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# Measuring the impact of disability benefits: a feasibility study

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ISER Working Paper Series

# Measuring the impact of disability benefits
# A feasibility study

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**Measuring the impact of disability benefits: a feasibility study**

Non-technical summary

The Disability Living Allowance and the Attendance Allowance pay up to £67 per week for people in need of care, and up to £47 per week for people with impaired mobility. The benefits are not means-tested, and there is no obligation to spend the money on particular goods and services. 4.5 million people receive benefits, totalling £14.7 billion per year.

Remarkably little is known about the impact of these disability benefits – what difference they make to claimants' care and mobility arrangements, to their overall standard of living, and to their social inclusion and sense of identity.

Straightforward analysis of survey data, such as the FRS, could be used to provide a much clearer picture of the types of people receiving this income, in terms (for example) of their pattern of impairments and their other sources of income.

The number of claims in payment is massively higher than originally predicted when the schemes were introduced, and this must mean that the benefits reach the target group more effectively than in the past. Research is in progress aimed at measuring take-up. But because entitlement eventually depends on the judgement of decision makers, there are both theoretical and practical difficulties in identifying eligible non-claimants.

Of course claimants and their families are better off than they would have been without the benefit, but the key question is whether the schemes provide effectively for the additional day to day needs associated with severe impairments. This overall objective can thought of in term of four aims, discussed in detail in the paper:

- Providing for additional expenditure on specific goods and services needed by disabled people (eg paid-for care services, cars)
- Improving specific outcomes (eg care received, mobility)
- Generalised compensation for additional expenditure (assuming normal income has already been diverted into additional needs)
- 'Enabling' a broadly improved lifestyle to counter the 'disabling' effects of impairment (eg social and economic participation)

The main difficulty in identifying the effects of the benefits lies in estimating what the outcomes would have been, if the money had not been provided. Options include:

- Cross sectional comparisons, controlling for disability characteristics
- Instruments for disability
- Comparing the same people, before and after receiving disability benefits
- Exploiting artificial variations in eligibility
- Exploiting administrative variations in take-up and award rates
- Before and after a policy change

The feasibility study recommends two immediate research projects: secondary analysis of existing data; and development of survey question sequences to measure expenditures and outcomes. The best prospect for an eventual answer to the questions raised lies with the new longitudinal survey of disabled people being commissioned by the Office for Disability Issues.

# Measuring the impact of disability benefits

A feasibility study

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February 2009

**Abstract**

Social security benefits designed to meet the extra costs faced by disabled people have been in place since the early 1970s, and currently cost nearly £15 billion per year. But remarkably little is known about the impact of these benefits – what difference they make to claimants' care and mobility arrangements, to their overall standard of living, and to their social inclusion and sense of identity.

The Department for Work and Pensions is considering how to study the impact of disability benefits in more depth. The Department commissioned this feasibility study, to summarise the questions and assess alternative research approaches, with a view to launching more detailed investigations.

**Keywords**: social security benefits, disability, social inclusion, Family Resources Survey

**JEL Codes**: J32, H53, H55

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This feasibility study was undertaken at the request of the Department for Work and Pensions. The DWP's liaison team is Mike Daly and Andrea Kirkpatrick. The views expressed are the author's, and the Department is not committed to implementing any of the report's recommendations. The report is also available as a DWP working paper at http://www.dwp.gov.uk/asd/asd5/wp-index.asp The paper includes some new analysis of the Family Resources Survey for 2004/05. The survey is commissioned by the DWP and made available through the UK Data Archive.

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## 1. Introduction

Social security benefits designed to meet the extra costs faced by disabled people have been in place since the early 1970s, and currently cost nearly £15 billion per year. Over the period the benefits have enjoyed bilateral political support, and the only major changes (eg in 1992) have been to extend entitlement and increase expenditure. Research has been commissioned to examine the practical operations of claiming and assessing benefit (Sainsbury and others 1995, Hawkins and others 2007). It is obvious that disabled people are better off with their benefit than without it, and some surveys have recorded their reaction when they start to receive it (eg Craig and others 2003, Age Concern 2008). But remarkably little is known about the impact of these benefits – exactly what difference they make to claimants' care and mobility arrangements, to their overall standard of living, and to their social inclusion and sense of identity.

The Department for Work and Pensions is considering how to study the impact of disability benefits in more depth. The Department has commissioned this feasibility study, to summarise the questions and assess alternative research approaches, with a view to launching more detailed investigations.

On the one hand, this review has taken a very broad view about what the purposes of a disability benefit might be, and what impacts might emerge. On the other hand, it has taken rather a narrow view about 'measurement' – we are looking if possible for quantitative estimates of what difference the extra money makes. The combination of loosely-defined policy objectives and precise research objectives creates an exceptionally difficult agenda. It requires data on a wide range of topics, focusing on a small proportion of the population. It requires a rigorous set of comparisons between the experiences of people receiving benefit, and a 'counterfactual' group of people not receiving the benefit, but in otherwise similar situations.

These issues are discussed in detail in the following pages. A research plan is proposed at the end which looks towards a large scale survey starting in about two years time – but it is not yet clear whether this can be attached to surveys of disabled people already in the pipeline, or whether an entirely new project is required. In the meantime, two smaller projects can be implemented over the next year or so, which

will provide some answers to the questions at issue, and also contribute to the development of a new study.

## 2. Overview of DLA and AA[1]

The research question addressed in this report concerns the 'impact' of two social security benefits available to elderly or disabled people. This section describes them, in the context of their history since the 1970s. Readers familiar with the benefits can skip the rest of this section.

The Attendance Allowance was introduced in 1971. It is paid at a higher rate (currently £67 per week) to disabled people who need both help throughout the day and supervision during the night. They can claim the lower rate (currently £45 per week) if they meet either the day or the night condition, but not both. Although initially confined to adults, AA was soon made available to disabled people of any age.

The Mobility Allowance (MobA) was introduced in 1976, providing £47 per week (current rate of the equivalent benefit) for people who cannot walk. It was confined (and its replacement is still confined) to disabled people whose eligibility is established before the age of 65.[2]

The Disability Living Allowance introduced in 1992 (DSS 1990) merged AA and MobA for disabled people under 65, renamed as the care component and the mobility component of DLA (DLAc and DLAm respectively). It offers new lower rates of benefit (currently £18 per week) for people who need help for part of the day or who cannot cook a meal (care component) or who need assistance when walking outdoors (mobility component). Attendance Allowance was retained for those over 65, so that the highest and middle rates of the care component of DLA are identical to the higher

[1] Note that this review is entirely confined to the two 'extra costs' benefits described here, often referred to jointly as 'disability benefits'. It does not address questions about other benefits paid to disabled people such as incapacity benefit, industrial injuries disablement benefit, or benefits paid directly to carers.

[2] If they establish eligibility before 65, people retain MobA/DLAm after 65 (for as long as they remain disabled). This is by no means a trivial concession: a third of higher rate DLAm payments go to over 65s

and lower rates of AA. As before, there is no equivalent of the mobility component for older claimants.

The main provisions are tabulated below. The weekly rates of benefit are in bold (rounded to the nearest pound), followed by the current number of claimants (in thousands at November 2007) and the annual cost (in £ billions).

| | **Attendance Allowance**<br>65 plus | **Disability Living Allowance**<br>Below 65<br>**Care component** | **Mobility component** |
|---|---|---|---|
| **Top rate** | Needs help throughout day<br>*and* supervision during night<br>**£67pw**<br>832K £2.9bn | 662K £2.3bn | Unable to walk<br>**£47pw**<br>1720K £4.2bn |
| **Mid rate** | Needs help throughout day<br>*or* supervision during night<br>**£45pw**<br>708K £1.7bn | 948K £2.2bn | |
| **Low rate** | | Needs help part of day, or cannot cook a meal **£18pw**<br>800K £0.7bn | Needs assistance when walking outdoors<br>**£18pw**<br>827K £0.8bn |

Although the two benefits have different names, it is often convenient to think of them as a single scheme with varying entry provisions. The wider DLA offers five rates of benefit (3 + 2) to people claiming under 65; AA is restricted to only two rates of benefit (2 + 0) for people claiming at 65 or more. Most of the following report treats them together.

