Review of existing research on the extra costs of disability

Mike Tibble
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Summary

• Currently there is disagreement within the evidence over the size of extra costs of disability, what drives/affects extra costs and how best to measure or estimate extra costs.

• It is clear from the evidence that measuring ‘extra costs’ is conceptually difficult. There is disagreement over what constitutes ‘extra costs’. Different studies have measured actual cost incurred, the costs of meeting need to a specified extent, and material deprivation experienced by disabled people.

• It is also methodologically difficult to measure extra costs. Four different approaches have so far been adopted and results differ widely between and within methodologies.

• Measuring actual expenditure on meeting disability-related needs (realised extra costs) may be a reflection of the budgetary constraints people face, rather than expenditure required to meet needs.

• Measuring the expenditure required to meet needs (potential extra costs) is difficult. There are problems deciding when needs are met, and it is difficult to measure hypothetical expenditure.

• Despite this disagreement and debate, all studies conducted to date have concluded that there are extra costs incurred by disability. Most studies conclude that disabled people’s needs are not fully met through services, and the cost of private provision to meet needs is not fully covered by extra costs benefits.

• There is some evidence to suggest that using care and mobility needs as a gateway to Disability Living Allowance (DLA) and Attendance Allowance (AA) may capture those with the greatest costs. It is not possible to state whether rates of DLA and AA fully meet the costs incurred by disabled people, although most studies conclude they do not, as concepts and estimates of costs vary widely. There is not a standard definition of costs used by all studies, and some definitions include costs DLA and AA are not designed to cover. Some studies also do not take into account the services provided by local authorities for the most severely disabled people, or the disability premiums in means tested benefits for disabled people on the lowest incomes.
1 Introduction

This working paper reviews the existing research evidence about the additional costs or deprivation disabled people face. It aims to be comprehensive in terms of methodologies examined, rather than inclusive of all extra costs/deprivation/budget standards studies. Some studies may not be included, generally as they used the same methods as others that were reviewed.

The costs to a disabled person of maintaining the same standard of living as an otherwise ‘similar’, non-disabled person depends on three factors:

- the amount of additional need they have as a result of their disability;
- the level of provision of free/subsidised services, by statutory or voluntary organisations;
- the effect of their disability on income, for example, disabled people generally have lower incomes than non-disabled people (as they are less likely to be employed).

The Government attempts to reduce the costs or deprivation disabled people face through:

- providing free or subsidised services;
- social security benefits;
- promoting equality in employment and access to services for disabled people (through the Disability Discrimination Act 1995).

One definition of ‘extra cost’ used by some studies is the expenditure by disabled people on needs that are not met by free/subsidised services.

This paper examines evidence on, and methodologies for measuring, the following:

- the expenditure by disabled people on needs that are not met by free/subsidised services. This may be disabled people’s actual expenditure, or that which would be required to meet needs to a certain extent (see Section 1.2);
• minimum incomes required to meet disabled people’s needs to a certain extent;
• deprivation experienced by disabled people, in comparison to non-disabled people.

It does not generally consider evidence on, or methodologies for measuring, the effect of disability on income.

Extra costs of disability are relevant to several benefits. Disability Living Allowance (DLA) and Attendance Allowance (AA) are the most obvious two, and this paper concentrates on these. However, the Independent Living Fund, Incapacity Benefit (IB), Severe Disability Allowance (SDA) and disability premiums of Income Support (IS) are also forms of extra costs benefits, as is the Disabled Students’ Allowance. IB, SDA and the disability premiums of IS imply that it costs more to be out of work and disabled than it does to be out of work and non-disabled, and may compensate for loss of income due to disability. The SDA is paid as a contribution to the extra costs of studying some disabled students face.

### 1.1 Background

DLA was introduced in April 1992 to replace AA and Mobility Allowance (Mob A) for people under 65 years of age when they claim help with their disability-related extra costs. DLA consists of two components – a care component (which is paid at one of three rates, depending on the extent of a disabled person’s need for attention, supervision or watching over by another person) and a mobility component (which is paid at one of two rates, depending on the extent of a disabled person’s mobility difficulties). AA, which was introduced in December 1971 is available to people aged 65 and over when they claim help with their disability-related extra costs. It is paid at one of two rates, depending on the extent of a disabled person’s need for attention, supervision or watching over by another person, and does not have a mobility component. The personal care and (for DLA) mobility criteria are proxies. The use of care and mobility criteria as proxies is based on the assumption (supported by Martin and White 1988) that personal care needs and mobility difficulties are likely to incur the highest disability-related extra costs, and therefore people with these needs or difficulties need these benefits most. Berthoud (1998) believes DLA and AA rates were informed by Martin and White (1988) and the DIG (1988) study. There is evidence from some studies to suggest that people with mobility and care needs are likely to face the highest costs. However, there is also more recent evidence that suggests other factors, such as income, household composition or location (Zaidi and Burchardt 2003, Smith et al., 2004, Kestenbaum 1999), also have a large effect on the level of extra costs. Recipients of DLA and AA are not required to use them for personal care or mobility related extra costs and are free to spend them as they wish.
It is important to note that although the aim of DLA and AA is to make a contribution to people’s disability-related extra costs and not to meet all these costs, the majority of studies reviewed in this paper discuss the extent to which DLA and AA do (not) meet these costs. In some cases, the authors’ (explicit or implicit) opinion is that DLA and AA should meet all of people’s disability-related extra costs.

There are two options for assessment of claims for extra costs benefits (Berthoud 1998):

- assess each case and the costs individually and make an individual award for each case;
- identify groups of people with impairments or disabilities judged to be of the sort to impose additional costs and pay fixed rates (as opposed to amounts calculated for each individual) on the basis of this.

DLA and AA take the second approach by paying fixed rates for groups of individuals that are assumed to have costs arising from disability (those with mobility and/or care needs). If it is assumed that DLA and AA should cover extra costs either completely, or to a specified extent, accurate average costs must be calculated/measured. If the first approach (making individual assessments and payments) is adopted, average extra costs are not required, though accurate individual assessments are.

1.2 Classification of types of need/cost

Extra costs arise from the extra needs that disabled people have, and therefore the two are closely related. Before discussing what affects extra costs it is useful to examine the range of different needs and costs that exist. This is necessary here for the sake of clarity, as the results of the studies included in this review use the following classification of costs.

Needs and costs can both be classified as:

- Special – goods and services which disabled people need but non-disabled people don’t (for example, an assistant or medication).
- Additional – items everyone needs but disabled people need more of (e.g. washing powder or heating).

NB. Large (1991) calls these ‘disability-created’ and ‘disability-enhanced’ costs.

Costs can also be:

- One-off – something that only needs to be bought once, for example, a lift in a building, though maintenance of this would be recurrent.
- Recurrent – for example, washing powder or an assistant.

Martin and White (1988)
In addition, needs and costs may also be:

- **Extra** – disabled people need to spend more than non-disabled people on special and/or additional needs.

- **Reduced** – though this may be less likely it is possible that disabled people do not need to spend as much as non-disabled people on some things.

Costs may also be:

- **Direct** – expenditure required to meet a need arising from the disability, for example, costs of medication or care.

- **Indirect** – a reduction in financial wealth or wellbeing (in comparison to a non-disabled person) resulting from the disability, for example, being out of work or on a lower income than a non-disabled person. DLA and AA are not intended to cover these costs, though other benefits (such as IB) or compensation through the courts may.

Finally, costs may be:

- **Potential** – the cost of completely meeting all of a person’s disability-related needs. Associated with this concept is the problem of defining what someone’s needs are; some kind of threshold is necessarily imposed. Notions of need are subjective, and are likely to vary between individuals and over time.

- **Realised** – what an individual (or household) actually spends on meeting disability-related needs.

This distinction raises the issue of the income constraint disabled people face. Unless they go into debt, disabled people have to reconcile expenditure with income. Disabled people also have needs that are not related to their disability. Spending on these non-disability related needs may have to be reduced to allow expenditure on disability related needs. Because of the budgetary constraint individuals face, estimates of potential extra costs may be higher than those of realised extra costs.

Studies vary in terms of how they deal with the budget constraint. Some methodologies (such as the comparative, and standard of living approaches) take non-disability related needs into account, while others (such as the subjective approach) do not. Some approaches are also more grounded in need, for example, the subjective and budget standards approaches, while the comparative and standard of living approaches examine differences in the allocation of resources.

There is no single definition of extra cost generally adopted within the literature, as is made clear below. Some seek to measure realised extra costs, others potential costs. Other studies attempt to measure neither, instead comparing material deprivation experienced by disabled and non-disabled people or comparing their spending patterns.
One further general problem is the fact that there are a variety of definitions of disability that have been used by these studies. This will affect who is included, and the average figures (where calculated). Where severity has been measured, there is also variation in how this was assessed, which has the same effect as above.
2 Different methodological approaches to measuring costs

Within the existing literature there are four different approaches to measuring the extra costs of disability. These different approaches have not superseded one another, rather they have developed in tandem – in fact Martin and White (1988) and Matthews and Truscott’s (1990) FES-based work deliberately used different approaches (subjective and comparative respectively) in an attempt to validate the results of each other. These approaches differ in terms of attempting to measure disabled people’s needs, and the costs of meeting these, or examining actual expenditure, and allocation of resources.

