across from the later chapter in the White Paper which proposed age-related additions to the severe disablement allowance. The relevance to the disability living allowance turned out to be that neither the mobility component, nor the new lower-rate care component, will be paid to people whose problems start after the age of 65. They will not even qualify for the income support disability premium. The government assumes that people who become disabled after that age can afford to pay their additional costs out of their pensions or pensioner premium. (This appears to be a different argument from the one used to exclude elderly claimants from the mobility allowance, which seems to be that old people are naturally less likely to need to move about.)

The new allowance will replace the separate application and assessment procedures of the old schemes with a single process (DSS, 1990b). The government plans that as many claims as possible should be decided on the basis of a detailed questionnaire completed by the claimant or his/her family, and supported by their doctor or other professionals. Medical assessment will be retained for a proportion of cases. Both benefits will pass through the same process for adjudication, review and appeal.

**Income-tested benefits**
There is no income-tested benefit designed specifically to meet the extra costs of disability. But features of the mainstream income-tested benefits contain an element of compensation for extra needs.
Additional requirements

Until April 1988 the supplementary benefit scheme provided a range of allowances which people could receive in addition to the basic scale rate. These started as ‘exceptional circumstances additions’ available at the discretion of local officers; in 1980 they became ‘additional requirements’ which could be claimed as entitlements. Heating additions were paid to more than half of all claimants, whole blocks of people being entitled on the basis of their age. A range of other payments could be claimed on grounds of individual need for such things as special diet, extra baths, regular wear and tear on clothing and so on. In 1987 claimants under the DHSS’s ‘sick and disabled’ category received an average of £3.70 a week in payments of this sort (DSS, 1989). The proportion judged to need each of the main extras was as follows:

- Heating: 61%
- Diet: 22%
- Laundry: 17%
- Others: 19%

In some ways additional requirements represented an ideal way of dealing with the extra costs of disability: a shelf of allowances from which items could be selected to meet the individual needs of each claimant; receipt based on entitlement which could be referred to a tribunal if disputes about the extent of need arose.

But the scheme did not work so well in practice. A large proportion of the money was spent on heating additions for broad categories of claimant, selected by a political process which did not necessarily recognise the greatest needs. Claimants were not especially keen to haggle over the cost of an extra bath (25p) with a DHSS officer who knew little about their problems. And (apart from the automatic heating additions) the majority of the allowances were not being claimed by the people who were entitled to them. This is demonstrated not only by research conducted at the time (Berthoud, 1984): the spectacular success of the Independent Living Fund (to be discussed later) shows how few people were aware of the domestic assistance addition which preceded it.

Premiums

Additional requirements were abolished in 1988, and replaced by income support premiums: an extra allowance paid at a flat rate to all
members of a ‘client group’. The premiums relevant to our present enquiry are those paid to pensioners and to disabled people:

<table>
<thead>
<tr>
<th>Premium Type</th>
<th>Single</th>
<th>Couple</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pensioner premiums:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-74</td>
<td>£13.75</td>
<td>£20.90</td>
</tr>
<tr>
<td>75-79</td>
<td>£15.55</td>
<td>£23.35</td>
</tr>
<tr>
<td>80+</td>
<td>£18.45</td>
<td>£26.20</td>
</tr>
<tr>
<td>Disability premium</td>
<td>£16.65</td>
<td>£23.90</td>
</tr>
<tr>
<td>Severe disability premium</td>
<td>£31.25</td>
<td>£62.50*</td>
</tr>
</tbody>
</table>

* The couple rate of the severe disability premium is paid if both partners qualify. The other couple rates are paid if either qualifies.

Although the 1985 Green and White Papers on the reform of social security justified all the client-group premiums in terms of the special needs of the various groups, there are some doubts how far they should be interpreted as meeting the extra costs of disability as defined in this chapter. Pensioners get a premium from the age of 60, although there is little evidence that pensioners as such face additional costs before their health starts to fail; an age-based proxy for disability would have had a different profile. The recent extra premiums for over-75s and over-80s were not based on additional needs (which could have provided a convincing justification) but on their lower chance of an occupational pension (which, though true, is an illogical ground for increasing the income support rate). It should also be noted that both pensioners and disabled people command a ‘premium’ over unemployed and short-term sick people in the national insurance system. These points all suggest that benefit rates for both groups have been based largely on their long-term dependence on social security, and on the lack of concern about their work incentives. In that case, the extra-costs element in the disability and severe disability premiums consists of the surplus over the ordinary pensioner premium: £2.90 and £17.50 respectively (for single people).