Adding together the two benefits, the two components and the various rates, there are currently 4.5 million people receiving payments totalling £14.7 billion per year.

The disability benefits are paid on the same terms to disabled people whether they are in work or not. The amounts are calculated without regard to the amount of income available to disabled people, or their families, from other sources. There is no obligation to spend the money on particular goods and services, nor to explain how it has been spent. They are contingent on characteristics thought to be associated with additional needs, and nothing else. There is close parallel with Child Benefit.

People receiving these benefits may automatically be entitled to claim the disability or severe disability premiums in income support, pension credit and other means-tested benefits. If they do, their incomes will be increased by more than the amount of the DLA or AA. But it is not clear that the additional income should be counted as part of the disability benefits scheme, and for the most part the impact of the means-test premiums is not considered in this report.

**3. Who benefits?**

A first question about the impact of a benefit is simply to record what sorts of people receive it and how much money they receive. This is not a difficult task in principle, and it does not take up much of this feasibility report. On the other hand, these straightforward questions have not been analysed in much detail, and such descriptive work is an essential prerequisite for more complex analytical approaches.

DWP statistics have reported the numbers of people receiving disability benefits by age and sex since the 1970s, and show both the persistent year on year increase in the number of recipients and the strong weighting towards older people (within each relevant age range). Although the statistics also record the main health condition associated with each claim in payment, the lack of base figures for the number of people with those conditions in the overall population makes them difficult to interpret, and it is necessary to turn to survey data such as the 1985 and 1996/97 disability surveys, or more recent regular sources such as the Health Survey for England or the Family Resources Survey, for data linking benefit receipts to health and other socio-economic characteristics.

Two examples illustrate the kinds of question that can be answered by survey analysis of this sort. Table 1 presents the results of multivariate analysis of the probability of receiving either DLAc or AA, on the one hand, or DLAm on the other. It shows that the characteristics of people getting the care and the mobility components of the two benefits are rather similar to each other, with mobility impairments almost as important a predictor of the need for care as of the need for mobility. Women, older people and people living alone are all more likely to receive the benefits than could be predicted purely on the basis of their impairments.

***Table 1: Logistic regression equation analysing the probability of receiving disability benefits, by types of impairment and demographic characteristics***

| | Care component | | Mobility component (age < 65) | |
|---|---|---|---|---|
| | Coefficient | t ratio | Coefficient | t ratio |
| *Types of impairment* | | | | |
| Mobility | 1.82 | 29 | 2.67 | 28 |
| Danger | 0.98 | 7 | 0.97 | 5 |
| Learning | 0.78 | 11 | 0.59 | 6 |
| Dexterity | 0.68 | 12 | 0.46 | 5 |
| Lifting | 0.64 | 10 | 0.44 | 5 |
| Communication | 0.51 | 7 | 0.56 | 5 |
| Coordination | 0.42 | 7 | 0.80 | 9 |
| Incontinence | 0.39 | 5 | 0.24 | 2 |
| Other impairments | 0.86 | 14 | 0.96 | 12 |
| *Demographic characteristics* | | | | |
| Woman | 0.43 | 9 | 0.35 | 5 |
| Age (per 10 yrs up to 70) | 0.04 | 2 | 0.09 | 3 |
| Age (per 10 yrs after 70) | 0.59 | 12 | | |
| Lives alone | 0.28 | 6 | 0.41 | 6 |
| | | | | |
| Constant | -5.11 | -41 | -5.69 | -32 |
| Sample size | 47,671 | | 36,963 | |
| Pseudo $R^2$ | 36% | | 41% | |

Source: Family Resources Survey 2004/05

As a second example, Table 2 shows how much income claimant-households receive, if their disability benefits are excluded from the calculation. The implication is that this is how much they would have received in the absence of the benefit. Among under-65s (whose non-benefit income may have been adversely affected by their disability) claimants' pre-benefit income is substantially lower than that of non-claimants. Among over-65s, both claimants and non-claimants have similar starting incomes, presumably because pension entitlements were determined before the onset of disability – but both groups of over-65s are worse off than non-disabled people of working age.

***Table 2. Median equivalent household income of DLA and AA recipients, before and after disability benefit***

| | Non-recipients | Recipients | Difference |
|---|---|---|---|
| *Under 65* | | | |
| Excluding DLA | £232 | £143 | -£89 |
| Including DLA | | £185 | -£47 |
| Gain from DLA | | £42 | |
| *Over 65* | | | |
| Excluding AA/DLA | £166 | £163 | -£3 |
| Including AA/DLA | | £207 | +£41 |
| Gain from AA/DLA | | £44 | |

Source: Family Resources Survey 2004/05

The findings reported in Tables 1 and 2 are not presented as an outcome of this feasibility study. They are intended simply to make the case for more detailed, and more frequent, analysis of the underlying characteristics of DLA and AA claimants, using survey data.

## 4. Take-up, claims and adjudication

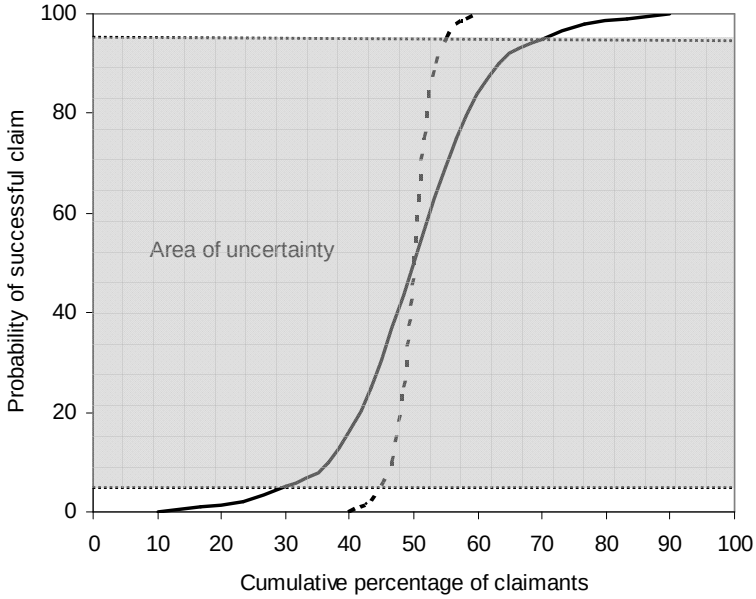
The previous section focussed on the characteristics of disability benefits recipients, assuming that they are the people who are going to experience the types of 'impact' discussed in later sections. A second set of questions asks whether they are the correct group of people, in terms of the eligibility criteria laid down. Have all eligible disabled people claimed their entitlement; have the DWP decision makers correctly awarded benefit to those entitled, and refused it to those not entitled?

Two well-known and striking facts about DLA and AA are highly relevant to these questions. When the original disability benefits were introduced in the 1970s, officials estimated that about 250,000 and 150,000 people would be eligible for the Attendance and Mobility Allowances respectively. The numbers had already passed 500,000 and 400,000 respectively by 1985, and latest counts for the equivalent rates of the current schemes are 3.2 million and 1.7 million. There is no suggestion that the prevalence of severe disability has increased at anything like this rate, even if the ageing of the population is taken into account. So there must have been either a big increase in the rate of take-up, or perhaps a big relaxation in the stringency of the assessment procedure (or both).

The second striking fact is that half of all claims for DLA (and a fifth for AA) are rejected. Many are submitted for reconsideration or appeal, and about a sixth of all claims initially rejected are eventually decided in favour of the claimant. These rejections, appeals and substitutions are much higher than for other types of benefit. They suggest a significant range of uncertainty among claimants, or among decision makers, or both, about exactly who is eligible for disability benefits.