2.1 Description of studies’ approaches and methodologies

Details of the methodologies of the studies looked at by this review are included here, grouped into the four broad approaches that have been adopted.

2.1.1 Studies using the subjective approach

Studies using this approach ask disabled people (or experts) to estimate what their additional expenditure is or would be (if they were to meet their needs to an extent) and on what items. Estimates of extra costs are then derived from respondent’s answers. Estimates based on what people actually spend are likely to be underestimates of what full costs actually are (as people are constrained by their income and have to balance their budget between disability related and non-disability related expenditure).

The key strength of the subjective approach is that disabled people themselves usually provide the estimates of increased spending. Depending on how the questions are asked, it is possible, within this approach, to partially compensate for the income constraint that inhibits the accuracy of the comparative method. For
example, respondents can be asked about what they would need to spend to meet their needs, whereas the comparative method can only ever ask about what respondents actually spend, when they are constrained by their income. This is done through asking disabled people what they would need to spend on additional or special needs. This approach does however, suffer from the fact that it is difficult for respondents to estimate what they would spend on items that everyone buys if they were not disabled. Studies that adopt this approach are therefore likely to produce more accurate estimates of spending on items purchased only by disabled people (or only needed because of disability), known as special costs. The version of this approach taken by Martin and White (1988) in the Office of Population, Censuses and Surveys (OPCS) surveys of disability is also restricted by the income constraint as respondents were estimating what they actually spent rather than what would spend.


**Martin and White (1988):** This study involved a survey of 10,000 disabled adults in private households, who were asked a module of questions relating to expenditure as part of the OPCS survey of disability, conducted in 1985.

**Disablement Income Group (1988)** This study was commissioned by the Disablement Income Group, a pressure group, and was a telephone survey of 87 people, a third of whom were receiving payments from the Independent Living Fund and two-thirds who replied to an offer of further information following a Channel 4 programme about the rights of disabled people to supplementary benefits. Large (1991, p110) describes the sample Thus: ‘All of these people had shown an interest in disability benefits and were struggling to match their income with their expenditure’ and indeed this could be considered an advantage in that respondents are likely to have given more thought to extra costs prior to the interview than respondents to the OPCS survey.

This study is generally not highly regarded in terms of methodology by authors of other texts cited here and is not mentioned in any great detail other than by Large (1991) who heavily advocates the study.

Woolley (2004) attempted to measure both realised and potential extra costs faced by families with disabled children. However, the sample is small (98 families), and biased (being drawn entirely from the Family Fund’s database). Therefore, its findings are not included here.

Matthews and Truscott (1990), referring specifically to Martin and White (1988) say that when producing an average figure for extra costs/spending on a particular group of items/services, disabled people who did not report additional spending were assumed to have the same spending as non-disabled people. In fact, at least some of them may have had reduced spending, which will affect the accuracy of the estimates of extra costs.
Large (1991), who supports the findings of the DIG survey, heavily criticises the methodology of the OPCS survey, believing that the way in which the questions were asked were bound to produce unrealistically low estimates of extra costs and that relative to the whole survey, the section on costs was too short. Large also believes that the OPCS used a low threshold of disability and therefore included a lot of people ‘whom few could pretend were disabled’ (p108), which would have the effect of lowering the average estimated cost for all disabled people.

Berthoud (1991, P69) on the other hand says that the OPCS survey ‘beats all its rivals out of sight for the size, accuracy and representativeness of its sample. Its questions are well-framed and neutral’. However, Berthoud also suggests that the people being interviewed would not have thought precisely about these questions beforehand and that a series of expenditure questions in the middle of a large survey may not have given respondents enough time to think about the answers and might have resulted in conservative estimates of costs. Putting the same point more strongly, Large (1991) suggests that the DIG study was stronger than the OPCS survey as those interviewed would have been more aware of their expenditure than those in the OPCS study.

The OPCS surveys (Martin and White 1988) may also be hampered by the fact that when people were unable to provide an estimate, an average of other people’s estimates was substituted for theirs. Overall, around 40 per cent of the sample could not provide an estimate for at least one item, and therefore had at least one average substituted (p36).

2.1.2 Studies using the comparative approach

This approach compares the spending patterns of disabled people with those of ‘similar’ non-disabled people. Studies ask both populations about how much they spend on individual items and the differences show where disabled and non-disabled people’s priorities differ.

The two studies that have adopted the comparative approach are Matthews and Truscott (1990) and Jones and O’Donnell (1995). Matthews and Truscott (1990) is focused on here as it was intended to complement Martin and White (1988). These studies controlled for income but did not make any attempt to produce overall estimates of extra costs, instead confining themselves to comparing differences in the spending of disabled and non-disabled people on particular items/areas. One strength of the comparative approach is that by measuring what people actually spend on goods and services, rather than asking them how much they additionally spend, the accuracy of the data may be increased. It is also likely that accidental or deliberate (for example, due to perceived social acceptability) inaccurate reporting of extra costs would be decreased by this method, as respondents are asked to record how much they spend in total on items rather than how much extra. This method also overcomes the problem inherent in the subjective method of the respondent having to estimate how much they would spend if they were not disabled.
However, the comparative approach is always hampered by the budgetary constraints of respondents, as discussed above, as there is no option to measure how much respondents would spend if income were no object. This means the approach cannot measure what the potential costs of disability are.

Matthews and Truscott (1990) used the comparative approach by conducting a follow-up to the Family Expenditure Survey (FES), (now the Expenditure and Food Survey (EFS)) asking about disability, using disability measurement questions based on the OPCS survey. The study recognises that measuring expenditure is not the same as measuring cost and that comparisons of expenditure produced by this method are hampered by the budgetary constraints disabled people are subject to. This study cannot produce a meaningful estimate of total extra expenditure as it had to compare households with the same total expenditure, rather than income, as it is a better indicator of purchasing power. Therefore the study could only examine differences in expenditure patterns, not overall expenditure. The study used data from the FES in the form of expenditure diaries that covered two weeks, which limits use at a very detailed level due to the possibility for those two weeks to be atypical (and the sample was too small to completely avoid this problem). Including only those who were disabled from the FES sample also meant that the sample for this survey was relatively small (Berthoud 1991). Matthews and Truscott’s study is also hampered by the fact that the FES collects data on expenditure for households rather than individuals. Therefore, extra spending on some items on behalf of an individual may be masked by reduced spending by the household on other items within the same group and will reflect increased spending on, for example, tobacco by carers (who may be parents of disabled children) (Berthoud 1991). This is illustrated by the fact that even in households where the disabled member was a child, there was increased spending on tobacco.

Martin and White (1988) also believe there are problems with the comparative approach around how to control for other factors. For example, should households where one member is unemployed because of disability be compared to non-disabled households where one individual is unemployed for a different reason or would this be an unfair comparison (it may, of course, depend on the reason for the disabled person being unable to work, for example, as a direct result of the disability or because of inflexible employment practices)? There may also be problems when trying to compare pensioner households as the proportion of people who are disabled increases with age and it may be difficult to find households with no disabled members to act as the control.

Matthews and Truscott (1990) compared estimates of extra costs produced by subjective and comparative methods. The authors stated that the subjective method does not include those who spend less than non-disabled people while the comparative method does, which may lower estimates produced by the comparative method through masking over-spenders in the average. As Matthews and Truscott’s study included those with reduced spending they believe that the estimates of extra costs it produced may represent the minimum additional spending necessary,
though there is no reason to assume that the lower average produced by including reduced costs has any relationship to minimum spending.

### 2.1.3 Studies using the standard of living approach

The standard of living approach was used first by Berthoud, Lakey and McKay in 1993 and then ten years later by Zaidi and Burchardt (2003). The standard of living approach is based on the assumption that disabled people experience a lower standard of living than non-disabled people with the same income, because of diversion of money resources to goods and services required because of their disability. A range of indicators of standard of living (unrelated to disability) is used and disabled and non-disabled people’s standard of living at the same income is compared. For a given standard of living it is possible to compare what incomes disabled and non-disabled people have, the difference being the extra costs incurred by disability. In this section, Zaidi and Burchardt (2003) will be focused on as it is the most recent and builds on Berthoud, Lakey and McKay (1993).

Zaidi and Burchardt’s (2003) study (and the standard of living approach in general) addresses many of the problems suffered by other studies. This study uses data from the Family Resources Survey (FRS) (1997 disability follow-up) and British Household Panel Study (BHPS) to look at standard of living (assessed by measuring ownership of various goods – see Table 2.1) and how this varies with disability for people with the same income.