There was a lot of argument at the time about whether the disability premium provided adequate compensation for the loss of additional requirements. The answer varied from group to group.

- Some claimants had assembled a large collection of additional allowances, especially if they had claimed the domestic assistance addition. The disability premium was not able to compensate for these big payments – nor could any flat-rate payment have done
so. There were therefore some significant losers both among existing claimants and among potential new ones. But they were a minority.

- Because most disabled people had not received much under the additional requirements regulations, they did not lose from their abolition. The majority of those entitled to the premium gained income.

- But these calculations refer only to those who received the premium under the simplified criteria introduced for income support. The government ignored those who fell outside the criteria, defining them automatically as not disabled. In fact more than half of the claimants who had previously received directly-assessed additions were excluded from the premium, and therefore lost money (Berthoud, 1986). It is likely that most of them were not at the top end of the disability scale, but they certainly had long-term health problems which had previously been judged to bring extra costs.

**Residential care**

Between 1980 and 1988 elderly and other disabled people were able to claim a ‘board and lodgings’ allowance if they lived in residential care or a nursing home, under the supplementary benefit scheme. The arrangements are continuing under income support until the ‘Griffiths’ policy of care in the community can be implemented by local authorities. The number of people benefiting from these payments rose from 13,000 in 1980 to 189,000 in 1990. Since it has been established that the great majority of them were in need of residential care (Bradshaw and Gibbs, 1988), it must be assumed that a similar number of people were failing to get the care they needed before 1980.

Residential and domiciliary care are covered by other contributions to this book; the board-and-lodgings payments are mentioned here simply to complete the record of extra-costs benefits. That part of the board-and-lodgings payment which exceeded normal supplementary benefit/income support allowances plus housing benefit could be considered directly analogous to the parallel additional requirements: a social security benefit to meet the actual additional costs incurred by individuals. Social security policy has leaned more and more towards fixed payments triggered by easily identifiable circumstances. Hence the desire of the Department of
Social Security to transfer responsibility for residential care to social services departments.

*The Independent Living Fund*

In order to help the small number of disabled people who were worse-off under the disability premium than with additional requirements, the government set up a charitable trust to make regular payments to disabled people who needed to pay for domestic or caring services. The Disablement Income Group accepted the responsibility for administering the Independent Living Fund (ILF), with considerable misgivings.

It was assumed that only a very small number of people would require this assistance – just a few hundred. The budget was originally set at £5m a year. Within two years the Fund was paying allowances averaging £64 per week to 4,260 disabled people (ILF, 1990), and the budget for 1991/92 has had to be raised to £62m. The original group of people qualifying for consideration was defined as those receiving the attendance allowance at either rate; whose resources (after allowing for care costs) were at or below income support level, and whose families were unable to provide the care they needed. While the budget has been expanded, the qualifying criteria have had to be restricted: people on the lower rate of attendance allowance, and people over the age of 75, are now excluded.

The government sees the ILF as a temporary arrangement, to be closed down when the transfer of responsibility for all care in the community to local authorities has been completed. On the other hand, the Fund has identified a vast reservoir both of unmet need and of demand for directly paid-for caring services. There have been calls for it to be allowed to continue in parallel with the Griffiths arrangements, though it is difficult to see how the responsibility for individual clients could be allocated between the two systems.

*Conclusions about extra-costs benefits*

The two main extra-cost benefits in 1990/91 cost £2.2 billion. It is difficult to estimate the extra-cost element in income support, but it must be substantial. Most of this money would not have been available 20 years ago.

The attendance allowance and mobility allowance, and the new disability living allowance, command a measure of support among all
commentators, though many would prefer something better. Some of the problems of detail of the two existing benefits will be addressed by the new scheme, though the exclusion of people solely on account of their age will remain a source of grievance.

Many of the disability organisations have expressed disappointment that a comprehensive costs allowance has not been introduced. To someone who is relatively new to this field, it seems ironic that continued weight should be placed on attendance and mobility needs in the assessment of extra-costs benefits, when the attendance allowance is not spent on care, and when at least one of the sources of information now available suggests that spending on transport is lower among disabled people than among the rest of the population. But progress towards a more systematic assessment of benefit in relation to need is hampered by two difficulties: confusion as to what the extra costs of disability actually are; and uncertainty as to the relationship between cash and services in the provision of care.

Acknowledgement
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Meeting the costs of disability


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Disability and social policy