The idea of measuring take-up usually depends on the idea that people either are, or are not, entitled to benefit, and the only issue is whether they have claimed. Once they have claimed, a decision maker rules on the entitlement question. There may be a grey area, though, where it is not entirely certain whether they are entitled or not. This may be true of all benefits to a certain extent, but the grey area may be quite wide for a benefit, like DLA and AA, which depends on the decision maker's overall judgement of the combination of answers to a series of questions. Consider the stylized presentation in Figure 1, below. The dotted line represents a benefit where 45 per cent of claims are almost certainly not entitled, 45 per cent are almost certainly entitled, and only 10 per cent are uncertain. The black line represents a benefit where only 30 per cent are virtually certain at either end, and 40 per cent are uncertain. (These figures are just to provide a pictorial illustration; it is not suggested that the actual area of uncertainty is as wide as either of the examples suggests.) The point is that for *every* benefit there will be a group of claims with around a 50:50 chance of success: this group is no doubt small for some benefits (eg Child Benefit), but may be larger for other benefits (eg DLA/AA).

***Figure 1. Stylised representation of the distribution of potential benefit claims by the probability of entitlement***




In the area of uncertainty, where the chance is around 50:50, we would expect one decision-maker to award benefit while another refused it, both reading from the same application form and medical evidence. This is not an error on the part of either decision-maker, nor a question of one being more generous than the other. Both have made perfectly legitimate decisions in a genuinely uncertain situation.

This line of thinking has important implications for the analysis of take-up and of assessment.

There have been persistent concerns that many eligible disabled people have not claimed, and some attempts to estimate the rate using survey data (eg Cooke and others 1983, Craig and Greenslade 1997, Daly and Noble 1996). Local welfare rights campaigns almost invariably identify disabled people who turn out to be eligible when they submit a claim. On the other hand, the steady rise in the number of claims in payment suggests that the take-up rate is now much higher than it was in the past.

If there is intrinsic uncertainty in the assessment of eligibility, the take-up question can no longer be represented simply as: what proportion of those who *are* entitled have claimed. That remains the question for those potential claimants whose entitlement is certain. But in the area of uncertainty, the question becomes: what

proportion of those who *may* be entitled have claimed; and what proportion of those claims would have succeeded if submitted. Take-up can still be calculated as a percentage rate (based either on the number of individuals or on the value of payments) even though we cannot assign individuals with certainty to the eligible or ineligible groups.

Another line of interest and concern has been the process of claiming, the assessment procedure, and consistency of decisions to award or refuse benefit (eg Hedges and others 1994, Sainsbury and others 1995, Hirst 1997, Hawkins and others 2007, see also debate about the DWP's Benefits Integrity Project in the late 1990s). Research has tended to focus on the claim procedure (eg whether claimants found the application form difficult to fill in, the request for medical evidence intrusive and so on) or on the outcome (discussed in terms of apparently eligible people being refused, apparently ineligible people being awarded benefit, or apparent inconsistencies between areas). There has been very little research directly focusing on the adjudication process itself, to investigate the scale of the area of uncertainty discussed above, to indicate which criteria in the evidence-base are critical in deciding a claim, or to examine possible areas of bias.

These issues about take-up and decision making are important, but they are not centrally relevant to measurement of the 'impact' of the benefits on which this feasibility study focuses. Moreover take-up, and some aspects of decision-making, are the subject of another major study commissioned by the DWP and being developed by the Policy Studies Institute (Kasparova and others 2006). Having flagged them up for consideration, they are left on one side for the moment, so that the current study can focus on impacts defined in terms of what difference the benefit makes to those who have claimed, and have been awarded, the benefit.

**5. Impacts on spending and outcomes**

The obvious, simply stated, impact of disability benefits is that recipients, and their families, have between £18 and £114 more income each week to spend or to save. The figures in Table 2 suggest that the benefits increase household income by a quarter on average. Some severely disabled people may see their income double when

their claim succeeds. So they are better off than they would have been if they had not claimed, or if the claim had failed.

Of course the extra money adds to the economic welfare of the families concerned, and this broad outcome is welcome in its own right. But since the £15 billion pounds might have been spent on other benefits, or on programmes outside the social security sphere, or on reductions in the overall tax burden, the impact has to be evaluated in relation to a set of objectives directly related to the target group – disabled people. There is some debate about what successive governments' direct intentions have been in setting up and continuing these schemes (discussed in the next section); but there is also a wider set of possible objectives of disability benefits, which are relevant to an evaluation of their outcomes.

The government's independent living strategy's aims (ODI 2008) are that:

* disabled people who need support to go about their daily lives will have greater choice and control over how support is provided;
* disabled people will have greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

DLA and AA contribute to that strategy. We propose a very broadly-stated objective for the twin disability benefits within which to evaluate a range of possible outcomes: *to provide for the additional day to day needs associated with severe physical or mental impairments*. To the extent that disabled people and their families are worse-off than non-disabled people with the same starting income, the benefits should counteract that disadvantage. But there is no intention to make disabled people better off than others on the same income (as a form of compensation). Nor are these benefits designed to counteract the low levels of employment and original income experienced by disabled people and their carers – that role is assigned (perhaps not very effectively) to incapacity benefit and the carer's allowance, plus the various means-tested benefits.

But the ‘additional day-to-day needs’ that make disabled people ‘worse off’ than non-disabled people are not easy to define, or to measure. The following sections discuss four approaches to the issues:

A. Providing for additional expenditure on specific goods and services needed by disabled people.
B. Improving specific outcomes.
C. Generalised compensation for additional expenditure.
D. ‘Enabling’ a broadly improved lifestyle (countering the ‘disabling’ effects of impairment)

In all cases, the question is whether the disability benefits are achieving these objectives, and doing so efficiently. A second issue is whether changes in some other policy programme might achieve them more efficiently, but these potential alternatives are not considered here.

*Aim A: Supporting additional expenditure on specific goods and services needed by disabled people.*

It is not difficult to identify certain kinds of goods and services that people might spend (more) money on because they are disabled. Such items can include personal care, household services (cleaning, gardening, decorating), extra heating, transport, and incidental medical expenses such as chemist’s goods.

A first issue is whether the attendance and mobility criteria used to assess entitlement to disability benefits imply that the benefits are intended to pay for care and for transport. The Attendance Allowance was originally intended to contribute to costs in general – *not* specifically to pay for care. Sir Keith Joseph, for example, introduced AA in 1970 as follows:

> ‘It was never suggested that £4 a week provided for in the Bill would be enough to provide professional help. . . . It would be a valuable additional cash resource for the long haul of chronic severe disability for households which had to bear the financial burden.’

Sir Nicholas Scott made much the same point in relation to the care component when introducing DLA in 1992:

> ‘The aim is to recognise the extra costs and disruption of normal family life that arise from the attendance needs of severely disabled people.’

DLA and AA are unconstrained cash benefits, and there has never been any suggestion that recipients were required to spend the money in any particular way – still less that they should account for its expenditure. There has nevertheless been a persistent assumption among policy commentators and service providers that DLAc and AA could be treated as a tranche of income available to pay for caring services, whether these were directly provided by local authorities and charged for, or whether hired in an open market (Griffiths 1988, Baldwin and Lunt 1996, Lakey 1995). And it was the apparently low level of caring services accessed by AA claimants which led to the Wanless report’s suggestion that the resources should be transferred into a more direct system of supplying and paying for such services (Wanless 2006).

Since the Mobility Allowance originally replaced several previous schemes which had provided direct assistance with mobility costs, it was much clearer that MobA was intended to help pay for the extra costs of transport (cars, taxis and so on), than that that AA was intended to pay for the extra costs of care – although, again, there was no requirement that it should be spent in this way. Since MobA has been converted into the mobility component of DLA, and less clearly labelled, it can be argued that the presumption in favour of transport costs has been weakened.

Whatever the policy intention, it is clear that the disabled people receiving these benefits have significant care and transport needs. So it is remarkable how little is known about how the money is spent. A recent survey (Hawkins and others 2007) is consistent with a hierarchy of allocation suggested many years ago (Horton and Berthoud 1990):

a. Many disabled people are cared for by a relative in a first layer of family obligation, living in the same household – their parent (among young disabled people), their partner (among couples) or sometimes their daughter or son (among older people). In such cases, there is a common household budget, often administered mainly by the carer. AA/DLA money is included in that budget with little differentiation. It will often be spent on items specific to the claimant, either

on disability related costs, or on ‘little extras’. It is very rarely used to pay for caring services – because the resident relative provides most of the care..

b. Other disabled people are cared for informally by someone in a lesser layer of obligation, living elsewhere — other daughters, sons or daughters-in-law, neighbours, and friends. In this case separate household budgets would be kept. The need-for-care benefits money is commonly paid over to the carer as a formal token of gratitude. But both sides are aware that the amount is nowhere near enough to be seen as a market transaction, payment for hours worked.

c. A minority of disabled people are cared for mainly by paid supporters employed by social services, by an agency or directly by the client. In such cases the need-for-care benefits money is part of the funding package, although other sources are always required to meet the total.