#### Table 2.1 Standard of living indicators used by Zaidi and Burchardt (2003)

<table>
<thead>
<tr>
<th>Items included in composite measure of standard of living for non-pensioners</th>
<th>Items included in composite measure of standard of living for pensioners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Video Player</td>
<td>Video Player</td>
</tr>
<tr>
<td>Tumble Dryer</td>
<td>Tumble Dryer</td>
</tr>
<tr>
<td>Dishwasher</td>
<td>Dishwasher</td>
</tr>
<tr>
<td>CD Player</td>
<td>CD Player</td>
</tr>
<tr>
<td>Access to a motor vehicle</td>
<td>Access to a motor vehicle</td>
</tr>
<tr>
<td>Microwave</td>
<td>Satellite TV</td>
</tr>
<tr>
<td>Mobile Telephone</td>
<td></td>
</tr>
<tr>
<td>Washing Machine</td>
<td></td>
</tr>
<tr>
<td>Home Computer</td>
<td></td>
</tr>
</tbody>
</table>

The study has limitations in that it didn’t look at disabled children or households with three or more people, though these are for sound methodological reasons. For some estimates, for example, single pensioners and couples where only one person is disabled the estimates from the FRS and the BHPS are ‘reassuringly similar’, which suggests this method is at least reliable (will produce similar results), even if not valid (actually measuring what you intend to measure). It is worth bearing in mind when considering the results of this study that the standard of living approach does not explicitly measure extra costs but rather attempts to produce equivalence scales for
disability. Equivalence scales show, in this case, how much greater disabled people’s incomes must be to attain the same standard of living as non-disabled people. Because of this it is dependent on the items included in the composite measure of standard of living and it is possible that households purchase these items at the expense of disability-related items or services. However, it has been argued that the actual indicators chosen do not greatly affect the outcome of the study. For example, households may feel that owning a personal computer is more important than some disability-related expenditure and therefore the standard of living approach is essentially measuring how households choose to budget, as does the comparative approach, and variants of the subjective approach that measure what people actually spend.

2.1.4 Studies using the budget standards approach

The budget standards approach has been developed by the Centre for Research in Social Policy (CRSP). It is similar to the subjective approach, in that disabled people are asked directly to state what their needs are. However, respondents do not answer in terms of expenditure required. Instead, focus groups develop an exhaustive list of items required for a reasonable standard of living (Smith et al. 2004). It is therefore similar to the subjective approach (when measuring potential extra costs), as disabled people are stating what they need. In contrast to the standard of living approach, the budget standards method measures disability related needs, although only one standard (‘Reasonable’) is used. It does not measure extra costs, instead presenting the income needed to achieve a certain standard of living.

Smith et al. (2004): This study developed minimum budgets for fictional (case study) disabled people in five different circumstances. These are:

- high-medium needs;
- low-medium needs;
- fluctuating needs;
- visual impairment;
- hearing impairment.

For each of these circumstances disabled people living in similar circumstances to each other (and those of the fictional ‘case study’ individual) participated in three focus groups (different people took part in each – 78 people in all):

- an orientation group to devise the details of a fictional ‘case study’ individual for use in later groups;
- a task group to negotiate and agree lists of minimum essential items in each area of the budget for the case study individual;
- a check-back group to resolve outstanding issues and make any amendments to the lists they felt necessary (intended to strengthen consensus).
The element of negotiation and agreement was designed to reduce the effect of personal perceptions of minimum need. The report states that there was strong agreement between the task groups and the check-back groups.

The agreed lists of minimum essential items were costed (after the focus groups had taken place) using prices at major retailers. These costed budgets were compared with figures for average expenditure of all one-person households from the EFS. Findings of the comparison with the EFS have not been given here, as they compare estimates of minimum budgets (potential costs) with actual expenditure (realised costs).

On average, focus groups consisted of five respondents, with a mix of ages, income, household circumstances, work history and experience of disability. In total, 78 disabled people took part in the research.

Dobson and Middleton (1998): This study did not aim to measure what people actually spent but instead asked a panel of parents (from 300 families drawn from the Family Fund Trust database) to produce an estimate of the minimum essential budgets for severely disabled children. Thirty-six focus groups were held with the parents, who were included in the study if their child had either restrictions in movement, sensory impairment or a traumatic or intermittent condition.

Problems associated with the budget standards approach are:

- thus far, studies have not developed ‘control’ budget standards for non-disabled people. Therefore, it is not known how the needs identified in the focus groups would differ from those of non-disabled people. Comparing minimum budgets required with average expenditure of all households does not provide an adequate control, as there is no reason to believe that average expenditure is that required to adequately meet non-disabled people’s needs;

- the standard of living required is not well defined, and is open to interpretation.

The budget standards developed do not adequately take account of services provided by the state, and assume that all items and services must be purchased by the individual.
3 Findings of the studies

3.1 Estimates of total extra costs

Although it is difficult to directly compare the results of the various approaches (and studies within the approaches), as will be noted later, Table 3.1 attempts to give an overview of the estimates produced.

Table 3.1 Estimates of overall extra costs

<table>
<thead>
<tr>
<th>Study</th>
<th>Estimate of overall extra costs</th>
<th>Variable(s) by which estimates are broken down</th>
</tr>
</thead>
<tbody>
<tr>
<td>Martin and White (1988)</td>
<td>Range from £7.24 to £20.59 a week</td>
<td>Severity level</td>
</tr>
<tr>
<td>Disablement Income Group (1988)</td>
<td>£81.06 a week (at 2001 prices – from Zaidi and Burchardt 2003)</td>
<td>None</td>
</tr>
<tr>
<td>Dobson and Middleton (1998)</td>
<td>£99.15 a week for a disabled child but budget standards estimate minimum budgets to be £117.95 to £170.68 a week</td>
<td>Age group and type of impairment</td>
</tr>
<tr>
<td>Matthews and Truscott (1990)</td>
<td>No overall costs – instead study produced estimates of differences in spending on particular items</td>
<td></td>
</tr>
<tr>
<td>Jones and O’Donnell (1995)</td>
<td>No overall costs – instead study produced estimates of differences in spending on particular items</td>
<td></td>
</tr>
<tr>
<td>Phillips (1993)</td>
<td>Estimated the cost of a package of care for a severely disabled person at £250 a week</td>
<td></td>
</tr>
<tr>
<td>Zaidi and Burchardt (2003)</td>
<td>Between 11 per cent and 69 per cent of income</td>
<td>Severity level and household type</td>
</tr>
<tr>
<td>Smith et al (2004)</td>
<td>Range from around £389 to around £1,513 a week</td>
<td>Level of need / Type of impairment</td>
</tr>
</tbody>
</table>
Zaidi and Burchardt (2003) produced a table that shows the ‘implied range of extra costs’ that DWP uses, based on comparing the ‘social assistance’ and extra costs benefits that were available (in 2001) to non-disabled and disabled people.

**Table 3.2  ‘Implied range of extra costs that DWP uses’ from Zaidi and Burchardt (2003)**

<table>
<thead>
<tr>
<th></th>
<th>Non-disabled per week</th>
<th></th>
<th>Disabled minimum per week</th>
<th></th>
<th>Disabled maximum per week</th>
<th></th>
<th>Implied range of extra costs per week</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Single person aged 24-59/64</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social assistance</td>
<td>53.95</td>
<td></td>
<td>91.85</td>
<td></td>
<td>191.05</td>
<td></td>
<td>37.90 to 137.10</td>
</tr>
<tr>
<td>Extra costs benefits only</td>
<td>0</td>
<td></td>
<td>14.90</td>
<td></td>
<td>95.55</td>
<td></td>
<td>14.90 to 95.55</td>
</tr>
<tr>
<td><strong>Single person over State Pension Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social assistance</td>
<td>98.15</td>
<td></td>
<td>135.80</td>
<td></td>
<td>195.95</td>
<td></td>
<td>37.65 to 97.80</td>
</tr>
<tr>
<td>Extra costs benefits only</td>
<td>0</td>
<td></td>
<td>37.65</td>
<td></td>
<td>56.25</td>
<td></td>
<td>37.65 to 56.25</td>
</tr>
</tbody>
</table>

Appendix A contains further details of the estimates of overall extra costs and extra costs for specific items produced by the studies reviewed.

3.2  The extent to which estimates produced by the studies are similar

It is difficult to directly compare estimates of extra costs on specific items/groups of items, as few of the studies break down expenditure into the same groups, which demonstrates the lack of a coherent approach to the measurement of extra costs. It is therefore difficult to examine the degree of convergence or divergence between estimates produced by the studies. Differences between the three approaches also increase the difficulty of comparing estimates from different studies.

Some areas where studies disagree or agree with each other have been noted in Appendix A and can be seen in the section on findings of the studies, above. Even a cursory examination of the figures produced by the studies for total extra costs shows that there is little in the way of agreement on the issue of overall costs. Estimates vary widely (even allowing for inflation, where this has not been taken into account in the figures quoted), though this is in part due to the fact that estimates are often for different definitions of household composition, types of impairment and severity level. This makes it very difficult to judge whether the disagreement is as wide as it first appears.
However, though there is much difference between estimates, both for total extra costs and within categories, most of the studies find that disabled people are likely to have additional expenditure on some goods or services as a result of their disability which in turn means they experience a lower standard of living than a non-disabled person with the same income.

Matthews and Truscott’s (1990) Study pointed out various items or groups of items where the OPCS’s subjective findings said disabled people spent more, but where the comparative findings showed decreased spending. Zaidi and Burchardt’s (2003) study produced estimates that were higher than those produced by Berthoud (from 1985 data) but Zaidi and Burchardt (2003) believe that this may not mean one of the studies is wrong; Costs may have risen due to the increasing availability of aids and assistance that have to be paid for and also the general difference in costs from the lowest to the highest level of severity is about the same in both studies (an eight-fold increase from lowest to highest). Berthoud (1991) also says that differences between the estimates the DIG and the OPCS surveys (Martin and White 1988) produced are not only down to the (substantial) differences between the samples. Re-analysis showed that if the OPCS sample was made to match the DIG sample profile they would still produce estimates of £12.80 per week and £50 per week respectively.

On the other hand, Berthoud (1991) believes that expenditure analysis carried out by Hyman (1977) that looked specifically at families with children who were in the highest severity categories produced figures similar to those produced by the OPCS study for similarly disabled children.
4 What drives costs (and variation in costs)?

From the evidence on additional costs it is clear that costs may vary between individuals with a number of variables. These are discussed under sub-headings below:

4.1 Impairment type

Martin and White (1988) found that the amount of extra costs a person had varied according to impairment type. They found that the impairments most associated with higher expenditure were impairments associated with locomotion; eating, drinking and digestion; and personal care. Hearing, communication and consciousness impairments were the disabilities that incurred the lowest extra expenditure (Table 4.1 shows the ranking of disabilities in terms of additional expenditure caused the study produced).

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Digestion</td>
<td></td>
</tr>
<tr>
<td>Locomotion</td>
<td></td>
</tr>
<tr>
<td>Disfigurement*</td>
<td></td>
</tr>
<tr>
<td>Personal care</td>
<td></td>
</tr>
<tr>
<td>Behaviour</td>
<td></td>
</tr>
<tr>
<td>Continence</td>
<td></td>
</tr>
<tr>
<td>Reaching and stretching</td>
<td></td>
</tr>
<tr>
<td>Dexterity</td>
<td></td>
</tr>
<tr>
<td>Consciousness</td>
<td></td>
</tr>
<tr>
<td>Seeing</td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
</tr>
<tr>
<td>Intellectual functioning</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
</tr>
</tbody>
</table>

* “Disfigurement” may include people with very severe disfigurements, for example, amputees.
The study also found that most disabilities cause higher costs for additional rather than special items, but that three did not follow this rule; seeing, personal care and continence disabilities all incurred higher special costs than additional costs.

Zaidi and Burchardt (2003) found that for non-pensioners, those with impairments associated with locomotion, limited independence, mental health problems and difficulties in reaching or dexterity have significantly higher costs than others. To some extent, these findings agree with Martin and White’s (1988); both studies found that locomotion impairments incur high levels of cost. However, the findings of the two studies are by no means a perfect match.

Dobson and Middleton (1998) found that costs vary by type of disability but not by a great deal. For example, all severely disabled children need extra clothes and bedding, money for trips to hospital, extra possessions and activities to enable them to develop their potential. Most also need equipment to make the child’s and the parent’s life possible within a normal home environment, which requires additional expenditure.

### 4.2 Severity of impairment

Martin and White (1988) found that additional costs increased with severity level and increased with severity level at a faster rate at higher incomes. They also found that within categories of items, expenditure on special items was not related to severity, but when expenditure on special items was taken overall, there was a relationship with severity. In addition, Martin and White (1988) found that within income bands, as severity increases, so does the likelihood of having regular disability-related expenditure. When actual figures of costs were examined, the increase in expenditure with severity was found to be steeper at higher income levels.

Zaidi and Burchardt (2003) believe that extra costs are a percentage of income for each point in a severity scale running from 0 (no impairment) to 22 (most severe impairment). For example, the extra costs a single non-pensioner faces are estimated to be 4.6 per cent of their income for each point on the severity scale. Thus someone in this situation with an income of £170 a week and an impairment with a score of three is estimated to have extra costs of £23 a week, while someone with an impairment with a score of 17 is estimated to have extra costs of £133 per week.

In contrast to this, Matthews and Truscott (1990) found that severity did not affect spending, other than on tobacco, health and domestic services.

Dobson and Middleton (1998) also found that, perhaps unsurprisingly, extra costs vary for those with episodic conditions (being lower when the condition is not so severe).
4.3 Household composition

Martin and White (1988) found that, as a proportion of household disposable income, extra costs decrease with increasing income, and that the more earners a household has the lower the proportion of income that is diverted to covering the extra costs incurred because of disability. Zaidi and Burchardt (2003) disagree with Martin and White on this issue, believing instead that extra costs are a proportion of income regardless of income level.

Martin and White also found that the difference in actual amount of money costs for disabled and non-disabled pensioners is smaller than the differences between non-disabled and disabled non-pensioners, though this may be due at least in part to the average lower incomes of pensioners.

Zaidi and Burchardt (2003) present the idea that it costs more for a single person than a couple with one non-disabled person and where both are disabled, as they may be able to share some equipment (though this may depend on them both having a similar need, or impairment). Household composition is one of the key factors Zaidi and Burchardt believe influences the amount of extra costs.

4.4 Income

Income affects extra costs in two ways. Firstly, most studies have found that extra costs increase with income. Secondly, disabled people of working age tend to have lower incomes than non-disabled people, as they are less likely to be in work (and have lower average wages than non-disabled people (DRC 2005)). This is, in itself, an element of the extra cost (in the wider sense) of being disabled, as it is presumed that disabled people’s incomes are lower because of their disability. The fact that working age disabled people generally have lower incomes also means that some estimates of extra costs may be based on incomes that are lower to begin with and therefore are likely to be under-estimates as costs increase with income.

4.4.1 The relationship between extra costs and income

Martin and White (1988) found that additional costs increased with income. People with higher disposable incomes were more likely to have regular disability-related expenditure and to spend more than those in lower income groups. Within severity bands, the proportions of people with extra costs rise with income, although the rise is more significant at lower than higher income levels. As stated above, as income increases, so does the rate at which costs increase with severity – essentially, the higher the disposable income, the steeper the slope of a graph showing how costs increase with severity.

Matthews and Truscott (1990) found that the items disabled people spent more on varied with income; those with higher incomes spent more on durables and clothing while those with lower incomes did not. This study also found that spending on ‘luxury’ items (those on which spending increases with income) such as gadgets,
aids and appliances related to disability increased dramatically with income. For other ‘luxury’ items such as clothing and alcohol, spending by disabled people rises with income but at a slower rate than that of non-disabled people, showing that the underspend by disabled people on these items increases with income.

Zaidi and Burchardt (2003) developed equivalence scales for disability. These show the access to goods and services disabled and non-disabled people have at the same incomes. The difference between the incomes at which disabled and non-disabled people achieve the same level of access could be interpreted as the extra cost of disability. This difference was found to be a proportion of income, rather than a single cash figure, the actual proportion depending on circumstances (for example, household composition and severity of impairment). Thus, Zaidi and Burchardt’s (2003) findings suggest income is a key factor in determining how much (in cash figures), extra costs are.

All the studies reviewed in this paper, regardless of which approach they adopt, estimate the extra costs incurred as a result of disability, such as additional heating, laundry and transport costs or special equipment. However, the opportunity cost of ill health and disability (ie loss of personal earnings, or earnings foregone by friends and relatives providing unpaid care) is not included (Berthoud et al. 1993).

### 4.4.2 Disabled people’s incomes

HBAI (Households Below Average Income) 2002/03 data shows that households with one or more disabled adult or child are more likely to be in the bottom two quintiles of the income distribution – over half of families with one or more disabled member are in the bottom two quintiles of the income distribution. Even these figures may be overstating disabled people’s income as these are generally taken to include income from benefits such as extra costs benefits, but do not take account of the extra costs themselves (Zaidi and Burchardt 2003), which is acknowledged in the HBAI publications. Some (for example, Burchardt 2000) have suggested that if income is to be used to compare the standard of living of disabled and non-disabled people, extra costs need to be taken into account. If this is done, in 1996/97, disabled people’s mean income was 62 per cent of the general population average (Burchardt 2000). Martin and White (1988) also found that equivalent incomes when extra costs are taken into account showed that disabled people are even more likely to be in the lower income deciles. (p63). The study also included some analysis of the financial problems households with a disabled member reported experiencing. This found that the number of problems experienced by households decreased as equivalent income or equivalent resources increase.