The Family Resources Survey suggests that only 11 per cent of DLAc/AA claimants living with other adults have any ‘formal care’ (that is, regular weekly help from people who are paid for their services); and 27 per cent of claimants living on their own. Since many of the formal carers will be paid by local authorities or other agencies, the proportion of claimants paying for the help out of their own pocket will be less than those figures imply. The General Household Survey showed that about 30 per cent of AA claimants were receiving formal care – but only 11 per cent were receiving five hours of help or more (Hancock and others 2007). The latter figures have been used to estimate that about £500 million of AA payments are used to pay for care (assuming AA is the first element of income used for that purpose) – 11 per cent of total AA expenditure.

On the other hand, regular weekly ‘care’ is not the whole story – a survey of older people who had recently claimed benefit suggested that while a quarter had spent some of it on ‘care services’ more than half had paid for ‘practical help at home - cleaner, gardener etc’ (Age Concern 2008).

On the mobility side, there does not seem to have been any analysis of how much DLAm claimants spend on transport. But it is known that over 470,000 people pay their mobility allowances directly to support the purchase of a car, scooter or powered

chair via the Motability scheme – 28 per cent of the number of people receiving the higher rate DLAm.

Caring services and transport are important areas of additional cost, but it is important for research to cover other potential disability-related costs as well. What are these extra costs, and how much do they add up to (for a summary, see Tibble 2005)? A survey of DLA recipients (Sainsbury and others 1995) reported an average of two items of expenditure per person required solely because of disability (incidental expenses of hospital visits, chemists items and so on), and another four items in which normal expenditure had to be increased because of disability (heating, transport, phone calls and so on).But the only structured survey which has tried to put a figure on these amounts with direct questions (Martin and White 1988) came up with an average total for very severely disabled people of only £28 per week (at 2007 prices[3]) – substantially less than the top rates of disability benefits. Either the benefits are more than generous in their allowance for extra costs, or survey respondents have difficulty in calculating them in response to a bald question. Indeed, the disability lobby lost no time in finding samples of disabled people with identifiable extra costs far above those reported by the survey (Thompson and others 1990).

An alternative approach has been to measure exact patterns of spending among a sample of disabled people, and compare them with expenditure among non-disabled people An analysis of disabled adults suggested that they spent more on durables and fuel - but less on transport (Matthews and Truscott 1990). A survey of families with disabled children suggested that they spent more on transport, food and durables (Baldwin 1985). Neither study indicated a large effect on purchase of services. One problem with this expenditure survey approach is the huge range of variation in detailed expenditure patterns, among disabled people and among the population at large, making it very difficult to identify the additional costs faced by particular disabled people with their particular conditions and impairments (for a review see Berthoud and others 1993). Another is that a disabled person (and family) faced with extra costs but a fixed income will have to reduce expenditure on other goods and services, so that an overall extra cost cannot be calculated.

[3] Inflation factor based on the top rates of AA/DLAc in payment in each year.

These essentially unconvincing attempts to measure the additional costs of disability illustrate two problems. One is that even if we knew how much this disabled person (and his/her family) was spending on a particular item, how can they or we estimate what they would have spent if they had not been disabled? The other is that their spending on any particular item is affected not only by their need for that item, but also by their requirement for other ordinary goods and services, within a given income. A 'need' for extra spending is not a quantifiable concept, independent of the 'resources' available to pay for it.

These problems arise in the context of historical attempts to measure the extra costs associated with disability. The task on this occasion, though, is to measure the impact of disability benefits. The question now is not how much more a disabled person spends than s/he would if not disabled, but how much more a disabled person claiming DLA or AA spends than s/he would if not claiming benefit (but still disabled). And the income constraint is no longer an issue – the question is how spending patterns respond to a targeted increase in income. We will discuss the measurement issues in more detail in a later section, but the conclusion at this stage is that estimating the allocation of marginal income should be easier than estimating the costs of disability.

*Aim B. Supporting specific outcomes*

When we ask what the impacts of DLA and AA are, an 'obvious' interpretation is to report how claimants spend the additional money. That interpretation has been discussed in the previous section. This short section simply makes the point that rather than enquire whether claimants spend money on care, transport, extra heating and so on, it may be more appropriate to analyse the impacts, if any, on the amount of care received, on claimants' opportunities to get out and about, on how warm they are and so on. This approach would be based on an assumption that care, mobility and other *outcomes* are not necessarily proportional to the amount of money spent directly on the relevant *inputs*.

- On the positive side, additional income from disability benefits might encourage and stabilise informal care arrangements, even though the cash was not paid to the informal carers. A steady mobility allowance paid over to the motability scheme

might be more effective at enabling people to get about, than the same amount of money paid occasionally for taxis.

- On the negative side, the availability of income to pay for care and/or transport might have less effect than expected, if it led to a reduction in the amount of support supplied free of charge by relatives and friends.

These issues should be addressed in any new study. The requirement is to collect data about these outcomes, as well as about spending on inputs.

*Aim C: Generalised compensation for additional expenditure.*

The two preceding sections have been based on an assumption that disabled people have costly additional needs (for care, transport, heating and so on), and that DLA and AA are provided to enable them to purchase those goods and services. The implicit assumption is that in the absence of the benefit they will not be able to pay for the additional costs.

An alternative assumption is that if people have real needs, they will pay for them anyway. Needs, after all, are items that people have to pay for, even out of a restricted income (while luxuries are things that people choose to buy only if they have plenty of money). But if disabled people feel obliged to pay these extra costs, they have to divert income from other, 'ordinary' goods and services, like food and clothing. On this assumption, the extra costs of disability are felt as a reduced standard of living and financial stress. And in that case, the role of disability benefits may not be to meet the extra costs directly, but to restore people's standard of living to the level it would have been (on a given income) if they had not had disability related costs.

This way of looking at things diverts the analytical focus from the goods and services paid for by the extra income, and looks instead at indicators of deprivation, hardship or financial stress. Berthoud and others (1993) and Zaidi and Burchardt (2005) have shown that disabled people have systematically higher levels of deprivation than non-disabled people on the same income, and have used these relationships to estimate an additional cost of living associated with disability. The question for the current study is whether the additional income from DLA and AA is more or less than is needed to

compensate for this additional cost. Preliminary analysis of the FRS supports this line of approach (Berthoud and Hancock 2008).

A feature of this interpretation of the impact of disability benefits is that the use of household based measures of income and of deprivation can automatically take account of the position of other family members, as well as that of the disabled person him or herself..

*Aim D: Countering the disadvantages of disability*

While improvements in care, mobility and financial well-being are all important aims, it can be argued that the real disadvantage of disability is the restricted lifestyle experienced by people with severe impairments. Such restrictions might be direct outcomes of an impairment (according to the medical model of disability) or consequences of social organisation which has not adapted to the varying needs of disabled people (according to the social model). These disadvantages are sometimes summarised by the term social exclusion; the now unfashionable word 'handicap' was intended to refer specifically to the 'exclusion' faced by disabled people (as opposed to those with other sources of disadvantage).

In that case, a key objective of disability benefits might be expressed in terms of countering that social exclusion. For example, personal care might enable people to get out of bed and take part in social and economic activities; better transport might allow them to travel to see friends, go to a restaurant, vote and so on.

The research programme should therefore include measures of social exclusion, to examine the relationship between impairments, benefits and these very broadly defined outcomes. There have been various attempts to develop multi-dimensional scales of social exclusion (eg Burchardt and others 2002, Barnes and others 2006, Levitas and others 2007), though it is far from clear what underlying construct these indices are measuring. Perhaps a new scale needs to be developed specifically to register disadvantages associated with disability.