According to Burchardt (2003), when people become disabled, by equivalising their income fully for disability, it can be shown that 41 per cent of those who were not in poverty to begin with enter poverty and of those initially in poverty 86 per cent remain in poverty.
Martin and White (1988) found that for disabled non-pensioners in severity categories 1 and 2 (lower – end of severity) earnings formed 56 per cent of their income while benefits formed 30 per cent (on average) while for those in severity categories 9 and 10 the position was almost reversed – 35 per cent from earnings and 55 per cent from benefits. Benefits do not generally bring household income up to the same level as a household containing wage earners. Therefore, the income of households containing disabled people are generally lower than those of equivalent non-disabled households, though not necessarily lower than other non-earning households, such as those where everyone is unemployed. The study also found that disabled people who were employed (and there is a far lower employment rate for disabled people – 51 per cent of disabled people are employed compared to 81 per cent of non-disabled people (DRC 2005)) were likely to be earning significantly less than their non-disabled counterparts in almost all circumstances. There was also some tentative evidence that wages decreased as severity of disability increased. Martin and White also thought that, for people over state pension age, the main source of income was the state pension; therefore incomes for this group would be subject to less variation than for those of working age. This may not be as true today as it was then, as private pensions now make up an increasing proportion of income for pensioners.

Burchardt (2000) also says that in 1985 and 1996/97 (the years for which survey data the study used is available) people with severity scores at the higher and lower ends of the scale had higher income than those in the middle. Basically, income falls from the lower categories to categories 7 and 8. One exception to the rule that income falls as severity increases are people in categories 9 and 10, who have slightly higher average incomes, due in part to their greater eligibility for extra-costs benefits such as DLA.

4.5 Geographical location

Although few of the studies specifically mention geographical location as a factor that causes variation in extra costs, there is a case for its inclusion here:

- the provision of free/subsidised services (either statutory or voluntary), is likely to vary according to area (Smith et al 2004);

- income, and the likelihood of being able to find paid employment, for example, is also likely to vary with geographical location;

- there are also other effects of location that may influence the cost of being disabled. For example, two people with the same mobility impairment, one living in a rural area and one in an urban area, may incur different levels of cost for private transport, if public transport is inaccessible.
4.6 Services

Another factor that influences the extra costs incurred because of disability is the level to which people’s needs are met through free or subsidised services, which may be provided by statutory or voluntary organisations. There is a general agreement that there is a lack of standardisation of local authority (LA) provision, and charges for assistance (Kestenbaum 1999, Smith et al. 2004).

Costs have increased since the mid 1980s because of the increase in available aids etc. that still have to be paid for and increasingly widespread charges for social services. Costs may have risen faster than inflation for two reasons. The first is that wages rise faster than prices, which will impact on the cost of personal assistance, and the second is that charging for LA social services is more commonplace now (in 1985 the only common LA charge was for meals on wheels – now 94 per cent of LAs also charge for other home care services) (Audit Commission 2000). These charges vary widely so it is difficult to make a meaningful average. Burchardt (2000) says that 12 per cent of expenditure on home care services is now recouped by LAs through charging, compared with seven per cent in 1984/85. Howard (2002) says that the two main systems of providing support (Independent Living Fund (ILF) and LA social services) have a history of expecting users to make some contribution for the services or cash they receive. For most of its existence ILF has taken into account the care component of Disability Living Allowance (DLA), at the time of writing the ILF took half of this as a contribution, and all of the Severe Disability Premium. LAs have discretion about whether or not to charge for services, but this has become more widespread as a result of budgetary pressures and many have also introduced tighter eligibility criteria for their services. By 2000, only six per cent of councils were not charging for services (except meals), the rest work out charges by a mixture of flat rate, and variable rates linked to either means tests, amount of use of the service or both.

Costs of care may also arise from loss of earnings for family members caring for the disabled person if they have to give up work or reduce their hours.

4.7 The relative importance of these factors

Martin and White used multiple regression and found that severity and type of disability only cause extra costs to vary by about 15 per cent, so there must be some other cause of the rest of the variation. They tested income and family type, but these account for only a small part of the remaining variation, leading the authors to conclude that factors other than those measured by the survey must account for the rest of the variation. The study concluded that extra costs cannot be predicted on the basis of severity and type of impairment alone.

Dobson and Cox (2003) found that level of need is more important in determining disabled people’s costs, than type of impairment.
5 Why is it difficult to measure/estimate costs

5.1 Measuring realised or potential extra costs

It is very difficult to measure and estimate the extra costs of disability. One issue to consider is that many studies (all of those using the comparative approach, some of those using the subjective approach and all so far that have used the standard of living approach) ask people what they actually spend (i.e. realised extra costs) which is not necessarily what they would spend (potential extra costs) if they had sufficient resources. This is because spending is limited by someone’s (or a household’s) income and affected by their budgetary preferences/decisions. Disabled people may not have sufficient income to pay for the additional things they would need to enjoy the same standard of living that a non-disabled person with the same income (excluding extra costs benefits) would have.

In addition, meeting disability-related needs means reducing expenditure to meet non-disability-related needs (discounting for a moment the effect of extra costs benefits). People on lower incomes particularly are unlikely to be able to cut back enough on non-disability related expenditure to fully cover the potential costs of their disability, as there is a minimum expenditure on some items everyone needs simply to survive. It is assumed that disabled people with extra costs will strike a balance (at a point they deem the ‘best’ for them or their household) between expenditure on disability-related and non disability-related items; in practice the decision is on how far to reduce expenditure on non disability-related items. Therefore, measuring what disabled people’s actual ‘extra’ expenditure is will produce underestimates of what the costs of fully meeting a disabled person’s needs are.

On the other hand, studies that aim to measure what disabled people would spend (their potential extra costs), have their own methodological problems. Perhaps the most fundamental of these is the issue of the accuracy of reporting of expenditure (discussed in Section 5.2). There are also problems around how to define the level of
needs that must be met when measuring potential extra costs. For example, the budget standards approach used by Smith et al. (2004) sets the level at ‘reasonable’, or sufficient for disabled people to reach a ‘level playing field’ with non-disabled people. It is by no means certain that everyone participating interprets this in the same way. Unless the level to which needs must be met is explicit, there is a danger that figures will relate to the cost of fully meeting all needs. Such estimates would not take account of available resources, and are likely to be impractical for the purpose of setting benefit levels.

5.2 Imperfect knowledge

All studies which ask respondents about expenditure (either actual or potential) are subject to errors due to imperfect knowledge on the part of the respondent (for example, inaccurate recall of expenditure). However, asking someone to estimate what their expenditure would be in a hypothetical situation may be more subject to these sorts of errors than asking what someone actually spends at the present time. Matthews and Truscott (1988) say that there are three implicit assumptions made by studies asking respondents to estimate extra costs:

- that disabled people are correct in attributing their expenditure to disability and not another factor;
- that respondents have an accurate recall of their own spending;
- that respondents have an equally accurate knowledge of other ‘similar’ non-disabled people’s expenditure or what they would spend if they were not disabled.

It is quite obviously difficult for a respondent to know how much they spend at the present time, in addition to what a non-disabled person would, on everyday items; Martin and White (1988) accept that estimates for special expenditure will be more accurate than those for additional expenditure. It is likely to be even more difficult for respondents to estimate potential costs. Matthews and Truscott (1990) believe that respondents’ answers to studies using the subjective approach are very sensitive to the methods used and the level of probing by the interviewer. Studies using methods such as expenditure diaries may mitigate some of this potential error, but it is still very possible for diaries to be completed inaccurately. The question of what ‘similar’ people’s expenditure is considered to be is less of an issue in studies using the comparative approach as control groups make this explicit.

It is also very difficult to measure the relative effect of multiple disabilities on the amount of extra costs incurred. People with more than one disability will have to attempt to separate the effect of each on their expenditure (Martin and White 1988).
5.3 ‘Opportunity costs’

It could be suggested that a fourth assumption could be added to the three Matthews and Truscott (1990) identified (listed above). When comparing the expenditure of disabled and non-disabled people, it is assumed that disabled people would have a similar income and family circumstances if they were not disabled. It has been shown that disabled people are over-represented in the lower income brackets and are more likely to be out of work and have fewer qualifications. In addition, the studies that have been conducted thus far do not take account of differences in expenditure preferences between disabled and non-disabled people. For example, disabled people may be more likely to consume today rather than tomorrow as a result of a shorter life expectancy and may have different preferences or (dis)incentives to save. Therefore, estimates do not take account of the ‘opportunity costs’ (for example, loss of earnings) disabled people face.

5.4 Particular problems with the standard of living and budget standards approaches

The standard of living approach, to some extent, overcomes some of the problems associated with the subjective and comparative approaches. These problems have been discussed above, and some also apply to the standard of living approach. However, this approach also has some problems unique to itself. Therefore, the issues and problems associated with the standard of living approach are discussed separately here. These are:

- It assumes that people spend on their disability-related needs first and then on standard of living indicators (this is a deliberate over-simplification to illustrate the point being made), when in actual fact it is likely they will spend on both types of need simultaneously. This method does not measure the extent to which disability-related needs are met.

- Measuring how much more a disabled person has to receive to attain the same standard of living as a non-disabled person of the same income is in effect measuring realised extra costs rather than potential extra costs. In effect this method (like all measuring realised extra costs) is measuring how tightly people have to budget (and therefore is not revelatory in saying that people on lower incomes have to budget more tightly).

- The results (that those on higher incomes have greater extra costs) would seem to suggest that benefits should be ‘reverse means tested’ ie more money given to those on higher incomes – this is clearly not practical. This is not unique to the standard of living approach but is stated most strongly in studies adopting this approach.
- Giving households the amount of extra income they need to achieve the same standard of living as non-disabled households with the same initial income does not necessarily mean that the disability-related needs have been met – merely that they budget in the same way as people on slightly higher incomes. However, this would mean that (if the household’s budget priorities are similar to the average) the household’s non-disability related standard of living was the same as a household with no disabled members and the same initial income.

The budget standards approach also has some problems unique to itself (as well as sharing some with other approaches). These include:

- thus far, budget standards for non-disabled people in otherwise similar circumstances have not been developed. Therefore, there is no control group;
- budget standards have not adequately taken account of services provided free, or at a subsidised rate, by statutory or voluntary organisations.

5.5 Verification of results

The range of estimates of extra costs produced by the studies examined here means that it is very difficult to verify results from any (existing or future) study. Results of previous studies are so diverse that there is no ‘cluster’ of estimates to provide a ‘ballpark’ figure with which to compare results and therefore the fact that a new estimate is similar to a previous one may not provide sufficient verification of results. Previous studies also adopt a range of methodologies (within the different approaches) and use different categorisations of expenditure groups or areas of extra cost. In addition some studies produce actual estimates in pounds and pence, while others show extra costs as percentage of income. All of this makes it extremely difficult to compare the results of studies to each other. Under these circumstances, the only way to judge how far the results of a study are likely to be accurate is to examine the methodology and make a judgement on how sound this is; As has been shown here and through the critiques of the other methodologies by the studies, this is no simple task.

5.6 Reduced costs and locating the budget balance point

Most studies (and methodologies) do not take account of how disabled people’s expenditure may be reduced in non disability-related areas, in order to allow some extra costs to be met. Knowing where expenditure is reduced, as well as where it is increased will allow us to understand how people adjust their budget to allow for extra costs. The comparative approach would appear a good way to examine this. However, looking at expenditure patterns will not show the reasons people choose to place the balance between disability related and non disability related expenditure where they do. Nor will this method show to what extent people are meeting the potential extra costs of disability, which means that this method is more of a way of seeing how people budget than what extra costs are.
5.7 Household expenditure

Most methods which have been used to estimate extra costs have looked at extra costs incurred by households rather than individuals. Households’ spending will necessarily be influenced by the needs of other members of the household (in households that contain more than one person) and therefore additional expenditure due to disability may be masked by reduced spending by other members of the household on some items. For example, disabled people may spend more on clothes which means that the non-disabled members of the household spend less on clothes – looking at household spending wouldn’t show this – there is no evidence to suggest the extent to which this occurs.

5.8 Factors not measured in studies

There is a lot of variation in expenditure around the averages and so many factors that can influence the extra costs people have that are difficult to take account of/are not measured in surveys (for example, the provision of subsidised services) that average figures for estimates are probably not the best way to present extra costs (Martin and White 1988).
6 How are extra costs being met (or not)?

As mentioned above, the additional needs arising from disability may be met or unmet to a greater or lesser degree for each individual. It is unlikely that any disabled person has all or none of their needs met. Instead, someone with additional needs arising from disability is likely to have some of their needs met and some not met.

Disabled people’s needs may be met through:

- services provided free or at a subsidised rate by the state or voluntary sector. Services may not be provided completely free but the portion of the cost that is subsidised will fall into this category;

- personal expenditure on goods or services required. The contribution towards costs provided at a subsidised rate that the individual makes will be included in this category.

The second category (personal expenditure) will include the spending of additional income from benefits intended to compensate for the costs of disability (for example, Disability Living Allowance (DLA) and Attendance Allowance (AA), and disability premiums of means tested benefits for people on low incomes). Another element of this category is the possibility for personal expenditure on extra costs to be subsidised by reductions in non-disability related expenditure. Evidence from the studies conducted using the standard of living approach (e.g. Zaidi and Burchardt 2003) suggests that disabled people are diverting resources from non-disability expenditure (as measured by ownership or access to items in the standard of living indicator) in order to meet costs that it is assumed are incurred as a result of being disabled. Thus disabled people strike a balance between meeting the needs incurred by being disabled and the needs incurred by non-disabled people. As has been stated earlier, some costs will not be met, either by the state or the individual. Large (1991, p107) presents a ‘first law of the extra cost of disability’: ‘if you don’t have the income you can’t pay for the expense, and if you can’t pay for the expense, the cost is deprivation’.
Benefit income also makes up a higher percentage of disabled people’s income than it does non-disabled people’s, so the effect of benefits like DLA and AA on the ability to meet costs/needs is very important.

Some households will also go into debt (though this will be limited by a credit limit at some stage) to pay for the costs of disability. Dobson and Middleton (1998) found that parents fill the gap between the expenditure they see as necessary and what they actually have (budget) by going into debt, spending less on themselves and other family members and completely altering their lifestyles and aspirations.

6.1 What are DLA and AA being used for?

Research by Horton and Berthoud (1989) showed that very few claimants used AA to pay for personal support. However, even though the care component of DLA is a way of identifying those with needs rather than supposed to be spent on care, there is still a commonly held belief that it is ‘supposed’ to be spent on care, particularly among Local Authorities who commonly require it to be paid over as a contribution to the cost of their services (Berthoud 98). Grant (1994) also found that many disabled people are in debt for a range of reasons (often directly related to their disability) and can be in the situation of using their DLA to pay off debts. In a sense, the more important consideration than where DLA/AA is being spent is whether those receiving the benefits are better able to meet their extra needs.
7 Policy implications – how great a contribution do DLA and AA make to covering extra costs?

There is general agreement from the studies that Disability Living Allowance DLA and Attendance Allowance (AA) do not fully (or sufficiently) cover the costs arising from disability. However, as has been previously shown, these studies produce widely varying estimates of extra costs and therefore there are question marks over the accuracy of the evidence base. Several of the studies show the gap between what they estimate to be the extra costs of disability and what benefits are available, implying (and in some cases explicitly stating) that benefits should be increased in line with estimates of costs. For example, Dobson and Middleton (1998) say that benefits for severely disabled children would need to be increased by between 20 and 50 per cent to meet the costs of the minimum essential budgets.

However, Berthoud (1998) says that as no-one believed the Office of Population, Censuses and Surveys (OPCS) (too low) or DIG (too high) estimates of costs DLA was set somewhere in the middle and may be about right, though the rates are generous in comparison with other benefits. Berthoud (1998) also points out that the rate of AA or DLA care component wouldn’t cover the care needs a lot of people have. Burchardt (2003) believes that the match between DLA/AA and actual costs incurred is far from exact and implies that rates should be increased.

Zaidi and Burchardt (2003) believe that nine per cent of non-pensioners and 30 per cent of pensioners face extra costs and receive no extra costs benefits. Some of this gap may be because of the lack of a mobility component (in AA) for those who become disabled over 65. About one per cent of non pensioners and two per cent of pensioners have no extra costs but get extra costs benefits. There are also between four-six per cent of people who get benefits that cover more than 150 per cent of
their extra costs (Zaidi and Burchardt 2003). Their paper includes a table showing how, if estimated extra costs (as calculated by the paper) are taken into account, the percentage of disabled people experiencing poverty is raised significantly above the figures produced by methods used in Households Below Average Income (HBAI) analysis. The paper states that the poverty rate among the disabled population overall is 61 per cent – compared with 35 per cent from HBAI analysis. Burchardt (2003) estimates that extra costs benefits cover around 41-51 per cent of extra costs, depending how prices are adjusted for today.

The studies also identify some areas where there are serious gaps in the provision of benefits. For example, pensioners with limited independence and locomotion impairments also have high costs but AA does not have a mobility component. The ineligibility of children under five for the mobility component of DLA causes parents real financial difficulties (Dobson and Middleton 1998).

Some believe that the situation has improved since the mid 1980s through the expansion of extra costs benefits – around half of the extra costs for those with impairments in severity categories 7 or 8 may now be covered by extra costs benefits, compared to one-third in 1985. Berthoud (1998) and Burchardt (2000) appear to agree that the changes to extra costs benefits have meant that people lower down the severity scale are getting some of their costs covered.