Craig and others (2003) have identified a series of more subjective social psychological benefits which older people identified as positive consequences of an

increase in income. These included physical independence, a sense of autonomy, participation, identity, dignity and peace of mind. These benefits are exceptionally difficult to measure systematically, but they are important. An evaluation of such outcomes should remain on the research agenda

**6. Counterfactuals**

If we want to know what difference DLA or AA has made to disabled people and their families, it is important to measure not only what their position is now, with the benefit, but also to estimate what that position would have been in some alternative circumstances, without the benefit. This alternative is often known as the 'counterfactual'. The difficulty of comparing the two positions, with and without the benefit, net of confounding factors, is known to econometricians as one of 'identification'.

In an ideal research world, we would find a sample of disabled people, and pay benefit to half of them chosen at random, and pay nothing to the other half. The differences in their outcomes would provide a true measure of the effects of the policy. In practice, it is not possible to make such a random allocation, and we have to look for natural situations in which the position of people with and without the benefit can be compared. The difficulty lies in ensuring that those without the benefit are as similar as possible to recipients, in all other respects. Six possible options are considered here:

*(i) Cross-sectional comparisons, controlling for disability characteristics*

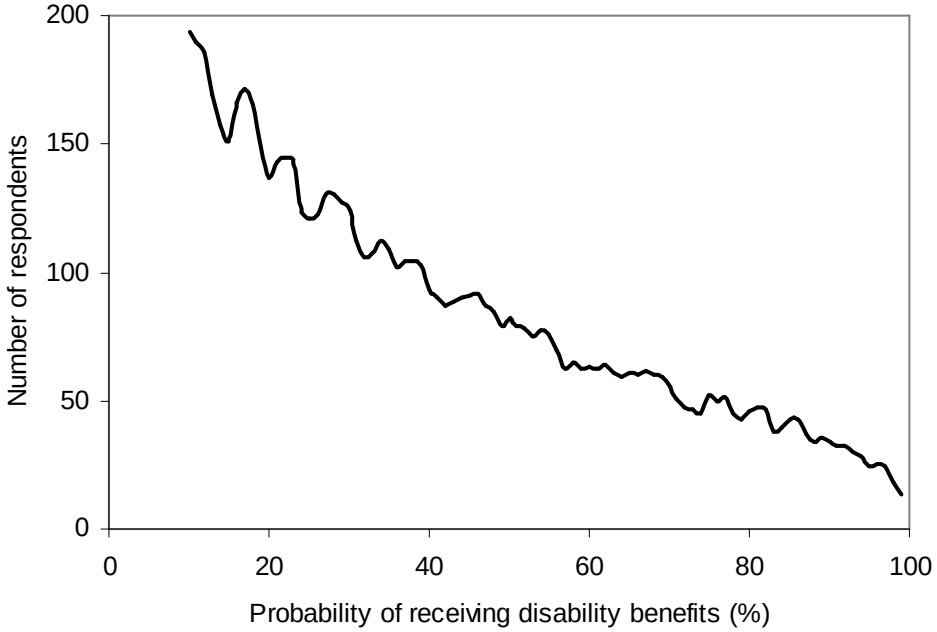
Clearly we cannot just compare the spending patterns and life-styles of disability benefit recipients with the rest of the population, because most of the rest of the population are not disabled.

But if analysis could be confined to moderately and severely disabled people, it may be possible to build an overlapping comparison group of non-recipients with very similar patterns of impairment. A preliminary analysis of the Family Resources Survey suggests that quite an accurate prediction of receipt of DLA and AA can be built up using just the types of impairments reported by members of the sample, plus age, sex and family structure (pseudo $R^2$ = 40%). The accuracy of this allocation of

probabilities would probably be increased if it was possible to add the other two main summary disability indicators – severity of impairments and reported health-conditions.

Figure 2 shows the number of adults in the FRS sample whose probability of receiving disability benefits could not be predicted with any certainty. (The large group of non-disabled people whose probability was close to zero are not shown in the graph.) About 4,000 individuals had impairments and demographic characteristics giving a probability in the range between 25 per cent and 75 per cent. An analysis of variations in outcomes between those who did and not receive the benefits could in principle be used to identify the treatment effects. Multivariate analysis techniques (eg propensity scores) have been developed to optimise the estimates of 'treatment effects' that can be derived from this kind of cross-sectional analysis.

***Figure 2 Distribution of predicted probabilities of receiving AA/DLAc in the FRS sample***




Source: FRS 2004/05
Note: prediction based on a logistic regression analysis using impairments and demographic characteristics as covariates. The vertical axis shows the number of respondents in each one percent range of probability (three point moving average)

For any given summary measure of impairments, the possibility remains that the benefit recipients are more disabled (in some unobserved way) than the non-

recipients. But it should be possible to set bounds on the extent of this bias, and so provide minimum or maximum estimates for the impact of the benefits.

*(ii) 'Instruments' for disability*

The underlying analytical problem is disentangling the mutual associations between three sets of factors: impairments, receipt of disability benefits, and outcomes. We want to know the effect of disability benefits on outcomes, independent of impairments; but impairments themselves affect receipt of benefits.

One complex analytical solution to three-way relationships like this to is to find a proxy for disability, which can be used as a substitute. The proxy is referred to in econometrics as an 'instrument'. The standard criteria for selecting an instrument are, first, that it should be strongly associated with the variable it is substituting for, and, second, that it is not directly associated with the outcome of concern.

The obvious potential proxy for disability is age. About one tenth of adults aged 20 report any impairments. Virtually all adults above the age of 90 do so. There is smooth rise in the probability of impairment between those ages. (A logistic regression equation using the cube of age to predict the probability has a pseudo $R^2$ of 12%.) So age fulfils the first criterion for an instrumental variable.

The difficult question is whether age itself is associated with the set of outcomes we wish to measure (independent of the impairments correlated with age). Section 5 of this paper suggested that the overall desired outcome should be defined very broadly, as 'countering the disadvantages of disability'. This has to be operationalised as a series of more clearly conceptualised measures, such as expenditure on disability needs, improved care and mobility, reduced financial hardship, and greater social inclusion. Among this battery of contributory measures, it is possible that some are independent of age. We are so used to the association between age and disability that many of the processes we think of as ageing may actually be a function of declining health and increasing impairments.

The analytical approach works only if the assumption that outcomes are independent of age itself is true. If the assumption can be challenged, the conclusions of the

analysis are open to challenge too. The approach cannot be recommended at this stage, but it would be worth further thought and preliminary analysis.

*(iii) Comparing the same people, before and after receiving disability benefits*

An alternative is to observe the change in spending patterns and life-styles that happens when people start to receive their benefit, treating the pre-receipt position as the counterfactual.

This approach has potential if it assumed, first, that impairments are fairly stable, and second, that there is a significant period of steady impairment before the disability benefit is claimed or paid. It would not work in cases where there is a rapid deterioration (or other change) in people's condition across the period. In practice, there will be diversity of experience, and it might be appropriate to locate recipients with stable patterns of impairment, measure the change in their spending patterns and life-styles after claiming benefit, and then infer that the same impact applies also to people with less stable patterns.

A further complication is that the way people spend their initial receipts of DLA and AA (probably including some back-payments) may not be typical of their long-run behaviour.

Nevertheless, this longitudinal approach would probably be the most powerful method of measuring impacts if accurate before-and-after data could be obtained. The main difficulties are practical. It is easy enough to locate recently successful claimants and interview them about the post benefit experience. The problem is to locate them in advance, to measure their spending patterns and life-styles before the money starts to flow.

- Interviewing new recipients retrospectively about their pre-benefit experiences would be interesting, but unlikely to provide rigorous counterfactual measures.
- Undertaking rapid interviews with people whose claim is being processed is another alternative, but the results are likely to be coloured by the expectation of an increase in resources. And it would be difficult to ensure that respondents did not think that the research interview was part of the assessment procedure.

- An ideal approach might be to screen a large sample of disabled people, and encourage claims among those who appear likely to be eligible. This would be a narrowly based but otherwise powerful survey design. An ethical issue would be that some of those encouraged to claim might not be awarded benefit, so their time would have been wasted and their expectations disappointed.
- This latter consideration suggests that the screened in sample should not be encouraged to claim, but the researchers should wait until a claim had been submitted and awarded in the natural course of events (using benefit records to identify the claim and trigger an interview). The problem here is that a very large sample would have to be screened to start with; and it could not be assumed that the claim and award had not been the result of some other change (eg deterioration in condition) after the screening had occurred.

*(iv) Exploiting artificial variations in eligibility*

Another approach would be to identify two groups of people with very similar impairments and other characteristics, one of which was eligible for benefit and the other not (for reasons which are not judged to be relevant to their needs).

The primary candidate here is that people who claim before their 65$^{th}$ birthday are entitled to claim the mobility component of DLA, and/or the lower rate of the care component. But those claiming AA after 65 are limited to the higher or middle rates of the care component. Comparisons of people claiming before and after their 65$^{th}$ birthday would provide a meaningful analysis, provided such issues as duration of impairment could also be taken into account. On the other hand, 65 is an important break-point in employment rates and pension provisions, so it would be very difficult to isolate the distinct impact of the disability benefit schemes. It would, in any case, be difficult to interpret the results of this very tightly drawn comparison as generalisable to the schemes as a whole.

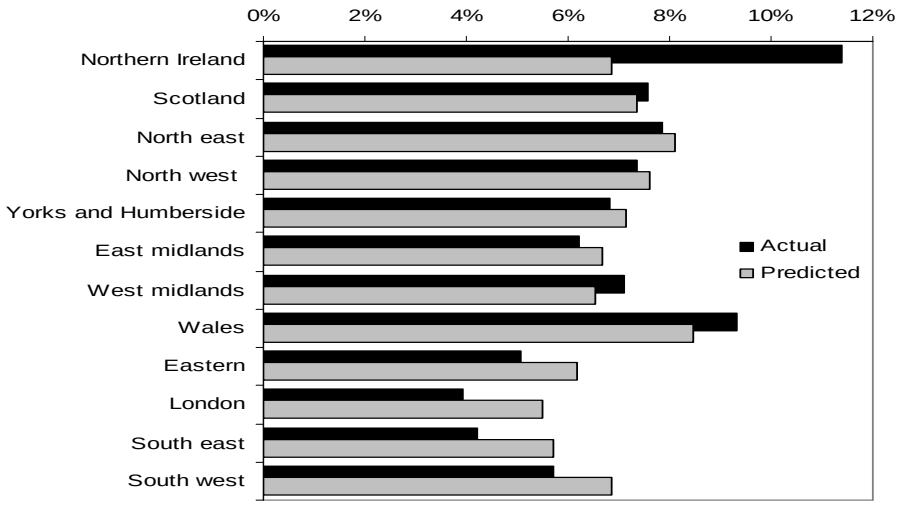
*(v) Exploiting administrative variations in take-up and award rates*

Some local authorities have been active in prompting claims through welfare rights campaigns, while others have not. And some of the DWP's Disability and Carers Benefits regional offices have higher rates of awarding DLA and AA than others.

These two (distinct) points could be generalised to show the variation between local districts in the probability of receiving the benefits, for any given set of conditions, impairments and severity. This allows the possibility of locating a group of people who are receiving benefits in high-density areas, but who would not be receiving them in low-density areas; and a counterfactual group living in low density areas, with the same impairments but no benefit. The approach would require an assumption of endogeneity – that is, that the area variations in take-up rates and in award rates are not influenced by (unmeasured) variations in need between the areas concerned.

This identification strategy could work if analysis revealed a clear cleavage between areas in their benefit densities. Figure 3 shows variations between government office regions in the proportion of adults receiving DLAc or AA, ranging between 3.9 per cent in London and 11.3 per cent in Northern Ireland. Only a small proportion of this difference can be explained by a prediction based on the impairment and demographic characteristics of the two regions. No doubt a wider range of spatial variation could be identified if the data were analysed at a finer grain by district, rather than crudely by region. On the other hand, the overall range of variations between areas provides only a weak explanation of why one person receives benefit and another does not, and it seems unlikely that this approach would nail down the impact estimates required.

***Figure 3 Proportion of adults receiving DLAc and AA, by region: actual, and prediction based on impairments and demographic characteristics***




Source: FRS2004/05

*(vi) Before and after a policy change*

The role and future of disability benefits are under discussion, especially in the context of the debate about paying for social care (Wanless 2006). Obviously, the research proposed in this report should contribute to discussion of policy options. But it is possible that the benefits will be changed, perhaps in a radical way, before the research can be undertaken.

Such a change would alter the research objectives (which should then focus on the impact of the new scheme). But the retargeting of benefits also provides an important opportunity to identify counterfactuals, assuming that the only difference between people claiming before and after the reform is the policy regime they face. People who receive more, or less, benefit can be compared with their equivalents under the previous system. This is sometimes referred to a 'natural experiment'.

The details of such a research design cannot be worked out until the nature of any reform is known. We will need to know, for example, whether existing claimants, or only new ones, will be transferred to the new scheme. The important point is that a before and after study needs to be planned from the moment the change in benefit entitlements is foreseen, so that a 'before' component of a 'before-and-after' study can be set up.

Obviously this line of approach depends entirely on future policy decisions, and cannot be built into planning research into the impact of the current system.

*Discussion*

Several research teams have asked claimants to describe how they spend their DLA or AA (Horton and Berthoud 1990, Hawkins and others 2007), or to comment in broad terms on what difference the money has made to their spending patterns or their life style (Craig and others 2003, Age Concern 2008). These studies usefully indicate the direction of change brought about by these benefits. But if the research brief is to 'measure' their 'impact', then we need a more rigorous set of comparisons. The requirement is for quantitative estimates of the difference in outcomes between people who do and do not receive disability benefits. The choice of a counterfactual is crucial to the design.

Six possible identification strategies have been discussed in the preceding paragraphs. Objections can be raised against each of them, so none is ideal. One possible conclusion might be that none of them is good enough, and that the attempt to measure impact has to be abandoned. An alternative conclusion might be that some of them are at least adequate, and should be pursued – so long as their limitations are recognised, and as far as possible minimised.

Among the six, three can be rejected as 'too clever' – relying on very strong assumptions, or focussing on too small an element of the overall picture. These three – (ii) *instruments for disability*, (iv) *exploiting artificial variations in eligibility* and (v) *exploiting administrative variations in take-up and award rates* – should probably be rejected as mainstream approaches to the research task. But independent researchers might perhaps be encouraged to develop them further.

One of the identification strategies – (vi) *before and after a policy change* – offers a high level of statistical validity, but will not be available for our purposes unless a major policy initiative is implemented.

The other two approaches – (i) *cross-sectional comparisons controlling for disability characteristics*, and (iii) *comparing the same people, before and after receiving disability benefits* – should remain in the frame as potential solutions to the research problem. Both cover the full range of (potential) benefit claimants. Both face a similar analytical difficulty - that there may be some unobserved difference in impairment levels or impairment dynamics between those who do and do not claim benefits – but at least the assumption is clear. It may be possible to place bounds on the estimated effects – the maximum and the minimum impact based on varying assumptions about the extent of the unobserved differences. Crucially, the more information about impairments is available, the more the issue can be taken into account in the analysis, and the less sensitive the results will be to the assumptions made.

We propose (below) a research strategy in which cross-sectional comparisons of available data provide a short-term answer to the question, and longitudinal analysis of new claims provides a longer-term answer.

## 7. Data requirements

*Coverage of groups in the population*

The experience of disability, and the impact of policy, depend heavily on the social position of the individuals affected. These variations have hardly been discussed in this paper, but it is essential for any new research to cover (or explicitly to exclude) the following sub-groups of disabled people:

> By broad type of condition: physical, mental
>
> By age-group: children, working age, older people
>
> By economic position: with/without a job (working age); by household income (excluding DLA/AA)
>
> By family structure: couples, living with carer other than partner, living alone.

*Information needed*

It has been argued, especially in section 5, that DLA and AA may have a very wide range of types of impact, from the very direct (providing for additional expenditure on specific goods and services ) to the very broad (countering the 'disabling' effects of impairment). It is assumed, for the moment, that the research objectives cover the whole of this range of impacts, though it would be legitimate for policy makers, disability groups and other stake-holders to debate whether some narrower and more precisely defined set of objectives might be more appropriate.