However, Burchardt (2000) states that the fact that extra costs benefits have been raised in line with prices rather than average earnings means that disabled people (particularly those who rely on benefits as a major part of their family income) have got poorer in relation to non-disabled people.
8 Conclusions

8.1 Disabled people have extra costs (in relation to non-disabled people) as a result of their disabilities

It is assumed (and most studies tend to support this assumption) that disabled people have needs arising from their disabilities that must (to some extent) be met through additional spending.

These needs may be met through:

- subsidised (or free) services provided by the state or voluntary organisations. Essentially (excluding voluntary organisations) this is expenditure by the state (voluntary organisations’ expenditure could be considered expenditure by society);

- private expenditure (which may include that from extra costs benefits and premiums).

In reality, of course, needs will be met to a greater or lesser extent, some being met fully, while others are fully unmet, with the majority being partly met. The majority of needs are also likely to be met by a combination of subsidised services provided by the state or voluntary organisations and private expenditure, rather than by one of these alone. The fact that private expenditure will probably have to be diverted from non-disability related items means it is likely that disabled people will have a lower standard of living than non-disabled people with the same income.

Benefits such as Disability Living Allowance (DLA) and Attendance Allowance (AA) could be placed in both of the above categories, depending on whether they are classed as being expenditure by the state or as expenditure by the individual (as technically the state spends the amount of benefit and so does the individual).
8.2 Several factors affect the extent to which needs/costs are met

As mentioned above, it is unlikely that any disabled person’s disability-related needs are either totally met or totally unmet. It is more useful to imagine a continuum from totally unmet to totally met need, with individuals’ position (for various needs) on this continuum being determined by a number of factors. The most fundamental of these are the ability to meet needs and individual’s or household’s expenditure preferences. These will be affected by:

- **The amount of ‘extra costs’ in the narrow sense.** The amount, and type of needs (and subsequent potential costs) arising from disability will affect the extent to which needs are met. The greater the extra costs, for a given income, the larger the proportion of income must be spent on disability-related items to meet need, or the less need will be met. In turn, extra needs/costs will be affected by additional factors. Some of these factors are those that have been identified by the studies examined here as affecting ‘extra costs’ in the broad sense, such as severity and type of disability.

- **The household/individuals’ income.** This will affect the amount of money available to be spent meeting the costs of needs arising from disability (as part of a wider budget). Although individuals’ preferences with regards expenditure will vary, it seems reasonable to assume that the greater the income, the greater the amount available to meet the costs of disability-related needs. The relationship is not quite this simple however, as the preferences of the household will affect the amount of income that is allocated to meeting disability-related needs.

- **The extent of subsidy of services provided by statutory or voluntary organisations.** Increasing the level of subsidy of these services (assuming they are relevant to the individual) will either decrease the amount of private expenditure required to meet a certain amount of need or increase the amount of need that is met. This may well vary according to type of impairment (some impairment types may have a higher level of subsidised service provided) and geographical location (there are differences in provision between Local Authorities).

Therefore, to measure the extent to which needs arising from disability are being met, extra need/cost is the starting point (or reservoir of unmet need) on which income and the level of subsidy of services will act.

There is a potential problem with all the studies that have tried to estimate the realised extra costs of disability; namely that what disabled people spend in addition to non-disabled people is by no means what is necessary to completely meet their needs. A further complication, if potential extra costs are to be measured, is the fact that, realistically, some judgement about what constitutes need must be made. As Berthoud (1998) points out; in the event, all studies make some assumption about what level of need it is ‘reasonable’ to meet, and attempt to measure the cost of this.
This assumption will not necessarily be the same as the assumptions households with disabled members make about what is reasonable. However, it could be argued that measuring realised extra costs adopts households’ own definition of what costs are reasonable, though the counter argument is that this is not a free choice, because of the income constraints they face.

8.3 Previous attempts to measure/estimate extra costs (the studies examined here) have used four approaches

These approaches and the associated problems with these are:

- **Subjective** – This approach can be used to measure both potential extra costs and realised extra costs. However, there are concerns with issues of accuracy of disabled people’s estimates of what they actually spend, what they would spend if they had the resources and how this compares to the hypothetical situation in which they are not disabled (which may mean they had a different job with a higher income as well).

- **Comparative** – This approach is problematic (in terms of producing an estimate of extra cost) because so far it has only allowed comparisons of spending patterns and therefore only really describes how disabled people allocate their budgets (where they strike a balance between disability and non-disability related expenditure). Theoretically, however, it is possible to derive estimates of realised extra costs using this method. Therefore this approach so far has been of limited use in setting benefit levels, and can only ever produce estimates of realised extra costs.

- **Standard of living** – The standard of living approach measures the difference in incomes required by disabled and non-disabled people to achieve the same standard of living. However, this method measures people’s non-disability related standard of living (through standard of living indicators not linked to disability-related needs), rather than their disability-related standard of living. Therefore, this method is not measuring the cost of meeting disability-related needs, but rather the extent to which people are able and choose to divert resources from non-disability related expenditure.

- **Budget standards** – The budget standards approach produces lists of items or services that respondents judge necessary to allow a reasonable standard of living. This is then costed, and presented as a minimum budget required by disabled people. Problems associated with the budget standards approach are:
  - Thus far, studies have not developed ‘control’ budget standards for non-disabled people. Therefore, it is not known how the needs identified in the focus groups would differ from those of non-disabled people.
  - The standard of living required is not well defined, and is open to interpretation.
  - The budget standards developed do not adequately take account of services provided by the state, and assume that all items and services must be purchased by the individual.
Many studies are also compromised by the fact they use data on the household level (though, for example, Zaidi and Burchardt (2003) restrict their analysis to households with fewer than three members, and Smith et al (2004) developed budgets for single person households). This may mask the costs of disability as expenditure on the same items for other (non-disabled) members of the household may be reduced to compensate for the disability-related spending on that item.

Estimates of realised extra costs may not measure the spending required to meet need to any particular level. This may be compounded by the fact that disabled people have disproportionately low average earnings, and therefore are likely to have to budget more tightly (Zaidi and Burchardt, 2003).

Because of the issue of the balance between met/unmet need, it is unlikely that measuring actual expenditure will ever produce an accurate estimate of how much it costs to meet needs. Instead, estimates show how far people are able to divert resources from non-disability-related expenditure. Therefore, the fact that some studies examined here suggest that the amount of money, in actual amounts, spent on disability-related items increases with income, could be expected. Findings from studies measuring realised extra costs therefore, may suggest that benefits should be greater for those on higher incomes. This would go against the flow of means tested benefits, and may suggest that relying on estimates of realised costs is unwise.

8.4 What we do know about extra costs

Within the literature there is general, if not universal, agreement on:

- the existence of extra costs of disability. Though Matthews and Truscott (1990) found no evidence of costs that must be met without regard to income and also stated that extra costs are not as significant as the lower lifetime earnings of disabled people;
- that DLA/AA at their current levels are not sufficient to meet costs (rates are lower than most, but not all estimates – though some estimates include costs that DLA/AA are not intended to cover).
8.5 What we don’t know

The studies examined here do not present a coherent view on the issue of extra costs arising from disability. There is a lack of agreement on:

- the size of overall costs and of costs for specific items/groups;
- the factors that influence the size of costs;
- whether realised or potential spending (including minimum budgets), or deprivation should be the focus of studies measuring the financial effect of disability;
- how to take account of services provided free, or at a subsidised rate by statutory and voluntary services.
Appendix A
Further details of estimates of overall extra costs and extra costs of specific items produced by the studies reviewed

A1. Estimates of overall extra costs

A1.1 From studies using the subjective approach

Martin and White (1988)

Table A.1 shows the estimates of costs per week this study produced (using figures updated to 2001 prices from Zaidi and Burchardt 2003).

Table A.1 Results from Martin and White (1988)

<table>
<thead>
<tr>
<th>Severity level</th>
<th>Estimated cost per week £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (OPCS category 1 or 2)</td>
<td>7.24</td>
</tr>
<tr>
<td>Moderate (OPCS category 5 or 6)</td>
<td>13.09</td>
</tr>
<tr>
<td>Severe (OPCS category 9 or 10)</td>
<td>20.59</td>
</tr>
</tbody>
</table>
Appendix – Further details of estimates of overall extra costs and extra costs of specific items produced by the studies reviewed

*Disablement Income Group (1988)*

This study produced an estimate of extra costs of about £81.06 per week at 2001 prices (updated to 2001 prices in Zaidi and Burchardt 2003).

**A1.2 From studies using the comparative approach**

Studies adopting this approach cannot produce an overall estimate of the additional costs of being disabled as they compare households with the same expenditure and are therefore confined to comparisons of expenditure on specific items/groups.

*Matthews and Truscott (1990)*

One of the main conclusions of the study is that at all income levels and on all commodities, disabled people’s actual spending more closely matched that of their income counterparts than other disabled people and therefore, evidence of ‘substantial, unavoidable costs of disability [that are] met without regard to cost or priorities’ is not to be found in research based on expenditure comparisons, though as Zaidi and Burchardt (2003) believe that extra costs rise with income this conclusion may only show that there are not fixed costs that all disabled people have to meet, and that extra costs are not fixed independent of income.