Assuming a wide range of possible outcomes means that a wide range of types of information will be needed. The following summary serves as a checklist, with commentary, for the data agenda:

Impairment: Although policy rightly focuses on the social and economic position of disabled people, rather than on the impairments themselves, a first essential element of any analysis of the impact of disability benefits is a detailed measure of impairments. The specialist disability surveys conducted in 1985 (Martin and others 1988) and 1996/97 (Grundy and others 1999) distinguished between three concepts: condition, type of impairment and severity of impairment. Although

new surveys may adopt a different measurement approach, a similar level of detail is required. The aim is not so much to compare the effects on (say) blind people with (say) wheelchair users, as to build up a systematic picture of the factors influencing a) the probability of receiving DLA or AA and b) expenditure needs, social exclusion and so on, so that cross-analysis can control for this crucial influence on both issues.

Household and family composition: Partners and other relatives are huge potential resources for disabled people, especially those in need of care. They also potentially share many of the disadvantages associated with disability. Some of the costs of disability fall on them; and some of the impact of disability benefits will be experienced by them. The new research must be explicit about families, rather than treat disabled people as isolated individuals.

Household income, including benefits received: The impact of one source of income (DLA or AA) can only be assessed in the context of all sources of income. There would be strong advantages if survey data could be linked to administrative data about the amount and duration of disability benefits.

Spending patterns: Measures are needed of household spending on key commodities such as personal services, transport, fuel and so on.

Social care: Given that AA and DLAc are based on the need for personal care, it is important to know how much care people are receiving, who provides it, how much it costs, and how far it enables people to take part in activities which would otherwise be impossible. Existing question sequences (such as the one in the FRS) are not easy to interpret.

Transport and mobility: Again, given the DLAm entitlement criteria, it is important to know what transport options are available to disabled people, and whether they are able to get out and about.

Deprivation and financial hardship: It has been argued that these indirect indicators may provide more realistic measures of the extra costs of disability, and of the compensating effects of the benefits under review.

Social exclusion, stress, sense of identity and so on: as discussed on page 16.

*Existing sources*

This is a huge list of topics. Since there has been no fully specialised survey of disabled people since 1985, it is not surprising that no existing source covers them all in the detail that might be required.

Since the first requirement is for detailed measures of impairment characteristics, it is helpful to review existing sources by that yardstick, before considering other aspects of their coverage.

* The Expenditure and Food Survey (EFS) is the only large scale survey with good spending data. But it does not carry any indicator of impairment and has to be rejected as an existing source. (Note though, that the survey reported by Matthews and Truscott (1990) attached a disability module to the then Family Expenditure Survey, and that approach could possibly be repeated.)
* The General Household Survey (GHS) and the Labour Force Survey (LFS) carry only a very simple set of questions about health problems which limit daily activities. While useful for identifying the population at risk, it is nowhere near detailed enough for our purpose.[4]
* The Family Resources Survey (FRS) and the British Household Panel Survey (BHPS) have enough questions to derive a crude scale of impairment – not ideal, but suitable for limited analysis. Both surveys also carry good information on income and on deprivation. The FRS is very limited in other relevant topic areas, while the BHPS, with wider topic coverage, has only a small sample of disabled people.
* Three surveys have fairly or very detailed questions about health conditions and impairments.

[4] I have argued elsewhere that the LFS is an inappropriate source for DWP/ODI statistics on the prevalence of disability or on the disability employment rate.

- The Health Survey for England (HSE) carried a disability module in 2000 and 2001. Astonishingly, it did not cover mental disorders. Subject to that limitation, it provides good impairment indicators – but addresses very few of the other issues listed above.
- The Health and Disability Survey (HDS) attached to the FRS in 1996/97 provides much the most detailed impairment measures. There is some information about extra costs and care services, and the FRS link provides good income data. But the survey is not strong on social exclusion outcomes. The data are more than ten years old, so the survey lacks credibility for current policy analysis.
- The English Longitudinal Study of Ageing (ELSA) follows a sample of people who were aged 50 or over in 2001. Although it does not have a systematic battery of questions measuring all aspects of impairment, there is a range of questions about impairments and health conditions on which to base a fairly detailed measure of disability. The survey provides acceptable data about household incomes, and can be linked to administrative data about disability benefits. The wide-ranging questionnaire offers an opportunity to analyse some (though by no means all) of the outcome measures discussed in previous sections.

Among the sources reviewed, only ELSA and the HDS come anywhere near meeting the requirement, though the limited sample coverage of one and the age of the other reduce their value. It is proposed (below) to analyse them as a short term measure, while consideration is given to possible new surveys.

*New surveys in the pipeline*

Three surveys already on the drawing board are of potential value to this research objective.

* *Understanding Society* (the UK Household Longitudinal Study) is a general purpose panel survey covering 40,000 households, commissioned by the ESRC. It can be thought of as a much larger version of the BHPS, although there will be substantial differences in topic coverage. The survey is likely to offer a crude scale of impairment, adequate income and deprivation data, and a wide range of social participation indicators, without focussing on issues of special relevance to

disabled people. The first full wave of fieldwork will be completed by the end of 2010.

* The Longitudinal Disability Survey (LDS) will be a highly specialised disability survey based on screening of an initial sample of 50,000 individuals, followed up annually. The Office for Disability Issues has commissioned ONS to carry out the development work. The questionnaire content is no doubt in negotiation between ODI and ONS, but it would be surprising if the topics relevant to the current investigation (discussed above) were not high on the list of priorities. It is possible that the LDS will meet our objectives, but that will not be known until the topic coverage has been clarified. Again, the first wave should be completed in 2010.
* The Policy Studies Institute has been commissioned by the DWP to develop a methodology for measuring take-up of DLA and AA (Kasparova and others 2006). It is likely (though not yet certain) that a large scale survey of disabled people will be launched to obtain definitive measures. The natural content of such a survey would focus very closely on characteristics likely to predict eligibility for the two benefits; but it could make sense to twin the objectives of that project with the current enquiry, and measure outputs such as spending patterns, hardship and social exclusion. There is no current timetable for such a survey.

## 8. Research plan

None of the existing data sets has the detailed questionnaire coverage on disability and on outcomes required for the wide-ranging evaluation of benefit impact discussed in the preceding pages. Although some of them have sample sizes large enough to support cross-sectional analysis (counterfactual (i)), no existing survey records enough new awards over a period to support much longitudinal analysis (counterfactual (iii)).

It is likely that new data will be required to provide a full answer to the questions posed – which are of course central to an understanding of disability, as well as to the policy evaluation set as the objective of this study. The new data could be obtained in the course of one of the two new surveys already on the drawing board, or it may be necessary to design a third survey. The proposed research strategy looks towards

large-scale data collection (by one means or another) starting in about two years' time.

Two interim objectives are, first, to provide preliminary answers to some of the research questions as a matter of urgency, and second, to contribute to the development of the new survey. Two short-term projects are proposed, each of which addresses both of these interim objectives. One involves quantitative secondary analysis of existing data. The other involves semi-structured interviews with a fairly small sample..

*Project A (short term): Secondary analysis of existing data*

The first proposal is to undertake secondary analysis of an existing data-set to explore the relationships between disability, benefits and the sets of outcome measures discussed in previous sections. This project can be undertaken much more quickly, and at much lower cost, than the possible new survey discussed below. It will provide indicative answers to the key questions during a period of policy debate, and will help to determine whether the larger and longer term investment in a new survey is worthwhile.

The most appropriate available data-set would be the English Longitudinal Study of Ageing (ELSA). The survey is based on repeated interviews with 12,000 individuals over the age of 50 (in 2001), of whom an estimated 4,300 are disabled and 1,500 receive DLA or AA.

Analysis of ELSA would mainly take the form of cross-sectional comparisons controlling for disability characteristics, and would be subject to the limitations of that approach discussed earlier – though the detailed impairment data helps to minimise the risk of unobserved differences between claimants and non-claimants. The survey interviews members of the sample every two years, and therefore provides an opportunity to compare the same people, before and after receiving disability benefits. But the scope for such longitudinal analysis will be limited by the small number of transitions that can be expected to occur over the period.