**A1.3 From studies using the standard of living approach**

*Zaidi and Burchardt (2003)*

Zaidi and Burchardt estimate extra costs to be between 11 per cent and 69 per cent of income (translated by Zaidi and Burchardt in the table below into actual amounts for disabled people on the mean income).

**Table A.2 Results from Zaidi and Burchardt (2003)**

<table>
<thead>
<tr>
<th>From Burchardt and Zaidi (2003)</th>
<th>Non-pensioner single</th>
<th>Non-pensioner couple both disabled</th>
<th>Pensioner single</th>
<th>Pensioner couple one disabled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean income</td>
<td>£170</td>
<td>£405</td>
<td>£122</td>
<td>£273</td>
</tr>
<tr>
<td>Low severity (3)</td>
<td>£23</td>
<td>£97</td>
<td>£28</td>
<td>£24</td>
</tr>
<tr>
<td>Medium Severity (9)</td>
<td>£70</td>
<td>£292</td>
<td>£86</td>
<td>£71</td>
</tr>
<tr>
<td>High Severity (17)</td>
<td>£133</td>
<td>£551</td>
<td>£162</td>
<td>£135</td>
</tr>
</tbody>
</table>

*Note – the severity score used by the FRS follow-up in 1996/97 were similar to the OPCS scale, but run from 0-22, rather than 0-10.*
A1.4 From studies using the budget standards approach

Dobson and Middleton (1998)

This study found that parents of disabled children allocated 60 per cent of their budget to clothe and feed the child, while these items accounted for less than a third of the budget for non-disabled children. The largest proportion of the budget for disabled children is spent on transport.

The study estimated that it costs on average £7,355 a year to bring up a severely disabled child – more than three times the amount needed to bring up a non-disabled child – and that the additional cost of a disabled child is £99.15 a week. Table A.3 below compares the estimated minimum budgets produced by the study with benefit income available (at the time the study was conducted).

Table A.3 Estimated minimum budgets compared to benefit income

<table>
<thead>
<tr>
<th>Age group</th>
<th>Mobility disability</th>
<th>Max benefit income (highest rate DLA)</th>
<th>Sensory impairment</th>
<th>Max benefit income (middle rate DLA)</th>
<th>Traumatic intermittent conditions</th>
<th>Max benefit income (middle rate DLA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–5 yrs</td>
<td>170.68</td>
<td>87.35</td>
<td>143.20</td>
<td>70.95</td>
<td>134.45</td>
<td>70.95</td>
</tr>
<tr>
<td>6–10 yrs</td>
<td>151.08</td>
<td>121.95</td>
<td>131.23</td>
<td>84.10</td>
<td>117.95</td>
<td>84.10</td>
</tr>
<tr>
<td>11–16 yrs</td>
<td>169.61</td>
<td>129.80</td>
<td>126.63</td>
<td>91.95</td>
<td>128.01</td>
<td>91.95</td>
</tr>
</tbody>
</table>


Table A.4 Estimated minimum budgets for various impairments/needs levels

<table>
<thead>
<tr>
<th>Impairment type</th>
<th>High-medium needs</th>
<th>Intermittent needs</th>
<th>Low-medium needs</th>
<th>Hearing impairment</th>
<th>Visual impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Costs of Personal Assistance</td>
<td>980</td>
<td>83</td>
<td>44</td>
<td>960</td>
<td>255</td>
</tr>
<tr>
<td>Other costs</td>
<td>533</td>
<td>365</td>
<td>345</td>
<td>376</td>
<td>376</td>
</tr>
<tr>
<td>Total</td>
<td>1,513</td>
<td>448</td>
<td>389</td>
<td>1,336</td>
<td>631</td>
</tr>
</tbody>
</table>

The study found that someone with high-medium needs a larger budget to meet their needs than someone with low-medium needs (Table A.4).
The single most expensive area of the budget for all but the low-medium needs budget was personal assistance (broadly defined to include interpreters for deaf people and trainers for blind people). This makes up 11-72 per cent of the budget totals. Smith et al. (2004) found that level of need is more important than type of impairment in determining extra costs.

The report also states that needs should be met through a combination of environmental improvements, enhanced service provision and increased levels of benefits/earnings from employment.

**A2 Estimates for specific items**

Various studies have produced estimates of extra costs for different specific areas of expenditure. The studies also break down the estimates to greater or lesser extents, which makes it difficult to develop a coherent view of the item/group specific estimates that have been produced. For this reason, this section of the paper looks at the studies individually, rather than attempting to integrate their findings on various expenditure groups/items.

**Martin and White (1988)**

This study found that the most common special cost (incurred only for disabled people) was chemists’ items and the most expensive was home care. The most common additional cost was fuel and the most expensive was food.

The study also looked at the things that disabled people say they need to spend more on, but could not afford to. These were identified as fuel, clothing or bedding and food. People may not allocate additional expenditure to these items either because the costs are greater than they can afford or because other costs take priority.

Among people with high extra costs, home services made up the bulk of this, as home services is one of the most expensive extra goods/services required. Food and travel were also expensive costs.

The things disabled people estimated they spent less on than non-disabled people were things such as going out and holidays, which they may spend less on because of constraints rather than because their disability means they do not need these things.

**Matthews and Truscott (1990)**

Matthews and Truscott (1990) estimated that disabled people spent £7.75 a week more on fuel, services, tobacco and durables and £8.70 less on transport. It is possible that spending on transport was lower than that of non-disabled people because disabled people didn’t have same level of physical/economic access to transport and didn’t travel as much as a result of this.
The comparison of the findings of this study and Martin and White (1988) found that comparative and subjective methods produce similar estimates of additional spending on some items (e.g. fuel), while the comparative method finds decreased spending on some items that the subjective method finds there is increased spending on (e.g. clothes and transport). The comparative method also shows increased spending on some things that the subjective method does not find increases in. One notable example of this is tobacco. This difference may be because of the perceived social desirability of reporting increased spending on tobacco, which could have more of an effect when asked directly to say how much more you spend on something than when asked simply how much you spend on a wide variety of things. When considering the example of tobacco it is important to note that the authors state there is higher consumption of tobacco in the ‘manual socio-economic groups’ and among people on low incomes, and the data available meant it was not possible to see if there was any direct link between disability and high tobacco consumption (let alone establish a causal relationship).

This study also found that disabled people spent more on ‘durables’ (including bedding), where the Office of Population, Censuses and Surveys (OPCS) survey did not find this (though gadgets, aids and appliances related to disability were excluded from the OPCS categories).

Matthews and Truscott (1990) found that spending on ‘luxury’ (in that spending increases with income) items such as gadgets, aids and appliances related to disability increased dramatically with increasing income, although it is unlikely that disabled people were spending this extra money on true luxury items (see p30). For other ‘luxury’ items such as clothing and alcohol, spending by disabled people rises with income but at a slower rate than that of non-disabled people. These findings suggest that as income rises, disabled people spend less on true luxury items than non-disabled people because they tend to spend most additional resource on items relating to their disability.

On a general level, Matthews and Truscott (1990) found that households containing a disabled person had to constrain their spending on luxury items such as clothing and alcohol (spending was cut back on these two items first), as a result of increasing spending on necessities. Therefore the study concludes that disabled people do have extra costs resulting from their disability. Patterns of expenditure support the notion that households with disabled people experience a lower standard of living than households with the same income but which do not contain disabled people. The results of this study were contrary to expectations – they appear often to be showing that disabled people spend less than non-disabled people with similar incomes. This may, however be because disabled people are often on permanently low incomes (and recognise this) whereas non-disabled people on low incomes may have more savings and also believe their financial situation will improve so are prepared to spend more. At higher incomes, disabled people may be earning enough to incur extra spending, or be saving more.
The authors suggest that the effect of extra costs of disability is of lesser importance than the effect of lower lifetime incomes of households containing a disabled person.

Jones and O’Donnell (1995)
This study estimated extra costs to be 45 per cent more on transport and 64 per cent more on fuel. Burchardt (2000) says that the authors attempted to devise an equivalence scale for disability (much like equivalence scales for family size) but felt that their estimated coefficients were not sufficiently robust to develop a full equivalence scale. However, the study did find that disabled households spent a greater share of their budgets on necessities and less on luxuries.

Dobson and Middleton (1998)
This study also found that many disabled people are in debt for a range of reasons (often directly related to their disability) and can be in the situation of using their DLA to pay off debts. This also meant they had to cut back on items needed for their disability – e.g. special food, extra heating.

Phillips (1993)
This study estimated the cost of a care package for a severely disabled person to be £250 a week (updated to 1998 prices).
References


Disablement Income Group (1988) Not the OPCS survey: Being disabled costs more than they said London: DIG.

DRC (Disability Rights Commission) Disability briefing June 2005 (DRC. London).