Within the limits of its questionnaire coverage, the main shortcoming of ELSA is that the sample is confined to people aged at least 50 in 2001. Working age adults over 50 can be compared with pensioners, but under 50s – about a quarter of all disability benefit recipients – would be excluded from consideration. Some limited analysis of the Health and Disability Survey should be undertaken to check whether the results for under 50s look similar to those for the age-range 50 to 64 .

This project could be commissioned almost immediately, and (depending on the availability of analysts with the appropriate skills) could be completed within nine months. It will provide policy makers and commentators with preliminary estimates of the impact of DLA and AA on several important outcomes, during this period of policy debate. The secondary analysis will also make a valuable contribution to thinking about the design of the new survey (Project C). It might even lead to the conclusion that the new survey should not be undertaken after all (either because the research questions had already been answered adequately, or because the questions seemed unanswerable).

*Project B (short term): Developing questions on expenditures and outcomes*

Although the objectives of DLA and AA have been discussed (above) in very broad terms, it is clear that evaluation of a weekly benefit has to include some analysis of the relationships between disability, income and spending patterns. The goods and services of interest can be defined narrowly as care and transport, or more widely to include heating, chemists goods and so on. But it is striking that policy issues are being debated in the absence of even basic information (such as how many claimants pay for personal care and other household services). None of the existing sources provide data on these expenditure patterns. Nor do they record specific outcomes (such as patterns of care, mobility, levels of home heating – see page 14) in anything like the detail required to understand their role in the chain of causality between disability, income and disadvantage.

Two attempts were made in the 1980s to estimate the additional costs of disability (see page 14). Neither approach was convincing, and survey researchers have effectively abandoned the attempt to address these issues since then. A conclusion of

this review is that the issues are too important to be abandoned, and that a new approach is needed.

Similarly, although several surveys have focused on the activities of carers (ie from the supply side), there have been no comprehensive measures of the packages of care available to disabled people (ie from the demand side). Nor have systematic question sequences shown whether, and how much, people get out and about.

The eventual objective (Project C below) is to ask structured questions of a large sample of people (disabled and non-disabled). Question sequences need to be developed before that. Within the limits on questionnaire length imposed by considerations of budget and respondent fatigue, the aim is to ask questions in sufficient detail a) to be sensitive to the way people actually spend their money and their time, and b) to provide an opportunity for quantitative comparisons between disabled and non-disabled, claimants and non-claimants.

A second short term project is proposed to develop such questions, and to provide some very preliminary answers. The project could start with genuinely qualitative interviews to find out, in an open way, how people think about the subject matter. But the main aim would be to develop, test and evaluate structured questions. This probably implies a sequential approach, trying out alternative methods on new samples as lessons are learned from early prototypes. It also implies a sample size large enough for numerical analysis (to show what the output would look like) even though the results could not be subject to statistical interpretation.

An appropriate model might include 20 open ended interviews, followed by up to 200 semi-structured interviews undertaken in three tranches of about 67. The sample would be structured to include non-disabled people, severely disabled people not claiming DLA or AA, recent awards and long-term recipients. (The latter two groups could be selected from benefit records). It should also cover (or consciously exclude) families with children, people of working age, and older people. The range should include people in couples, people living with a carer other than their partner, and people living alone.

Although this is a small-scale project, it will be resource intensive. It could be commissioned within the next few months, following more detailed consideration of its objectives and approach. It would take up to a year to complete.

*Project C (medium term): New quantitative data*

The research objectives require data from a large sample of disabled people who do, and do not, receive DLA and AA. Ideally it will observe people who claim the benefits, both before their claim and after their award. It will provide detailed data about their impairments, and about the wide range of spending patterns and broader outcomes identified between pages 9 and 18, as well as background information about their incomes and family structures. Since existing surveys fall some way short of these requirements, it is appropriate to consider collecting new data.

An 'ideal' design might be as follows:

1. Contact a large sample of households
2. Ask a sequence of questions to identify (severely) disabled people.
3. Among those screened in as disabled, ask detailed questions about impairment, household and family composition, household income, spending patterns, social care, transport and mobility, deprivation and financial hardship, social exclusion, stress, sense of identity and so on.
4. Ask a parallel set of questions of non-disabled people, probably a sub-sample of the large group of non-disabled people originally contacted
5. Link the survey data to administrative records showing which disabled people were receiving DLA or AA (and the amounts received)
6. Undertake cross-sectional analysis to compare those receiving benefits with those not receiving them, controlling for impairment characteristics.
7. Possibly (but not essentially), encourage claims for DLA and AA among those disabled people who appear to be eligible. This is an option which requires careful ethical consideration.
8. Use administrative records to identify survey respondents who are awarded disability benefits over the course of the following 12 months.
9. Re-interview those awarded benefit, to see what else had changed. (Possibly, re-interview a sample of those not awarded benefit, as a control group.)

10. Undertake longitudinal analysis to compare the current circumstances of those who had been awarded benefit with their own circumstances before the claim, controlling for changes in impairment characteristics.

As a guide to the scale of screening operation required, a sample of 10,000 households should yield approximately 4,000 disabled people, 1,400 disability benefit recipients and 200 new awards over a 12 month period. The yield of new awards would be higher if it was possible to encourage claims among apparently eligible candidates (step 7).

The longitudinal survey of disabled people commissioned from ONS by the ODI will meet many of these requirements, or could be adapted to meet them. It should include many of the questions about impairments, resources and outcomes needed for this evaluation. It will be on a scale appropriate to address the impact questions raised by the current review, and the sample structure is close to the requirements of the evaluation proposed here. It will have the longitudinal structure appropriate for following up people after they claim benefits. An essential next stage will be for ODI and DWP to discuss the design of this survey with ONS to see how far they can meet the objectives set out here.

It is less clear at this stage whether the survey under consideration to measure the take-up of disability benefits can be adapted also to meet the evaluation objective. It will probably have to be on a similar scale. An obvious advantage is that it will have to identify samples both of actual claimants, and of eligible non-claimants, who provide natural counterfactuals. On the other hand the questionnaire will have to focus on establishing eligibility, and it is not certain that there will be enough space to enquires about outcomes as well. The Department should discuss these issues with PSI as the development work approaches a full-scale survey design.

If neither of these two already-planned new surveys meets the requirement, it will be relevant to consider an entirely new investigation. The key issue for a new survey would be the scale and method of the screening operation. The three options would be:

- Face to face screening at a new sample of addresses. This would be the best, but also the most expensive, option.
- Screening at a new sample of addresses, using low-cost data collection techniques such as post or telephone. This would be much cheaper, although response rates to these modes are often lower than face to face interviews. In principle the data collection should work – but the postal screening used in the 1985 survey seems to have underestimated the number of disabled people in the population.
- Use existing large scale surveys to do the screening. This would be the cheapest option, because no new fieldwork is required (for the screening), and many of the basic questions would be asked in the original survey anyway. (It is very similar to the approach used for the Health and Disability Survey in 1996/97.) The disadvantage is that non-response to the original survey reduces the representativeness of the sample available for screening. As a guide, the Family Resources Survey (25,000 households) would yield about 500 new awards over a 12 months follow-up period. Carrying the screening on for two years would double this yield.

The design outlined in steps 1 to 10 above will provided a powerful base for measuring the impact of disability benefits. The main question is about its implementation, whether combined with one of the two surveys already planned, screened from scratch, or piggy-backed on an existing survey. We suggest that the option of using the FRS for screening should be considered a base option, so that alternative approaches can be compared with that both for effectiveness and for cost.

A new survey such as that described would take up to two years to design and commission. (Some of the development work is included in our proposals for short-term work, Projects A and B.) Fieldwork would take a year for the cross-sectional survey if linked to the FRS, with detailed cross-sectional analysis available about a year after the data collection had been completed. Data collection and analysis of the follow-up of new awards would add a further 12 months to this sequence. So the project as a whole would be completed 5 years from now. The output looks a long way off – but long-term investments are needed to answer long-term questions. Policy

makers in 2013 will welcome the pay-off in terms of their much greater understanding of the impacts of policy on disabled people.

***Existing research***

Note: not all of the following are directly referred to in the text**:**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